Universidade de Aveiro Departamento de Economia, Gestão e Engenharia Industrial
2015

NINA KATARZYNA SZCZYGIEL

CONSEGUIMOS? DE PARCERIAS INTERSECTORIAIS À QUALIDADE DE VIDA E SATISFAÇÃO DO UTENTE, VIA PRESTAÇÃO DE CUIDADOS CENTRADOS NO DOENTE

YES, WE CAN? FROM INTERSECTORAL PARTNERSHIPS TO QUALITY OF LIFE AND USER SATISFACTION THROUGH PATIENT-CENTERED CARE PROVISION

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o júri

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palavras-chave

parcerias intersectoriais, colaboração, acidente vascular cerebral, qualidade de serviço, satisfação do utente, Careperf, qualidade de vida, análise das redes

resumo

A Organização Mundial de Saúde reportou que 15 milhões de pessoas sofrem um acidente vascular cerebral anualmente, em todo o mundo. Portugal não é excepção na tendência global, sendo o AVC a causa principal de morte no país. Os sobreviventes com frequência experienciam morbidade, incapacidades várias e dependência nas actividades da vida diária, com enormes custos para o indivíduo, a família e a sociedade. Foi estimado que, no Reino Unido, os custos anuais diretos do AVC rondam os 4 biliões de libras, não tendo sido encontrados números referentes à situação em Portugal. O AVC, devido à sua prevalência e incidência, é pois um exemplo claro de como a realidade actual coloca os decisores sob enorme pressão, quando organizam e gerem os cuidados prestados à população, dadas as actuais limitações orçamentais, de forma a lidar com aspectos de saúde que passaram a estar bem para lá daquilo com que o sector da saúde pode lidar sozinho.

É consensual que a taxa de sobrevivência nestas situações não é um indicador suficiente para a qualidade dos cuidados prestados. No caso do AVC, a qualidade de vida depois da fase aguda pode tornar-se um enorme problema, requerendo normalmente cuidados de saúde e sociais de longo prazo e outro tipo de assistência, e com o apoio social informal representando não só uma parte muito importante do cuidado prestado mas também um contributo enorme para o bem-estar do sobrevivente. Esta crescente necessidade por serviços complexos e multidisciplinares coloca a questão da qualidade de cuidado global e da satisfação do utente que os experiencia de forma ainda mais premente.

A comunidade internacional tem vindo a reconhecer, de forma crescente, a importância e o potencial das parcerias intersectoriais na produção de mudança estrutuctural e social sustentadas como elemento fundamental de estratégias de saúde e sociais. A necessidade urgente de colaboração entre uma ampla variedade e diversidade de entidades que prestam serviços de assistência em Portugal, por norma muito fragmentados, implica uma perspectiva multi-dimensão, multi-entidade e inter-sector. Um ambiente colaborativo pode ser encarado como uma rede de relacionamentos organizacionais entre prestadores de serviços, sendo que as entidades de saúde e sociais parecem hoje estar, por natureza, embutidas na perspectiva de rede, dado representarem relações complexas de trabalho e pessoais.

Esta tese tem como objetivo estudar a acção colaborativa intersectorial disponível para doentes que sofreram um AVC em Portugal. Mais concretamente, pretende-se avaliar o impacto das parcerias existentes sobre a qualidade de vida dos doentes, a qualidade percebida do serviço experienciado e a satisfação com os serviços prestados, e analisar a realidade colaborativa no contexto Português.

O estudo representa o primeiro esforço nesta área, não tendo sido encontrado qualquer outro semelhante publicado, o que torna este trabalho ainda mais relevante nas circunstâncias actuais, pelos contributos teóricos e práticos que proporciona.

keywords

intersectoral partnerships, collaboration, stroke, service quality, user satisfaction, Careperf, quality of life, network analysis

abstract

The World Health Organization reports that 15 million people experience cerebrovascular accident annually worldwide, of which 5 million die. Portugal is not an exception in the global tendency, with stroke constituting the principal cause of death.

Survivors frequently experience morbidity, disability and dependency in activities of daily living, representing huge costs to individual, family and society. The UK data estimate the annual direct cost of stroke care to around £4 billion, with no data of that type found with respect to Portugal. Stroke, due to its prevalence and incidence, is hence a clear example on how today's reality puts policy makers under enormous pressure to organize and manage care of the population, given current budget limitations in order to deal with aspects of health that have moved well beyond of what the health sector can handle alone.

It is consensual that a survival rate is not a sufficient outcome indicator of quality of care. In case of stroke patients, quality of life after the acute phase may become a huge problem, commonly requiring long-term health and social care, and other assistance, and informal social support which represents both, relevant caregiving patterns and an enormous contribution to a person well-being. This increasing demand for complex, multidisciplinary care services raises a question on their quality and user satisfaction. Nevertheless, a few have deliberated these concepts within a multiple-setting which is turning vital to guarantee and improve coordination and continuity of care.

International community has increasingly recognized the importance and potential of intersectoral partnerships in producing sustainable structural and social change as a fundamental element of health and social strategy. A pressing need for collaboration between a broad range and diversity of entities providing mostly fragmented care services in Portugal entails a multidimensional, multi-stakeholder and cross-sector perspective. Collaborative environment can be approached as a network of organizational relationships between service providers and health and social care entities seem today to be by nature embedded in the network perspective as they represent business and personal relationships.

This thesis aims to investigate the status of intersectoral collaborative action for stroke patients in Portugal. Particularly, its objective is to evaluate the impact of existing partnerships on patients' quality of life, perceived service quality and satisfaction from care, support and assistance services they experienced, and to analyze ways they function in the Portuguese context.

To our knowledge, no study of this type has ever been developed, making this work relevant under current circumstances, and for the theoretical and practical contribution it provides.

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LIST OF ABBREVIATIONS AND ACRONYMS

ACES - groups of primary care centers also designated Primary Care Trusts (*Agrupamentos de Centros de Saúde*)

ADL - activities of daily living

ARS - Regional Health Administrations (*Administrações Regionais de Saúde*)

BTS - Bartlett’s test of sphericity

CARE - the Cooperative for Assistance and Relief Everywhere

CCN - the Community Care Network

CEO - Chief Executive Officer

CFA - confirmatory factor analysis

CFO - Chief Financial Officer

COO - Chief Operational Officer

CSR - corporate social responsibility

DALYs - disability-adjusted life years

ECR - Regional Coordinating Teams (*Equipas Coordenadoras Regionais*)

EEC - the European Economic Community

ERS - the Health Regulation Authority (*Entidade Reguladora da Saúde*)

EU - the European Union

EU-15 - EU Member States before May 2004

EU-27- EU Member States after January 2007

GP - general practitioner

HFA - Health for All

HiAP - Health in All Policies

HIP - Hospital Infante D. Pedro [Aveiro district, Portugal]

HRQoL - health-related quality of life

ICIDH - the International Classification of Impairments, Disabilities, and Handicaps

INE - the National Statistics Institute (*Instituto Nacional de Estatística*)

INEM - the National Institute of Medical Emergency (*Instituto Nacional de Emergência Médica, I.P.*)

IPJ - the Portuguese Institute of the Youth (*Instituto Português da Juventude, I.P.*)

IPSS - Private Institutions of Social Solidarity (*Instituições Particulares de Solidariedade Social*)

ISP - intersectoral partnerships/intersectoral partnering

KMO - the Kaiser-Mayer-Olkin measure of sampling adequacy

NGO - non-governmental organizations

NHS - the National Health System

OECD - the Organization for Economic Cooperation and Development

PAII - the Integrated Support Program for the Elderly (*Programa de Apoio Integrado a Idosos*)

PCA - principal component analysis

PCT - Primary Care Trusts

PHC - primary health care

PPP - public-private partnerships

QoL - quality of life

RNCCI - the National Network of Integrated Continuous Care (*Rede Nacional de Cuidados Continuados Integrados*)

SEM - structural equations modeling

SLS - Local Health Systems (*Sistemas Locais de Saúde*)

SS-QoL - the Stroke-Specific Quality of Life Scale

SU - stroke unit

TEC - the Treaty establishing the European Community

TFEU - the Treaty on the Functioning of the European Union

UAG - Management Support Units (*Unidades de Apoio à Gestão*)

UCC - Community Care Units (*Unidades de Cuidados na Comunidade*)

UCSP - Personalized Health Care Units (*Unidades de Cuidados de Saúde Personalizados*)

UN - the United Nations

UNICEF - the United Nations Children's Fund

URAP - Shared Assistance Resources Units (*Unidades de Recursos Assistenciais Partilhados*)

USAID - the United States Agency for International Development

USF - Family Health Units (*Unidades de Saúde Familiar*)

USP - Public Health Units (*Unidades de Saúde Pública*)

VIF - Variance Inflation Factor

WHO - the World Health Organization

An enourmous increase of chronic and long-term conditions in last decades is a global phenomenon requiring substantial organizational shifts in health and social care provision. However, organizing care interventions across a multiple-setting, in spite of unquestionable interest of policy makers, is still sporadic. Portugal is no exception in that tendency and, undoubtedly, there is a pressure on change of the collaborative paradigm between care service providers in the country. An improvement of the system effectiveness would lead to a better care delivery and meeting the system users' needs in a more efficient way creating conditions for satisfaction with care services they experience. The present thesis defies the existing situation and aims to investigate the status of intersectoral collaborative action in Portugal directed specifically for patients who underwent cerebrovascular accident. Particularly, this work has an objective to evaluate the impact of existing partnerships on patients' quality of life, perceived service quality and satisfaction with care, support and assistance services they experienced, and analyzing ways they function in the Portuguese context. The general premise behind this doctorate proposal is to introduce theory and develop methodology that can bring significant insights to practice in care provision. These fundamentals will be an answer to the exigency of the health and social systems improvement in Portugal, which is an object of concern of successive governing parties.

The concept of a health care system has been, since its establishment, designed to orientate the underlying population toward acute care, having as a primary concern rescue of human life written in its foundations. Decades of economic, social and demographic changes have led to significant modifications in several aspects of life and health does not constitute any difference here. Incidence and prevalence of long-term and chronic conditions are directly linked to longer life expectancy as they tend to increase with age; on the other hand, literature provides rich evidence on how unhealthy lifestyles deteriorate health status proving that, at least partially, health condition remains in hands of a person. That feeling of empowerment and responsibility for the own health state may play an important role in policy making nowadays, especially in what patients with long-term conditions concern. As long-term conditions cannot be cured but can only be controlled by medication and eventually by other treatments or therapies, if not accompanied by healthy lifestyle, they raise a risk of an unexpected severe health incident such as cerebrovascular accident. People with two or more long-term conditions are proven to need and use more health and social care services, including emergency care and community services

(McKevitt et al., 2003). Hence, aspects of health have moved beyond of what the health sector can handle on its own.

Demographic, socio-economic and epidemiologic challenges have been pressing concern of policy makers for more than a decade and are real (Pierson, 2006). Along with an increasing demand for care services, attempts to conceptualization and measurement of service quality, patient satisfaction and quality of life have led to an intense theoretical discussion on these concepts and their relation (Badri, Attia, & Ustadi, 2009; Baker & Taylor, 1997; Marcussen, Ritter, & Munetz, 2010; Parasuraman, Zeithaml, & Berry, 1994; Raposo, Alves, & Duarte, 2008; Tam, 2007; Taylor & Cronin, 1994). Nonetheless, a few have braved to balance them against a multiple-setting context. The challenge puts thus policy makers under enormous pressure on how to organize and manage the system in eyes of budget limitations and urges ordinary projects on the economic and social policy basis. International community has gradually recognized the potential and importance of intersectoral collaborations as a fundamental element of health and social strategy. Partnering across sectors encompasses particular concepts of collaboration bearing in mind different areas of action, ranging from strategy planning, development of exact structures and processes, up to implementation of the project throughout partners and systems.

It is commonly acknowledged that patients' reports on their health and satisfaction with quality of care services are as important as providers' perspective and many self-reported health measures (Aragon & Gesell, 2003) among which quality of life is now considered one of the most widely regarded and extensively used (Kind, 2001; Varricchio & Ferrans, 2010). Providing quality care and assuring patient satisfaction while maintaining sustainability of health and social systems is a challenge to countries. Health care organizations operate in an extremely competitive environment and managing patient perceptions on service quality and satisfaction is mandatory to survival. A growth of customer-centered initiatives has been observed (McNulty & Ferlie, 2002), but this shift is much weaker than in other sectors. Portugal lags behind others in what efficiency and effectiveness of care concern and approaches conducting to continuity of care are only beginning to take place.

On the other hand, health is understood as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946, p. 100) and, consequently, provision of health care services is currently widening from being delivered to an ill person to approaching the general population, with efforts shifting beyond acute episodes to focus on health promotion, prevention and rehabilitation.

For that reason, research leading to understanding and practice of patient flow, among such interventions and interactions, is required. The pressing need for collaboration inside and between several entities constituting a network of care, seen nowadays as a sort of remedy for inefficiency, lack of coordination, unacceptable long waiting lists, medical errors, patient discontent and ever growing costs supported by health and social care systems, makes this approach not only obligatory, but vital. A rise of demand for complex, multidisciplinary care services in an aging society and scarce resources increases an urgent need to provide tools and methodologies to guarantee and improve the coordination and continuity of care (Andreasson & Winge, 2010; Hebert et al., 2003).

The model of intersectoral partnerships (ISP) is based on understanding that sectoral differences are beneficial in creating innovative solutions (Charles & McNulty, 1998). As experience shows, ISP may increase social cohesion while producing sustainable structural and social change (Ministry of Health, 2005; Peake, Gallagher, & Valentine, 2008) and have demonstrated a great success when one-sector initiatives failed. The purpose of cross-sectoral collaboration moves beyond multiple organizations working together to accomplish what a single organization could not achieve. The challenge resides in encouraging engagement in a continuous dialogue that would lead to coherent, cohesive need-based planning and implementation, and sustainable, meaningful system change (Public Health Institute for the California Endowment, 1998).

In today’s world, a collaborative action is deemed to be a reasonable response exceeding the potential of competition in reaching a strong competitive position on the market. Collaborative linkages between health and other areas have been increasingly described in literature. As evidence shows, their multidisciplinary nature entails excellence requiring health professionals to adopt a change of practice in order to work effectively in different settings and to collaborate with professionals also from outside the health arena. Methods to determine a baseline, measure achievements along several axes, analyze multidimensional information and use results for future planning must somehow capture this dynamism.

Collaborative environment can be approached as a network of organizational relationships between service providers to a group of customers of interest. In the today’s networked society and economy, health and social care organizations seem to be by nature embedded in the network perspective as they represent business and personal relationships between diverse entities providing mostly fragmented care services to the population. Care provision involves currently different types of organizations, from different sectors, of different structures and sizes, different visions and organizational cultures, and different philosophies and operational policies. The network theory allows for analyzing these organizations and linkages existing between them from the perspective of a variety of network indicators and characteristics. Network agreements have proven to already be established in issues addressing public health matters, however, perspectives for their applications are broad and bring a promise to advance toward better health outcomes for the society involving agents across-sectors. The latter is of special relevance as the health care sector capacity has reached its limit to respond the population health care demand and health care services are nowadays strictly bound with other care services due to particularity of prevailing long-term health conditions.

A social network origins from understanding that a social phenomenon should be firstly perceived and investigated through properties of relations within and between units of analysis, instead of the properties of these units. The network approach is based on the social exchange perspective (Cook, 1977; Emerson, 1972), which points into two relevant features. Firstly, a relationship between parties is only possible when all find it profitable at any level. Second, in business relationships, cooperation is an informal process of coordinated actions between organizations (Blankenburg Holm, Eriksson, & Johanson, 1996). Network analysis understands social systems as networks of dependency relationships resulting from differential possession of scarce resources at the nodes and a structured allocation of these resources at the ties (Wellman, 1983).

While network analysis is considered to be a well-established concept, its usefulness has not reached its peak in health and social care yet (Luke & Harris, 2007). Currently, complexity and uncertainty of the environment and the surrounding dynamics make health and social care sectors not very much different from other sectors from the economy. Rutten and Boekema (2004) argue that large enterprises need to enter into the collaborative environment in order to share their knowledge and get the partners’ knowledge and skills in return, yet, the same applies to organizations involved in health and social care provision and the prospective to exchange knowledge and build synergies resorting to external contexts. Due to their interdependency, actors from the health and social care arena have been pressured to interact with other entities, having the interaction broadened from a number of organizations, in either the health or the social care, to more widespread contacts, in some cases happening on a daily basis, jointly with private or voluntary sector entities also participating in care and support services delivery. This situation has arisen to provide a response to comprehensive care needs of the country population.

Collaborative networks are considered variations of social networks, where relationships between actors are of a collaborative nature. While the basic task of a network in a business relationship is to manage economic transactions between different parties of the network, one cannot forget that social entities belong to the organizational typology as well and a dynamics of relationships derives from interpersonal relationships between individuals composing them (Granovetter, 1973; Uzzi, 1997). Therefore, it remains equally valid to apply a micro-level approach to networks, examining patterns of connections, shared norms and personal emotions between individuals besides a commonly assumed macro-level (Leek & Canning, 2011).

The Portuguese health care is built upon three coexisting and extended beyond each other systems (Barros & Simões, 2007): the National Health System (NHS), special health insurance schemes comprising certain professionals (health subsystems) and voluntary private health insurance. The National Health System exists since 1979 (Pisco, 2006) and is taxed-based providing general and universal coverage of care. The responsibility for developing health policy and managing the NHS relies on the Ministry of Health. Co-payments are required for primary care, secondary health care appointments, hospital admissions and diagnostic exams. In addition, health subsystems function as special health insurance schemes and are based on employee and employer contributions covering total or partial care. Special health insurance schemes apply to a group of professions such as civil servants, bank employees and soldiers. According to estimates, around 25% of the population benefit from a second (or more) layer of health insurance coverage through health subsystems and voluntary health insurance (Barros & Simões, 2007).

Since 2002, the Portuguese health system has adopted a number of measures to improve its performance. They have included reorganization of the public network of services, creation of long-term care units, public-private partnerships (PPP) for new hospitals, and the reform of primary care (Barros & Simões, 2007). Still, one of the major concerns in Portugal is the rise in health care expenditure. Total health spending accounted for 10.7% of GDP in 2010, more than one percentage point higher than the OECD (Organization for Economic Cooperation and Development) average of 9.5%. Health spending in Portugal increased in real terms by 2.3% per year in average between 2000 and 2009; however, this growth rate slowed down to 0.6% only in 2010 (OECD, 2012c). Despite recognized improvements in population health, this growing concern about spending levels and awareness of waste in resource allocation have motivated some policy steps toward restructuring process.

Five Regional Health Administrations (*ARS - Administrações Regionais de Saúde*) are in charge of implementing national health policy objectives, developing guidelines and protocols and supervising health care delivery.

Portuguese primary health care is nowadays provided by a mix of public and private health service providers. This network incorporates primary care system integrated within the NHS, private sector primary care providers, and professionals and group of professionals in a liberal system which the NHS contracts or with which develops cooperation agreements (Barros & Simões, 2007). For a specialist or a hospital appointment (with an exception of emergencies), a general practitioner (GP) referral is necessary. General practitioners function as gatekeepers to the system.

Traditionally associated to primary health care health centers have been an object of a reform aimed at restructuring the whole primary care system. Still, at the date, the reform has not been entirely finalized. Three Primary Care Trusts (*ACES - Agrupamentos de Centros de Saúde*), public, administratively autonomic services constituted by a number of functional units, existed in the district of Aveiro, ACES Baixo Vouga I, ACES Baixo Vouga II and ACES Baixo Vouga III, until their merger into ACES Baixo Vouga in 2012 (Ordinance no. 394-A/2012, article 2).

Hospital emergency department is, in its assumption, medical facility specialized in acute care of cases without prior appointment. However, emergency facilities have become a common choice for patients who, independently on a reason, cannot obtain a medical appointment within the primary or secondary health care. In Portugal this is a particularly serious issue and a number of non-urgent cases in an emergency room are elevated due to long waiting lists, both for GP and specialist consultations. It is estimated that around one fourth of patients in a hospital emergency department do not need immediate medical care (Barros & Simões, 2007). While the new primary care reform deems a guarantee to admission, even in case of a family doctor absence, the same does not apply to patients of traditional health centers (Szczygiel, Pinto, & Santana, 2011).

Hospitals have been subject to two types of reforms. There has been a redefinition of the existing NHS supply of hospital services resulting in closing several maternity departments and announcing new hospitals to be built under public-private partnerships. On the other hand, changes have been introduced to the public hospital model, namely to management rules and payment systems (Barros & Simões, 2007). Most hospital services are provided according to the integrated model, directly run by the NHS. Nonetheless, decentralization has not been fully possible and cooperation between the primary care services and the hospital care has not yet been satisfactorily accomplished.

Specialist care is provided within hospital ambulatory services and by private providers on a basis of agreement with the Ministry of Health. Private care provision consists of diagnosis, therapeutic and dental services, usually requested by the National Health System, and private consultations in private structures, for private beneficiaries (Council of the European Union, 2007).

Social care is of responsibility of the Ministry of Labor and Social Solidarity, which is also responsible for social benefits such as pensions or unemployment and incapacity benefits. There is a social action system consisting mainly of family and social services with casual benefits in form of cash, directed to population in risk or situation of poverty and social exclusion to groups such as children, youth, people with disabilities and the elderly. Benefits are personalized and their attribution depends on the discretionary decision of a social worker (Ferreira, 2003). A direct provision of social and family services is in majority of cases made by non-profit organizations, Private Institutions of Social Solidarity (*IPSS - Instituições Particulares de Solidariedade Social*). Social care services are provided in day centers, nursing homes and at home as personal aid and home care. Non-profit organizations manage or own 81% of social equipment and services while central and local government manages only 4%. Recently, the for-profit sector has achieved an important weight in the provision of family services, accounting for 13% (Ferreira, 2003). Day centers, nursing homes and residences for the elderly provide a broad range of services including meals, laundry services, bathing or assistance while taking medication.

In light of the increasing awareness toward changing conditions and circumstances, a network of long-term care was brought to life with an objective to face the new reality and population needs (Barros & Simões, 2007). The National Network of Integrated Continuous Care (*RNCCI - Rede Nacional de Cuidados Continuados Integrados*) was created by Decree Law no. 101/2006 within the scope of the Ministry of Health and the Ministry of Labor and Social Solidarity. This network combines teams providing long-term care, social support and palliative activity with its origins in communitarian services (Barros & Simões, 2007). The network delivers services in convalescence, medium-term care and rehabilitation, long-term care and maintenance, and palliative care units, and within day care and autonomy promotion.

The Portuguese population reached 10.6 million people (INE, 2011) and has been steadily increasing. While the population of the country has been rising, at the same time the number of births has been declining and the crude birth rate has been below the EU[1]-15 average since 1990. In 2006, life expectancy at birth was 82.3 years for females and 75.5 years for males (Barros &

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[1] EU – the European Union

Simões, 2007). The median age of the population has been gradually rising, from 31 years in 1986 to 40 years in 2008 (Barros, Machado, & Simões, 2011).

Currently, the amount of the elderly is still below the European average but represents the largest and the fastest growing population group in the country. It is estimated that between 2005 and 2030, the number of Portuguese aged 65 and above will increase from 16.9% to 23.3% and those aged 80 and older will increase from 3.7% to 6.4% of the total population (Eurostat, 2008). The increase of the population over 65 years accompanied by a steadily declining number of births and the decrease of the population under 15 will give origin of a ‘double aging’ effect (Barros & Simões, 2007). With traditional reliance on family as the first line of care provision of informal social care and support (Costa-Font, 2010; Duarte & Paúl, 2006/2007), institutionalization has been for long considered the third way to deal with the population aging (Jacob, 2002). Nowadays, a high labor market participation among Portuguese women and changes in social bonds have verified the situation, explaining a decreasing availability of informal caregivers. A number of women on the labor market has been growing and is currently 62.5%, one of the highest levels in the EU (Eurostat, 2010), decreasing women’s availability as potential caregivers (Costa-Font, Gori, & Santana, 2011). Also, few last years have been marked as a period of a negative growth or an economic stagnancy, with a high unemployment rate (Pordata, 2013), companies insolvencies and a wave of emigration seeking employment. Estimates suggest more than 70 000 leaving the country every year, of whom more than a half is of age below 29 (OECD, 2012a). Another migration is that from the inland to large cities on the coast line offering more employment opportunities and higher quality of life. All these factors expose changes in existing relationships which may lead to social isolation.

Resemblance to that observed in other developed countries does not make it less alarming (Abreu & Peixoto, 2009; Shetty, 2012). The whole developed world is aging leading to escalation of persons with multiple chronic and long-term health conditions, which prevalence increases with age. Similarities between Portugal and other developed countries are also visible in mortality statistics which appoint into non-communicable diseases, especially of the circulatory system. Diseases of the circulatory system include those related to high blood pressure, cholesterol, diabetes and smoking; although, the most common causes of death have been cerebrovascular and ischemic heart diseases. The order is, however, inverted comparing to other European countries, in which the ischemic heart disease is characterized by higher mortality indices. In Porugal, stroke remains the principal cause of death accounting for, as estimated, three deaths per hour (Martins, 2006; Sá, 2009). The standardized death rate of 147.9 per 100 000 inhabitants places Portugal at the top of the rank in Europe (Eurostat, 2014). To survivors, cerebrovascular accident is an important factor leading to morbidity, disability and dependency in activities of daily living (ADL) (Correia et al., 2004; Moutinho et al., 2013; OECD, 2012b; Stineman et al., 1997; Young & Forster, 2007) what imposes high costs to the patient, relatives and already overburdened health and social care systems (WHO, 2010a). It is a source of physical and emotional burden, which has a strong impact on patient's life and may affect life functions until the end of life. Supporting post-stroke recovery and rehabilitation, in a form of available care and services, physical or financial aid, spiritual or moral relief or any other assistance is necessary to help stroke survivors adapt to living with effects of stroke, and to help caregivers adapt to their role providing more suitable and adequate care to their significant ones.

The experience with an entity offer results in a subjective opinion of the evaluator. Perceived quality is defined as a consumer's judgment about the entity overall experience or superiority (Zeithaml, 1987). It is a form of an attitude and results from a comparison of prospects with insights of performance (Parasuraman, Berry, & Zeithaml, 1988). In the service area, measuring service quality is more complex due to characteristics of service (Parasuraman, Zeithaml, & Berry, 1985) and, as quality is a very superficial and subjective concept, it is difficult to evaluate precisely or take a direct control over a service (Yoo, 1996). Together with a question of service quality, attention should however be driven into measurement techniques and underlying them measurement instruments.

Literature provides strong evidence on two measurement instruments in the area of service quality. The SERVQUAL has been proven to be a well-developed, multi-item instrument with a five-dimensional structure. The instrument sets up expectations and experiences as perceived by a customer in five dimensions: the tangibility aspects of the service; the reliability of the service provider; the assurance provided by the service provider; the responsiveness of the service provider; and the service provider's empathy with customers. The SERVPERF arose as a subsequent instrument to measure service quality as a result of work of Cronin and Taylor (1992). The SERVPERF appears to be an interesting alternative to the SERVQUAL with an ease at use, as the number of items was reduced to a half. The original items employed by Cronin and Taylor (1992) from Parasuraman et al. (1988) were deemed sufficiently well developed in order to be maintained in the empirical part of the research. The instrument has been considered to be more efficient (Cronin, Steven, & Taylor, 1994) and analysis of structural models developed on basis of the SERVPERF has pointed into the theoretical superiority of the scale.

Satisfaction with a service is suggested to be approached as a function of two independent elements: the functional element and the performance-delivery element, i.e. the service (Czepiel et al., 1985). What allows for a judgment on a level of satisfaction with both, a good and a service experience is denominated the disconfirmation paradigm. The disconfirmation paradigm holds that predictions customers make in advance of consumption act as a standard against which customers measure an organization's performance. As such, satisfaction should be approached as a gap between expectations of a client toward a service to be experimented and an effective execution of this service (Oliver, 1980) and can be defined as evaluation resulting from the fact that experience has been at least as good as it was expected to be.

The relationship between service quality and satisfaction, although a subject of decades of research, has been fuzzy. Both of them pretend in fact, to evaluate a process of service delivery from the point of view of a consumer. Service quality and customer satisfaction have both been defined as matching the expectation of a service with what has actually been experienced by a customer. Satisfaction can be determined by a broader set of elements, also from those that come from outside the immediate service delivery. Quality is deemed to be determined more by external cues while satisfaction is determined by conceptual cues. Judgments of service quality do not depend on experiences with the service environment or providers and those of satisfaction do. Finally, service quality judgments are made based on ideals and excellence in relation to service delivery, while satisfaction judgments are based on predictions/norms for service delivery (Ting, 2004). Oliver (1980) suggests that in the absence of prior experience with a specific service provider expectations define an initial level of perceived service quality and the first contact with the service allows for revision of that initial level of service quality. Further experiences lead to subsequent disconfirmation and modification of the current opinion, changing eventually the level of perceived service quality. Finally, the redefined level of perceived service quality has an impact of a consumer purchase intentions toward a concrete service provider. In this way, Oliver's (1980) research states that service quality and consumer satisfaction are similar but distinct constructs. They are related in that satisfaction arbitrates effects of prior to the experience perceptions on service quality to result in a revisor service quality, derived from the experience.

Both conceptual and operational root has given a special attention to identifying a relationship among and between these constructs (Cronin, Brady, & Hult, 2000), and a nature and direction of a relationship between service quality and customer satisfaction has been subject of a particularly intense debate (Cronin & Taylor, 1992). Previous experience is, in the first place, essential to evaluate satisfaction. While it is necessary to have a direct contact with a product and experiment it in order to make judgments about a level of satisfaction, in case of service quality this requisite is not met. Hence, it is possible to judge service quality without knowing a product from the first hand. Second, satisfaction is influenced by a series of past experiences while service quality usually comes from a specific experience. Third, satisfaction is dependent on a value (Anderson, Fornell, & Lehmann, 1994). A body of literature providing opinion in this matter is rich. Cronin and Taylor (1992) support the viewpoint that satisfaction ensues service quality offering evidence that service quality contributes to overall satisfaction. Bolton and Drew (1991) consider satisfaction as an antecedent to service quality. When the term ‘service quality’ is used to refer to a global, long-term attitude toward a service provider, customer satisfaction is generally recognized as an antecedent of quality. In situations where the term is used to refer to something more concrete, such as quality of delivered service, then there seem to exist a stronger tendency for seeing quality as an antecedent of satisfaction (Zeithaml, 1988).

In the health care setting, where care entities are deemed to provide the same or similar types of services, quality of provided service may, however, vary among until diverse levels. Conversely, nowadays patients are not only more aware of alternatives of the existing offer, but rising standards of service have increased their expectations. Patients are becoming more critical on service quality they experience. Patient satisfaction rankings are used to judge quality of care provided by a health care organization, an individual physician’s quality of care and to determine physician reimbursement in different settings (Weingarten et al., 1995). Service quality and patient satisfaction can be therefore used as a strategic differentiation tool aimed at gaining the strategic advantage on the care market which other organization will find hard to compete with (Lim & Tang, 2000).

The World Health Organization (WHO) reports that 15 million people globally experience a stroke annually (Mackay & Mensah, 2004). Of these, 5 million die and remaining patients continue their lives with permanent or temporary disabilities (Green & King, 2010) requesting health and social care and other assistance, relying on goodwill of their relatives in activities of daily living, frequently long-term and sometimes up to their days. While the primary objective of a medical acute intervention is, with no doubt, a patient’s survival, the question arises when it comes to the future, when acute care installations are left behind and the process of adaptation to the new reality is initiated, hence a question regarding quality of further life. This issue in case of cerebrovascular disorder gains a special significance as stroke is the most common cause of disability and dependency in activities of daily living (Stineman et al., 1997) imposing high costs on care systems and patients’ caregivers (WHO, 2010a). Stroke, therefore, as a medical condition with all its implications requires care systems to work in collaboration to provide patients with maximum necessary and potential services in order to enhance their quality of life.

Nowadays, assessment of quality of life has been considered one of the most important ways to measure outcomes after stroke.

Measuring quality of life is useful in gaining a better understanding of patients' reaction to illness and for developing a curative process, as well as in monitoring the efficacy of medical care. The interpretation of quality of life findings may be complicated by a wide variety of methods used in evaluation of quality of life (de Haan et al., 1993). Still, it is vital to consider quality of life measures from a patient and an institutional perspective. They can offer a great potential in informing economic analyses and resource allocation decisions, and influencing health care policy (Guyatt, Feeny, & Patric, 1993). On the patient's side, quality of life instruments help quantify the result of interactions between received care (Siekierski & Rutkowska, 2008), coping capabilities and received social support.

Quality of life measures comprise generic scales or health profiles, disease-specific scales and scale batteries (Patrick & Deyo, 1989). Generic measures may be suitable for use with a variety of patient populations and allow for different types of comparisons across patients groups. Disease-specific measures are destined to tailor a specific condition and have been so far developed for several health conditions. While they cannot offer cross-disease comparisons, they are more sensitive to issues particularly relevant among a specific population of patients from the point of view of quality of life. The third option is a battery of scales for measuring a particular dimension or an aspect of health. These can measure ADL, social functioning and cognitive functioning, among others (de Haan et al., 1993). In case of patients with cerebrovascular disorder, the procedure of collecting any type of data, including data on quality of life, requires balancing between response rates and costs, especially those perceived by patients. Possible patient burden should be evaluated and taken into account when designing data collection methodology of any study involving stroke survivors.

The main goal of this thesis is to investigate the status of intersectoral collaborative action for stroke patients in Portugal. Particularly, this work aims at evaluating the impact of existing partnerships on patients' quality of life, perceived service quality and satisfaction with care, support and assistance services they experienced, and analyzing ways they function in the Portuguese context.

More specifically, the thesis aims to:

a) systematically review the Portuguese legislation on intersectoral partnerships in health and social care, and analyze their character and application;

b) conceptualize intersectoral partnerships, identifying established theories, models and methods;

c) identify expectations of stroke patients discharged from the stroke unit and their general awareness of the care system;

d) demonstrate experiences of stroke patients with entities providing care and support services, and the care system in general;

e) establish the level of perceived service quality provided to stroke survivors and their satisfaction with them;

f) propose a service quality measure adapted to health and social care context and verify its feasibility through exploratory principal component analysis and confirmatory factor analysis;

g) demonstrate perceptions of informal social support and its relevance in post-stroke daily life;

h) evaluate the scope and importance of social network support with an adequate assessment measure;

i) verify quality of life of stroke patients in the 2nd and 6th months after discharge from the stroke unit and comprehend its implications for their daily life;

j) determine the structure of the institutional network of entities providing care and support services for stroke patients discharged from the acute stroke care unit in the district of Aveiro;

k) demonstrate the institutional perspective on collaborative aspects of care provision and the care system functioning from the viewpoint of the network member;

l) determine the extent of collaboration intensity between entities constituting the network of care for stroke patients;

m) analyze the status of intersectoral collaborations in care services for stroke survivors with special attention to legal, structural and functional aspects of these arrangements;

n) propose a framework of a patient-centered collaboration intensity model in an intersectoral setting.

In order to fulfill the aims of the thesis, extensive review of literature was the starting point to be confronted in a real setting, comprising stroke patients discharged from the stroke unit and confronted with the reality and an actual status of cross-sectoral initiatives. Subsequently, it was necessary to engage two different but complementary data collection phases. First one encompassed a six-month follow-up process of each subject, beginning in the stroke unit and comprising qualitative and quantitative assessment methods. For quantitative methods, it involved a development or a methodic translation of measures assessing patient's expectations and experiences with care, service quality, quality of life and informal social networks. Qualitative methods were related to interviews carried out in the 6th month after discharge with an objective to evaluate service quality experience with institutions not assessed quantitatively and provide a vision of the care system as seen from the perspective of a stroke patient. The second data collection phase comprised two elements. First was developed after having previously identified the existing providers of care and support services for stroke survivors, and its objective was to determine the level of intensity of collaboration between the members constituting this network. The second element involved interviews with the key informants representing groups of entities providing care and support for patients who underwent cerebrovascular accident.

The thesis is composed of two parts. The first, theoretical part, includes four chapters and lays the theoretical foundation of the study, providing a framework on collaborations and intersectoral action, networks in an organizational perspective, service quality and satisfaction, and quality of life. The second part of the thesis elucidates the empirical analysis, presenting the research methodology underlying the present study, the results and their discussion. Limitations of the study are also provided.

The first chapter addresses the intersectoral approach to partnerships and collaborations. It brings closer definitions and forms of collaborative linkages, together with available frameworks for collaborative action and collaboration intensity, with a discussion on collaborative engagement in health and social care. Collaboration between health and social services has been acknowledged by policy makers in many countries and care systems as a fundamental solution for systemic exigencies. While its popularity has reached a peak in the last years, the potential of collaboration, especially the one crossing system boundaries, has been continuously recognized since the 1970s. Intersectoral partnerships are thus proposed as particularly well suited to addressing complex social problems that cannot be solved by single sectors and organizations acting alone. The chapter presents historical development of the concept of intersectoral action and its existence in international documents. The results of the systematic review of the Portuguese legislation concerning the interest in intersectoral approach in health and social care conducted within this work are provided in this chapter.

The second chapter reviews relevant literature on networks and their importance for organizational arrangements. It presents the theoretical framework of networks and discusses the concept, development and relevance of the network analysis, as health and social care organizations can be successfully approached through networks to pursue with their activities. The chapter brings closer advances in the development and evolution of the network theory over time and its application into social sciences. The forms, types of networks and participating actors, and characteristics of networks are depicted and discussed.

The third chapter derives from an extensive literature review carried out on constructs of service quality and satisfaction. It conceptualizes services in economics and identifies their unique characteristics. To support an ongoing discussion of academics on a relation between service quality and satisfaction, both concepts are presented and evidence from literature is provided. The chapter presents models of service quality identified in literature and discusses instruments measuring service quality. It illustrates how service quality construct can be applied to health care services.

The fourth chapter provides literature review results on quality of life as a concept, and generic and disease-specific assessment measures applied in studies on perceived quality of life. The chapter defines quality of life and its general aspects focusing on notions of quality of life and health-related quality of life. It concludes with an extensive debate on measurement of quality of life, both in terms of persons with general conditions and in patients with cerebrovascular accident. Generic and specific measures found to be employed in studies with stroke patients are presented together with their key features.

The fifth chapter discusses and justifies the way the research was carried out. It introduces general methodological issues followed by the rationale of the study. Research framework and design provides contextualization of the study, especially useful for readers not familiar with the Portuguese health and social care context; and explains in detail applied literature search strategy. It provides procedures applied in two study phases, with research instrument selection and development. Data collection, processing and analysis are presented.

After clarifying methodological choices of the research, the sixth chapter presents and interprets results of the empirical study. It characterizes patients participating in the study and the study variables with a closer focus on relationships between them found relevant for fulfilling the study objectives. It discusses subjects’ expectations and experiences with entities involved in provision of care and support in lens of service quality and user satisfaction concepts. The relevance of these factors for stroke patients, variation of patients’ quality of life throughout the study span, together with informal social network and its importance for quality of life are demonstrated and discussed.

In order to balance the vision gathered from patients, the perspective of a care provider on the current collaborative status of the system is also provided with the use of a theoretical model as a basis for the considerations. This is done in chapter seven. The study contributes with a general vision of entities currently offering cross-sector care and support to stroke survivors in the district of Aveiro and maps collaborative linkages between them.

Finally, in the last chapter, the main findings and conclusions are presented providing a proposal of a measure of service quality more specifically focused on the particularity of health and social care services, together with the implications of the study. Deliberations on limitations of the work and suggestions for future research close the chapter and the thesis.

PART ONE

CHAPTER ONE:

APPROACHING PARTNERSHIPS THROUGH THE INTERSECTORAL DIMENSION

In today's world, a collaborative action is deemed to be a reasonable response to the competitive environment surpassing the potential of competition. Different types of collaborative arrangements, established on a more formal or informal basis result from joining forces of representatives of different agents and sectors of the economy. For specific issues affecting the population health and social care, mutual actions of different sectors of the society have been their driving force, gaining significance over time and in a global context. Intersectoral partnerships have been identified as an important strategy for addressing health challenges societies are facing as a result of demographic, economic, social and epidemiologic changes in the contemporary world (Kickbusch & Quick, 1998).

There is a body of evidence demonstrating existence of health and social inequalities, in both, urban and rural settings, independently of political, social or geographic factors. Several public policies have successfully appointed sources, level and character of such inequalities, but a burning challenge to address complex needs with a multi-stakeholder and coordinated approach still remains. Policies of all sectors that concern health directly or indirectly need to be analyzed and aligned to maximize opportunities for health promotion and protection. Because many social and environmental factors interact to influence health, development of partnerships allows for a more comprehensive approach improving health in communities. Collaborative linkages between health and other areas have been increasingly described in literature. They require health professionals to adopt excellence in strategies of change in practice to work effectively in different settings and to collaborate with non-health trained professionals. Generally, public actors specifically face a need to consider fully a decision on joining a collaborative initiative and reflect on a problem in cause, the most suitable, even if idealistic, solution, and comparing different alternatives, including traditional approaches, as well.

Collaboration among organizations of all kinds, together with cross-sectoral partnering, has been a major subject of interest in health care and public health industries (Greenwald, 2008). A significant barrier to these approaches is lack of effective relationship between organizations. From a focus on separate organizations, new challenges ask for health and social care to be delivered across organizations requiring transforming occasional, often informal partnerships into a serious, long-term commitment (Jackson et al., 2008).

No one in the public or private sectors has currently responsibility for overall health status of the Portuguese population and its improvement. Persistent disparities in health as well as new and evolving disease risks have increasingly moved public health organizations to seek additional capacity and expertise through collaboration with other institutions. Some advances have been registered in this matter, especially in what multi-disciplinary and multi-sector approach to health care concerns. Established in 2006 the National Network of Integrated Continuous Care has had a valuable contribution in the cooperation between entities involved in health care provision. Despite a number of recognized achievements of the RNCCI, the tendency to collaborate has not spread in the same scope into and within the social care.

In this chapter the rationale of a partnership engagement jointly with its intersectoral dimension will be brought closer and discussed. A theory behind partnerships especially intersectoral partnerships is particularly scarce, and, on the other hand, accessible classifications and taxonomy related to partnering definition are abundant with no clear and formal conceptualization in use. Therefore, this chapter, after presenting the concept and rationale of collaboration in Section 1.1, brings results of literature review of existing approaches to defining collaborative bonds which are presented in Section 1.2. Intersectoral collaborations are discussed in Section 1.3 in light of public-private partnerships, as a type of partnerships perhaps most present in communication media. Section 1.4 discusses a continuum intensity of partnering followed by a sectoral approach to the economy in Section 1.5. Section 1.6 addresses determinants of partnerships, while the next deals with evaluation of partnership issues. Section 1.8 provides evidence of relevance of intersectoral partnerships in international context devoting special attention to international documents and events which focus, at least partially, on intersectoral action in health and social care. Section 1.9 focuses on intersectoriality in health and social care in the Portuguese context and provides results of the systematic review of legislation on intersectoral action in this matter.

1.1. Collaboration concept and rationale

Facing current challenges in health and social care provision, entities opt for cooperative, collaborative, competitive or neutral strategies toward organizations with which they interact, or, considering them individually, a mix of those. The problem of cooperation lies in explanation why an individual should present cooperative behavior that would benefit other individuals

(Hamilton, 1963). Research trying to comprehend the origin and evolution of cooperative behavior has been intense and yet, agreement between social and biological sciences on the origins of cooperative behavior has been poor (West, El Mouden, & Gardner, 2011). As Fehr (2004) acknowledges, evolutionary psychologists have sought to answer the "puzzle" of human collective action for decades (p.449). Among theories that may come to explain this phenomenon lie kin selection, reciprocity, cultural group selection and game theory.

Kin selection and reciprocity are theories tending to explain behavior in small groups. Kin selection, discussed as a concept first by Darwin in his "The origin of species", assumes a conscious choice to support the reproductive success of a person's relative or relatives (kins) even on a cost of the own reproduction or survival. West, El Mouden and Gardner (2011) understand kin selection as "process by which traits are favored because of their effects on the fitness of related individuals; the way in which natural selection may be separated into direct and indirect components" (p.232). Kin altruism is a term for altruistic behavior which evolution is supposed to have been driven by kin selection.

In evolutional biology, reciprocity refers to development of altruistic or cooperative behaviors bearing in mind the probability of future mutual interactions. In literature, the theory exists formally under a designation 'reciprocal altruism'. The theory was developed by Trivers (2002), as an attempt of explanation of mutual altruistic behaviors among unrelated individuals, which kin theory could not explain. The idea behind the theory of reciprocal altruism was that individuals (organisms) would support each other if there was an expectation of a return of that favor in the future. The author did not limit the theory exclusively to human beings – relations could occur among unrelated organisms, including members of different species. Two assumptions of reciprocal altruism theory were: (a) more than one contact between involved individuals so that the favor could be returned; and (b) the ability to recognize the individual and match them with the right favor (Shannon & Schmidt, 2002). Clearly, in case of more frequent contacts, those who have refused to return a favor and have been identified would prejudice their eventual help requests in the future as information about their behavior would spread.

Cultural group selection offers a convincing explanation on how large-scale complex societies have been formed. The theory focuses on large societies of anonymous individuals and requires persistent cultural differences between existing groups that are able to remain as human beings present a set of attributes supporting the maintenance of groups over time. Without between-group variation, cultural group selection could not occur as there would be no group differentiation to select for. Through cultural group selection, culturally specific cooperative behavior can evolve to support large societies as a result of cultural exposure rather than biological evolution.

Game theory is considered the principal approach in comprehending the phenomenon of cooperation. Game theory is a study of strategic decision making between two rational and intelligent parts, varying from cooperation into conflict. In the logic of game theory, John Nash described the Prisoner's Dilemma, which brought him the Nobel Prize in Economics in 1994. In the Prisoner's Dilemma, two prisoners under investigation may choose a number of strategies of cooperation or defection. Choices to be made are taken under limited information and can result in either conviction of both with stiffer penalties, or conviction of both with more indulgent penalties, or a conviction of one and acquittal of another. Cooperation in the Dilemma appears to be the best option for both prisoners, resulting in milder penalties and lesser overall penalty in total. The level of cooperation tends to be higher with less fear and less greed of the players. Traditional game theory results in both players obtaining worse pay-off than if each one chose to diminish the sentence of their accomplice at the cost of spending more time in prison themselves. Abramovay (2000) agrees that the Prisoner's Dilemma shows individual immediate interests as opposed to "socially optimal allocation of resources" (p.382).

A number of theories appear also in the economics literature trying to explain the tendency of organizations getting together into a joint activity. The theory of transaction costs is one of the widely discussed. It considers how an organization would manage the boundary of its activities so as to minimize the sum of its production and transaction costs. In this case, if a collaborative engagement offers cost minimization, it will be considered a feasible option in the eyes of the market requirements.

The stakeholder theory of the company assumes this organization to be a center of attention of a group of different stakeholders and, in consequence, form relationships with some of them in order to minimize environmental risk and ambiguity, and align different interests.

Other theoretical perspectives appearing in the economics literature include theories of strategic choice and organizational learning. The strategic choice considers an organization one of several actors of the market and looks at reasons that bring into light opportunities to improve its relative market position, increase its competitiveness by profit and growth imperatives. Expanding geographically and broadening the scope of products/services, organizations aim to develop. Organizational learning models suggest that organizations, build upon human beings, enter in a process of learning and join collaborative arrangements in order to learn from another, increase organizational skills and competencies and eventually, create an added value.

Interorganizational systems supporting inter-agency collaboration must accommodate a wide range of factors from an external environment and participating organizations as part of their design and operation. Views that different partners hold regarding the parameters of their roles and values that guide their approach to service delivery are likely to exert profound effects on engagement with collaborative initiatives (Mitchell, 2009).

The rationale behind the collaborative engagement is that an organization is capable to achieve more of what could do without the collaboration, and create synergies. Lasker et al. (2001) define synergy as the extent to which the involvement of partners improve their capability to undertake action, activate objectives achievement, be accountable and respect the stakeholders' needs and expectations. The authors conclude that key determinants of the partnership synergy include partner characteristics, relationships among partners, characteristics of the partnership arrangement, resources, and factors deriving from the external environment of partnership. Nevertheless, synergy cannot be considered a clear and predictable outcome of partnership (Dowling, Powell, & Glendinning, 2004). Some body of research actually suggests that nearly 50% of partnerships dissolve within the first year of their existence and before even achieving the first set of objectives (Kreuter & Lezin, 1998). Because of these difficulties, Weiss et al. (2002) recommend measuring partnership synergy as a proxy for effectiveness since it can be measured more easily than outcomes. Their theory assumes that partnership that has maximized synergy has achieved the full potential of collaboration.

1.2. Forms of collaborative linkages

One of the enduring problems of research in the field of interorganizational studies is that there is no common and accepted meaning for terms that are typically used to describe forms of interorganizational relationships such as collaboration, alliance, coalition, cooperation, coordination or partnership (Williams & Sullivan, 2007). Huxham (1996) underlines that these terms embrace cooperation, coalition, joint working, network, alliance, partnership and a number of others, all meant to be synonymous in illustrating collaborative engagement. At the same time, some scholars specify one of these concepts distinguishing it from the others on a basis of the own or adopted definition (Horwath & Morrison, 2007).

There is diverse literature body characterized by "a cacophony of heterogeneous concepts, theories, and research results" (Oliver & Ebers, 1998, p. 549). Conceptual confusion and differential framing processes often lead to misunderstanding and conflict during the further process of collaboration. Ling (2000) concludes that literature on partnership amounts to “methodological anarchy and definitional chaos” (p.82).

There is considerable definitional imprecision in the language that describes the range of activities that are encompassed within the terms ‘partnership’ and ‘collaboration’ (Huxham, 2000). Numerous conceptualizations of collaboration surely add richness to research, although they habitually hamper its strictness and cumulativeness (Thomson, Perry, & Miller, 2009). Following the report “Achieving public sector outcomes with private sector partners” (2006), for the purpose of this work, the definition of ‘partnering’ has been adopted as a comprehensive designation encompassing a wide range of mutually profitable procurement relations between the public and private sectors that engage a collaborative approach to achieving care sector outcomes. The relations in cause can include partnership in the legal business meaning, and other commercial arrangements between the parties which adopt a collaborative approach. Together with ‘partnering’, ‘collaboration’ term, as related to collaborative engagement and bonds, will be used synonymously.

Collaborations and partnerships are not a homogenous form of governance, but consist of a diverse and complicated set of institutions, with different focuses, scales of operation, durations and histories, and patterns of sector representation and funding (Edwards et al., 2000, p. 10).

1.2.1. Coalition

Coalition can be defined as a temporary union for a shared cause. While certain resources may be pooled, working relationships will most often not be at the same degree of close cooperation as in pure partnerships. Forming coalition takes a collaborative action to a level which addresses a need of change in policy, service design and delivery or service gaps (Huxham, 1996; Winkworth, 2005). Horwath and Morrison (2007) describe this level as “joint structures which sacrifice some autonomy” (p.56).

O’Neill et al. (1997) propose an interesting interpretation of coalition theory applying this concept to health-related intersectoral action. The authors explored the usefulness of coalition theory as a theoretical framework through which they claimed it was possible to approach the health-related intersectoral action theoretically and practically. This was because coalition theory, although previously applied to studies on political alliances, shared some parameters that might be relevant for analyzing cross-sector initiatives. These parameters comprised: rewards people expect to gain from participation in coalition, political assets they have to bring to coalition, non-utilitarian preferences they develop, coalition rules for decision-making, and organizational context in which coalition operates.

1.2.2. Alliance

Some collaborative arrangements have gained other taxonomy. Alliance can be approached as a union of various groups and organizations for mutual benefit and support of a shared cause. It is a private and public sector actors' initiative to deliver a specific project and comply with a certain project goals and achieve planned outcomes. The parties work together as an integrated team which is provided with incentives to achieve high performance and all its members commit to working through collaboration, innovation, and mutual support (Office of the Auditor-General, 2006, p. 5).

For Mays, Halverson and Kaluzny (1998), collaborative arrangements are synonymous of an alliance. They conducted a descriptive study within a nationally selected group of local communities and supplemented it with detailed case studies of eight analyzed communities. Alliances were observed predominantly in areas such as service delivery, planning and policy development, surveillance and assessment, and education and outreach. Their primary objectives included acquiring organizational knowledge and skills, addressing common resource needs and pursuing a shared organizational mission. Finally, the authors reported that structurally, alliances were activated through informal collaboration, contractual agreements, shared governance, and shared ownership.

1.2.3. Cooperation

Cooperate is to act together in a harmonized manner in order to achieve common goals. Mutual benefits may not constitute a unique driving force toward cooperation as cooperation may also be driven from pleasure to share activities (Argyle, 1991). Horwath and Morrison (2007) describe cooperation as "joint working together on a case-by-case basis" (p. 56). Not all organizations have a potential neither are all environment supportive to cooperative actions. This way of working together is typically developed between skilled practitioners regardless of agency, policies and procedures and with a view to different goals. At this level, there are limited or no formal agreements and work focuses on an individual, case-specific situation (Horwath & Morrison, 2007).

There is a number of ways in which public authorities and a non-governmental sector can interact. They often occur, *de facto*, in a formula unnamed by any of the parties. Cooperation is considered an initial level of possible stronger future relationships actors may establish. It is difficult to objectively identify cooperation to happen, however, a presence of elements such as repeatability of contacts or an agreement between parties may attest it. This requires more organizational involvement than infrequent contacts and networking, and is considered particularly important from a point of view of people who find uncoordinated systems unfriendly. For instance, agencies that initially contact to share information about programs may decide to move it a step further and change their program content and schedule in order to better serve their mutual client groups. Hence, these activities aim to improve service accessibility for mutual service users (Huxham, 1996). Research literature shows that dealing with vast amount of societal problems can be tackled through interorganizational cooperation (Pearce & Doh, 2005).

1.2.4. Coordination

Coordination can be seen as a process in itself and a snapshot of a degree of integration in which, as Horwath and Morrison (2007) state, there are “no sanctions for non-compliance” (p. 56). Coordination becomes relevant whenever the decisions of two or more units (actors, policy networks, etc.) are interdependent (Hogl, 2002). For policy coordination, understood as a process, one needs to take into account its total duration, number and typology of its stages, number and character of involved actors and policy cycle stage in which it is inserted. Policy coordination as a degree for integration represents efforts toward strengthening coherence and consistency of policy programs and initiatives, and identifying the existence of policy gaps. These deficiencies should ideally be eliminated by means of successful coordination. Coordinated activities aim to improve service accessibility for mutual service users (Winkworth, 2004), what requires a higher level of organizational participation than unstructured contacts and gains a particular relevance when uncoordinated systems are additionally not user-friendly (Huxham, 1996). This allows therefore for a better meeting mutual client groups’ needs.

Literature mentions the term ‘coordination’ in different contexts, including multi-level coordination, policy positive and negative coordination, and coordination between diverse sectors of the society. A social issue usually goes beyond geographic or administrative boundaries, created artificially by humans. There is often a need to coordinate action between different involved bodies and also vertically, between international, national, regional and local authorities. Scholars discuss also the logic (Putnam, 1988), potential threats and pressures of multi-level governance.

The concept of negative and positive coordination can be applied to links between different policy and economy sectors as well as to horizontal relations between the State, business and civil society. An interesting discussion on positive and negative coordination aspects of coordination is the one made by Zingerli, Bisang and Zimmermann (2004). Positive coordination implies a higher degree of cooperation with actors trying to optimize the utility of a large number of activities over time. After an initial evaluation of engagement options, the ones offering optimal solution in a long-term perspective are chosen and voted for. The decision continuum is treated as a whole rather than individually, by which a choice offering some disadvantages for a party is not excluded from the beginning, but can still be considered feasible in light of hope for future compensations. Negative coordination implies a low degree of cooperation with single actors aiming to optimize the utility of each activity at a specific point of time. Any policy proposal bringing with itself possible costs is immediately criticized and into a high degree; these negative reactions constitute a major part of the policy decision making process. Therefore, only those proposals beneficial or neutral to all and so not vetoed, have a chance to pass, what limits significantly the scope for action of the one in charge of coordination. In this way, a number of policies are vetoed and readiness for change in the status quo is on the bottom line. From the welfare theory perspective, positive coordination promises far better results for maximizing general welfare than negative coordination. There are numerous cases in which general welfare can reach the optimum only at the cost of some losses supported by given parties, thus negative coordination provides a very restricted ability to promote social welfare.

Intersectoral coordination derives from inter-agency interest, responsibility and involvement into an issue in cause. Such issue is influenced by a variety of forces, from political and economic through social into legal or even environmental ones. Cross-sector coordination refers to the need of synchronizing strategies, procedures and measures of different policy domains. Literature mentions also, in contrast, the intra-sector approach or intra-agency coordination as means to policy integration where all elements of a single policy domain should comprehensively take a problem in question into account, such as environmental protection mentioned by Lafferty and Hovden (2003). Whereas single agencies can implement intrasectoral approaches, intersectoral coordination should be mandated by the government.

1.2.5. Collaboration

Like “community”, partnership is a word of obvious virtue (what sensible person would choose conflict over collaboration?) (Clarke & Glendinning, 2002, p. 33). Collaboration does not necessarily make sense as an approach for addressing every development need, but it is vital under two specific conditions: when a particular social problem is so complex that it exceeds the capacity of one actor be solved by working in isolation, and when a specific problem issue goes transversely through fundamental interests of multiple stakeholders.

Although there is considerable variation in the use of terms, collaborative practice models usually refer to several common strategies and levels of working together. Literature provides numerous definitions of collaboration. Interorganizational collaboration is a term used to describe a process that “can emerge as organizations interact with one another to create new organizational and social structures” (Thomson et al., 2009, p. 23). Bardach (1998) defines collaboration as “any joint activity by two or more agencies working together that is intended to increase public value by their working together rather than separately” (p. 8). Sowa (2008) finds this definition useful as it requires from an inter-agency collaboration “two or more organizations working together; some kind of activity; and some kind of public value produced through the activity” (p. 301).

Sowa (2008) refers also to Gray’s (1989) definition as to “a mechanism through which parties that see different aspects of a problem can explore constructively their differences and search for solutions that go beyond their own limited vision of what is possible” (pp. 300-301). Mattessich, Murray-Close and Monsey (2001) define collaboration as a mutually beneficial and well-defined relationship entered into by two or more organizations with a commitment to a set of common goals, a jointly developed structure and shared responsibility, and mutual authority and accountability. They sustain that relationships based on trust and a shared vision have a potential of enhancing the ability of parties to achieve qualitatively better outcomes.

Clairborne and Lawson (2005) state that collaboration is “a form of collective action, involving multiple agencies working together in response to special mutually dependent needs and complex problems. Agencies come together to collaborate because no one alone can achieve its missions and goals, improve results, and realize desired benefits without the contributions of the others” (p. 2). The Public Health Agency of Canada (2008) definition of collaboration refers “a recognized relationship among different sectors or groups, which is formed to take action on an issue in a way that is more effective or sustainable than might be achieved by the public health sector acting alone” (p. 9). For Scott (2005) collaboration is “all interaction aimed at working together, both informal and formal, which occurs across the boundaries of different organizations and sectors” (p. 133). UK Audit Commission (cited in Dowling et al., 2004, p. 310) describes it as “a joint working arrangement where partners are otherwise independent bodies cooperating to achieve a common goal; this may involve the creation of new organizational structures or processes to plan and implement a joint program, as well as sharing relevant information, risks and rewards".

This concept of a collaborative linkage emphasizes several points (Williams & Sullivan, 2007): collaborations involve collectively devised strategies for responding to environmental turbulence; collaborations tend to be imprecise, emergent, exploratory and developmental in character; collaborations serve as quasi-institutional mechanisms for accommodating differing interests in society and for coordinating interorganizational relations; they represent a nascent form whose legitimacy as an institution is still being negotiated which can result in more permanent forms of institutional arrangements; and collaborations serve as vehicles for action learning involving processes of reframing or redefining the problem domain (pp. 16-17).

Lawrence, Phillips and Hardy (1999) characterize collaboration as: "a cooperative, interorganizational relationship that relies on neither market nor hierarchical mechanisms of control, but is instead negotiated in an ongoing communicative process". In this understanding, it is not a market mechanism on its own that arbitrates collaboration and importantly, "whereas hierarchies are associated with a willingness on behalf of members to submit to both direction and monitoring of their superiors, collaboration involves the negotiation of roles and responsibilities in a context where no legitimate authority sufficient to manage the situation is recognized" (p. 481).

According to the conceptual model framed by Gray (1989), collaboration process involves four key characteristics: partners are independent, decisions are made together, the process is beneficial and evolving, the project is of collective responsibility of all partners.

Collaboration may be referred as partnership when stakeholders voluntarily enter into a commitment with a view of mutually beneficial outcomes, join resources and share risks. Therefore, a partner in this understanding is perceived as a complementary party able to contribute into optimizing and achieving a more complete solution. In this context, collaboration is seen as a solution to coordinate services rather than just solving an emergent problem. In this case, the question on what happens to the partnership agreement when the goal is achieved does not apply. According to O'Looney (1997), "collaboration refers to partnership formation that is believed to bring about change" (p. 32). Wilson (2000) considers collaboration to be the most effective tool to "create something entirely new" (p. 700). Noteworthy, Eweje (2007) uses terms partnership and collaboration interchangeably.

The variation in use of collaborative terminology is considerable and can be grouped as networking and communication, cooperation and coordination, collaboration, integration and “whole of community’ partnership” (Huxham, 1996). Scholars mention the term “whole of community’ collaboration” or “whole of community’ partnership” (Huxham, 1996; Winkworth, 2004) as that referring to links between a wide range of community partners that go beyond formal collaboration. Strategies of a collaborative taxonomy use tend to build upon each other along a continuum of complexity and commitment. For some authors collaboration takes place within a variety of contexts and involves different levels of members’ integration. Horwath and Morrison (2007) deem the term ‘collaboration’ to be a general starting point to describe different phases of integration.

The rationale for collaboration appears obvious as much as it is aimed to promote multidisciplinary practice (Horwath & Morrison, 2007). Hudson (1987), considers that collaboration will only occur under certain conditions, namely: organizational homogeneity (e.g. structural or cultural similarity); domain consensus (i.e. agreement on what each organization will and will not do); awareness within organizations of their interdependence; benefit to be gained for both sides; and absence of alternative organizations with which to collaborate.

As collaborative arrangement is not straightforward, Gray (1989) comes with her proposal for the dynamics of a collaborative process. In this three-phase practice, the first phase, called the pre-negotiation or problem-setting phase, addresses six issues: all involved actors need to reach a shared, common definition of the problem in question and relate this problem with the interdependence of the parties; the stakeholders need to make a commitment to collaborate; the stakeholders may come to identify other stakeholder not yet involved in the arrangement who may be vital for the success of the collaborative engagement; the stakeholders need to recognize and accept the legitimacy of the other participants; the stakeholders need to reach a decision on a possible leader or convener who can bring the parties together; and participants need to categorize and determine resources necessary for the collaboration. In the second phase, named direction-setting phase, the parties determine their own objectives comparing them to the individual objectives of the others. Six steps are essential for completing this phase: establishing rules; establishing the agenda; organizing sup-groups; seeking for information vital for the problem in cause; exploring different alternative solutions; and reaching agreement and setting up the procedure to be followed. The last phase encompasses the implementation process during which the structures for the implementation shall be established, the agreement is monitored and compliance is ensured.

Collaborative partnerships, according to Gray (1989), can be broadly grouped under two headings: those aimed at resolving conflicts and those designed to develop and advance shared visions for the future. Collaboration involves activities between organizational bodies between different professional and occupational groups, functions, levels of intervention, as well as between those for whom collaboration seeks to benefit. The aim is to build an initial level of trust, at first best undertaken person to person (Huxham, 1996) and only after moving forward to relations between organizations. Hughes and Weiss (2007) emphasize that collaborative attitude needs to be actively fostered by leaders and present throughout all phases although practice shows that only at a very limited scope promotion constitutes an actually implemented point of the agenda. Huxham (1996, p. 29) points out that although collaboration between services can produce significant improvements for service users, it does not tend to produce long-term ownership by communities themselves or to increase significantly communities control over their own destinies.

Martin-Misener and Valaitis (2008) conducted a literature review on collaboration in primary care and public health. Among selected papers that reported specific collaborations, each paper was categorized according to Lasker, Weiss and Miller's (2001) models of medicine and public health collaboration. Categories were chosen based on the prime objective of collaboration as defined by authors. Results of the literature review are depicted in Table 1. From the total number of papers, the biggest share, 22.5%, encompassed Synergy III, focusing on improving quality and cost effectiveness of care by applying a population perspective to medical practice. Synergy IV, using clinical practice to identify and address community health problems, was reported by 17.5% of reviewed works; Synergy I, improving health care by coordinating services for individuals and Synergy VI, shaping the future direction of the health system by collaborating around policy, training and research, was reported in 15% reviewed works, each.

Table 1. Models of medicine and public health collaboration as identified by Martin-Misener and Valaitis (2008)

Models of medicine and public health collaboration after Lasker et al. (2001)			
Synergy	**Models**	**Synergy**	**Models**
Synergy I: Improving health care by coordinating services for individuals	• Bring new pe rsonnel and services to existing practice sites • Establish one stop centers • Coordinate services at different sites	**Synergy IV:** Using clinical practice to identify and address community health problems	• Use clinical encounters to build community wide databases • Use clinical opportunities to identify and address underlying causes of health problems • Collaborate to achieve clinically oriented

			community health objectives
Synergy II: Improving access to care by establishing frameworks to provide care for uninsured	• Establish free clinics • Establish referral networks • Enhance clinical staffing at public health facilities • Shift indigent patients to mainstream medical settings	**Synergy V:** Strengthening health promotion and health protection by mobilizing community campaigns	• Conduct community health assessments • Mount health education campaigns • Advocate health-related laws and regulations • Engage in community-wide campaigns to achieve health promotion objectives • Launch "Health Communities" initiatives
Synergy III: Improving the quality and cost effectiveness of care by applying a population perspective to medical practice	• Use population-based information to enhance clinical decision-making • Use population-based strategies to "funnel" patients to medical care • Use population-based analytic tools to enhance practice management	**Synergy VI:** Shaping the future direction of the health system by collaborating around policy, training and research	• Influence health system policy • Engage in cross-sectoral education and training • Conduct cross-sectoral research

Source: Martin-Misener & Valaitis (2008)

Among authors approving the generalist vision to portray collaboration by the use of any of the terms, it seems there is a common agreement in using designation 'cooperation' and 'collaboration' (Thomson et al., 2009). In her study, Polenske (2004) alerts for similarities between them as both refer to relations between public or private actors, different in length and strongly dependent on the context they are inserted. Still, she recognizes their use as synonyms an evident failure and considers them distinct concepts. Silva (2007) supports this viewpoint, making an observation that successful collaboration can evolve into cooperation since cooperation attaches partners into functions not limited by sectoral disparities.

Cooperation is told to occur on the horizontal level offering potential gains to all involved partners, although their motivations may not be similar. Collaboration can occur on both, horizontal and vertical levels, and assumes to be on basis of support (or from a 'pleasure to cooperate') that one entity provides to another. On the horizontal level, links between organizations from different sectors yet working on the same, local, regional national or international level, are established. Vertical linkages are set up between organizations operating within the same sector but on its different levels. At the community level, action can be better adjusted to local conditions and reality so that information on national and international levels may exert influence on action taken at the local level, and regulate the proceedings. In fact, legal adjustments are sometimes needed to put a formal solution into practice. Polenske (2004) in turn associates horizontality to cooperative and verticality to collaborative actions making horizontality and verticality differential facets between cooperation and collaboration.

Explicit, but not obligatorily exclusive gains are guaranteed for one side, but further implicit benefits in corporate image or reputation are an added value to the core arrangement. Thus, cooperation as an interorganizational strategy offers a potential to meet both parties' strategic objectives and contribute to the increase of their market competitiveness.

No specification as for a type or character of an entity is made an assumption when cooperative or collaborative links are set up. In cooperation, partners act in a complementary, inversely to competitive mode, always on an equal position, guaranteeing their own organizational and managerial independence. Collaboration in itself implies existence of a project manager in charge of long and short-term objectives and fully responsible along the performance continuum. Winckler and Molinari (2011) go further and point out that alliances motivated by common gains are considered cooperative; however, if established between current competitors, are considered coopetitive. In case of alliances offering benefits to one of the engaged actors, we are dealing with supportive, that is, collaborative attitude.

The balance for collaborative engagement in literature appears mixed. While some scholars (Gray, 2002) deem its capacity to enhance quality, cost effectiveness and accessibility of delivered services, and to reduce gaps and eventual duplications, others (Whetten, 1981) declare that it can decrease an adaptive capacity of the network as a whole and point out at costs as sometimes higher than those of isolate initiatives.

1.2.6. Partnership

A number, variety and typology of definitions available in literature on partnerships provide some of which a level of ambiguity might cover practically any type of interaction between organizations, or, taking into consideration the sectoral approach, comprise at least some of the sectors, if not all. Partnership between two or more organizations is a result of assembling a settlement with a view into specific objectives, resulting from strategies of these organizations. Partnership is hence a voluntary agreement between partners to work cooperatively on a shared initiative. It means both parties agree to work together in implementing the program recognizing clearly each other's role in the process of implementation (Blagescu & Young, 2005). Partnerships are based on a shared vision, values, objectives, risk, benefit, control and learning. They also involve a joint contribution of resources, whether these are financial, human or logistic. The degree of independence/interdependence is unique to each relationship, and depends on context, and “evolves over time” (Bartel, Igras, & Chamberlain, 2007, p. 8). Utting and Zammit (2006) highlight their complexity: “It has come to be an infinitely elastic concept, embracing a range of actors, each inspired by different motivations and objectives, and involving varying types of relationships between the partners” (p. 19). They propose a definition of partnership as a relationship that results from putting into practice a set of principles that create trust and mutual accountability.

A United Nations report to the General Assembly (2003) proposes a slightly idealistic designation of partnerships that states these are “commonly defined as voluntary and collaborative relationships between various parties, both State and non-State, in which all participants agree to work together to achieve a common purpose or undertake a specific task and to share risks, responsibilities, resources, competencies and benefits” (p. 4).

As for the Public Health Agency of Canada (2008), partnership is defined as “collaboration between individuals, groups, organizations, governments or sectors for the purpose of joint action to achieve a common goal. The concept of partnership implies that there is an informal understanding or a more formal agreement (possibly legally binding) among the parties regarding roles and responsibilities, as well as the nature of the goal and how it will be pursued” (p. 12). The authors of the report on partnering arrangements for projects define partnering as a generic term “encompassing any mutually beneficial commercial procurement relationship between public and private sector parties that involves a collaborative approach to achieving public sector outcomes” (Office of the Auditor-General, 2006, p. 4). Seitanidi and Ryan (2007) understand partnership as one of the community involvement phases. Motivated by corporate social responsibility, it represents a symmetrical, collaborative relation directed to a social cause and is one, the most recent, of several forms used by companies to interact with the community, differing in its concept from philanthropy, charitable donations, benefactions, patronage, sponsorship and cause-related marketing.

The term ‘partnership’ is therefore commonly used in a generic way to describe many different forms of association between two or more actors. This diversity is a reflection of how development partnerships operate in a multi-level and multi-sector governance environment and how complex are systems consisting of various interdependent actors. These actors are also part of other subsystems which influence their action. Patterns of partnerships (of a varying size and scope) provide basis for various forms of categorization, drawing a distinction between relationships, alliances, networks and strategic partnerships. Relationships are based around a set of more limited, time-sensitive transactions with no shared accountability for outcomes. Alliances are links on shared issues, a common feature of agency working at the local, regional or country level. Networks involve participation in a loosely controlled system-driven arrangement engaging many actors and multiple cores of connectivity. Finally, partnerships are established between agencies and are strategic when through a strong task focus they aim to achieve a significant increase in the results of the agency's core business, or enable a partner or partners to move into a new field of activity. The premise behind complementary partnerships is that organizations should stick to what their core business is, contribute to their key competencies and determine which of these core competencies the most appropriately would add value to each of the participating organizations. A partnership is not the end goal in itself but a mechanism to deliver a project and meet the objectives. Partnerships are effective where they are developed on basis of an understanding on what is available in the field, where they enhance the capacities of existing resources, determine the best ways to fill gaps and are open to a change of roles and modifications of partnership as partnership matures and the capacity develops.

Waddock (1989) distinguishes social partnership among other interactive organizations. The term 'social partnership' is used to describe an initiative of organizations from more than one sector and as a synonym to a public-private partnership but with a special emphasis on a social dimension of its activity. The author stresses out that social partnerships originate from the environment and its needs, and it is the environment and its forces that direct the further development of partnership.

Berger, Cunningham and Drumwright (2004) demonstrate that social alliance is a specific type of partnership involving arrangements between a public non-profit and a private sector corporation dedicated to economic and social concerns. Social partnership addresses issues that go beyond organizational boundaries and traditional goals and lie within the traditional realm of public policy. The intensity of collaboration can be presented on a solid line, in which a foundation of a new, separate enterprise constitutes one of its extremes. This form of association appeared first between private enterprises and later between the public and private sectors commonly known as public-private partnerships. Eweje (2007) argues that partnerships can be an important source of value for the society in general as long as their principal objective they have been established for is to solve the most pressing social problems. Social issues may be addressed through long-term joint efforts that involve capacity, resource and knowledge share. The challenge sets in comprehending structural differences between entities and the specificity of the common initiative. Socially responsible position and engagement in citizenship programs is not uncommon and perceived as a manner to transmit to potential customers an idea of concern in public issues (Eweje, 2007). Globally, government and non-governmental agencies are now viewing social partnerships as means for improving service delivery and building enhanced capability at the local level (Alexadiou & Ozga, 2000).

One of the most widely promoted approaches to collaborative linkages between the civil society and business is that of strategic partnership. In most definitions, partnership is strategic when it involves "a core business or program of activities of both partners" (Ashman, 2001, p. 1098). Strategic partnerships are thought to differ from past forms of relationships between sectors in very important manners. Firstly, they are not philanthropic relationships in which business charitably donates funds to civil society organizations. Secondly, civil society does not stay in opposition to corporate behavior and rationale as it looks to a given strategic business partner to create programs truly jointly and in which business capacities are critical to solving development problems. Finally, strategic partnerships between business and community organizations comprise functions that go beyond community relations (Eweje, 2007). According to Waddell (2000), strategic partnerships are "win-win" relationships based on mutual gain to the partners in areas of their strategic interests (p. 25). Eweje (2007) argues that strategic partnerships and collaborations will be essentially trust-based, rather than formal contract-based.

One view on collaboration through partnership is based on the assumption that organizations are willing to combine resources to achieve objectives they would not be able to achieve individually. Benefits of partnership working are often referred to as 'collaborative advantage' (Huxham, 1996) or 'synergy' (Lasker et al., 2001). Dyer and Singh (1998) argue that competitive advantage in the relationship can be achieved in four different ways: by sharing risk and investment in assets that are specific to the relationship; by improving learning - through better knowledge exchange that lead to joint learning; by allowing synergy to take place through the combination of resources and capabilities; and through efficiency, leading to lower transaction costs. The philosophy of synergy consists in creating a whole that is more than would be simply the sum of the individual parts. Rather by combining knowledge, resources and skills, partnership is able to develop new and better ways of thinking and acting which offers a much greater potential to results that a simple exchange of resources. Hastings (1996) distinguishes between resource synergy and policy synergy where resource synergy refers to cooperation and coordination in allocating resources, and hence implies better ways of working through gains in efficiency. In contrast, policy synergy is concerned with developing new and innovative solutions, which, if it leads to better ways of doing things, can be seen as delivering gains in effectiveness. Policy synergy brings together different partners and pools resources and knowledge may lead to new and innovative approaches. If these partnerships include non-State actors who represent user communities then this also has a potential to align with networked governance (Slater et al., 2007). As with synergy, partnerships are often considered to be positive and self-evident mechanisms for delivering local governance. In already evaluated partnerships results seem to be mixed and some authors argue that partnerships should not be seen as necessarily positive as performance has appeared to be variable.

The discussion on a potential of partnering is reinforced by Rein et al. (2005) pointing that partnerships "are not an easy option and, by their very nature, they require a sophisticated multi-disciplinary approach to ensure that they are able to meet their objects. It may also be argued that, potentially, partnerships are resource-hungry and require additional funding and support which, in turn, are likely to detract from the resourcing of projects" (p. 128).

Among the reasons of why actors choose to enter partnerships are (Brinkerhoff, 2002b): to enhance efficiency and effectiveness through a reliance on comparative advantages and a rational division of labor; to open decision-making processes to promote a broader operationalization of a public good; to provide the multi-actor, integrated solutions required by the scope and nature of the addressed problems; and to move from a no-win situation among multiple actors to a compromise and a possible win-win situation.

Partnerships can range from fairly informal associations and go through more coordinated efforts to collaboration in which organizations share, plan, pool resources and engage with one another - and with the community - at many levels. While the relational view emphasizes benefits of close collaborative relationships, it does not explain circumstances in which collaboration can be more (or less) effective and hence, it does not give direction about when and how close to collaborate (Mena, Humphries, & Wilding, 2009). Bartel, Igras and Chamberlain (2007) distinguishe five types of partnership arrangements presented in Table 2.

Table 2. Illustrative partnership efforts as defined by their structural relationship according to Bartel, Igras and Chamberlain (2007)

Type of relationship	Description	Examples	Some advantages & disadvantages
Contracting and subcontracting	One agency plays the lead role and pays other agencies to provide specific good and/ or services.	Bi-lateral projects. Partners are defined as either prime or sub. The lead agency has greater responsibility for ensuring that the project is implemented according to donor plans.	*Advantages* Highly effective in environments requiring speed and risk-taking. *Disadvantages* Less cross-organizational learning or benefits.

Dependent or semi-independent franchise	A local organization functions as a field office for a large international agency which provides some or all of its direction and funding.	International Planned Parenthood Federation (IPPF). Affiliates follow normative guidelines established by umbrella agency (in order to be allowed to use the name IPPF), but often are responsible for local organization, fundraising, programs, etc.	*Advantages* Field offices work semi-independently but gain some technical assistance and funds from lead agency. *Disadvantages* Affiliates must conform to the agenda and policy norms of the lead agency.
Affiliation only	Loose alliance without formal structure and broad based volunteer structure. Depends on board, steering committees, and technical working groups. Partners act as equals.	White Ribbon Alliance. Operates with open membership (any organization can join) with the goal of increasing advocacy and awareness of the issues of safe motherhood. The WRA uses a "secretariat" model of administration, which is a variation of leadership model described above. The secretariat staff only undertakes administrative tasks; volunteers undertake all programmatic activities.	*Advantages* Limited costs, promotes fast, personalized and flexible decision making. Appropriate for situations where sharing knowledge and data is the key goal. *Disadvantages* Since it often lacks paid staff and dedicated leaders, depends on commitment of volunteers to accomplish tasks.
Alliance or coalition	An agreement between two or more agencies stating that the involved parties will act in a certain way in other to achieve a common goal. Partners are more or less equal.	Three NGOs[2] working in post–conflict Kosovo agreed to implement an RH training program using the same program model and materials in three distinct regions. The organizations agreed to common program guidelines, met routinely to discuss consistency of programming, but did not share funding or staff.	*Advantages* Minimal sharing of resources, which allows greater flexibility of membership. *Disadvantages* Depends to a large degree on volunteer commitment to accomplish shared tasks.
Consortium	Two or more agencies that pool resources to create a new legal entity in order to achieve a goal. The originating agencies each provide funds and human resources to create the new legal entity, but the	Reproductive Health Response in Conflict (RHRC). Consortium, a group of 7 agencies that pool resources and share responsibility for activities relating to reproductive health in situations of forced displacement and armed conflict.	*Advantages* Agencies with different proficiencies each contribute unique skills in joint effort toward shared goal of greater programmatic quality and scale. *Disadvantages*

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[2] Non-governmental organizations

	organizations do not merge.	Time to reach consensus on advocacy or other issues. Depending on how a consortium is financed, it may depend on volunteer commitment.

Source: Bartel, Igras, & Chamberlain (2007)

Gray (1989) distinguishes four types of partnerships:

1) Exploratory: brings an increased level of independence consciousness; specifies well the parameters of the relation and the problem: creates trust and faith;
2) Advisory: leads to a common agreement with an objective to analyze existing options and agree on the solution;
3) Confederative: approves and implements consensual agreements reached by the parties; coordinates behaviors; exchanges resources cooperatively;
4) Contractual: agreement based on a formal contract, institutionalized.

Murray (1998) proposes a five-stage model of a collaborative process: a pre-contact phase; a preliminary contact phase; a negotiating phase; an implementation phase; and an evaluation phase. The author argues each of these phases needs to be successfully negotiated in order to achieve sustainable collaboration and failure at any level ends the particular collaborative arrangement and additionally hampers possible further collaborative efforts. Four sets of factors influence successful negotiations of phases and these are related with the type of collaboration, characteristics of the organization entering into collaboration, process of developing and implementing the collaborative process and with all range of environmental and contextual factors that impact the collaborative linkages.

Gray (1989) describes the collaborative arrangement as a three-level process. In the first phase, ‘problem setting’, the problem is cause is defined, and stakeholders and resources identified. The second phase, ‘direction setting’, involves establishing rules of the engagement, setting the agenda and exploring available options. The last phase encompasses implementation and monitoring.

Wilson and Charleton (1997) extend collaboration into a five-stage process with different activities predicted to be occurring at different stages (look Table 3).

Table 3. Stages in the partnership process according to Wilson and Charleton (1997)

Stage	Activities
1.	Partners come together through mutual recognition of a common need, or in a joint effort to obtain public funds. If they have not worked together before, the partners begin the process of overcoming differences in backgrounds and approach, building trust and respect. There may be a need for training, building each partner's capacity to operate in this new organization.
2.	Through a process of dialogue and discussion, the partners establish the common ground and work towards agreeing a vision and mission statement for the initiative. The original core group might agree on the need to involve more individuals and organisations in the initiative. The partners develop mechanisms for assessing needs and quantifying the size of the task they propose to undertake. The initiative combines the information generated by the needs assessment exercise with the vision and mission statement to produce an agenda for action.
3.	The formal framework and organisational structure of the partnership is designed and put in place. The partners set specific goals, targets and objectives linked to the agenda for action. Where appropriate, the executive arm of the partnership selects or appoints a management team to oversee the work of the initiative.
4.	The partnership delivers to its action plan, whether this be service provision or some other function. The executive arm seeks to maintain the involvement of all partners, formulates policy decisions and ensures the continuing accountability of the partnership. There is an ongoing process of assessing, evaluating and refining the operations of the partnership.
5.	Where appropriate, the partners should plan their exit strategy. This involves developing a new set of goals for the survival and continuation of the work of the initiative in some form. They should seek to create 'life after death' by transferring the assets of the partnership back into the community with which they work.

Source: Wilson & Charleton (1997)

In the US context, Warner (2003) has suggested the existence of three phases for the partnership constructing. The first phase, partnership exploration, allows partners to conduct the explorative dialogue, assess possible benefits, costs and risks. The second phase, partnership constructing, involves effective communication toward development of the common vision, establishing the structure for collaboration, attributing roles and dividing resources, and building trust among the partners. The last phase, partnership maintenance, concerns the measurement of partnership results, adapting to external and internal changes along with further institutionalization and growth or phasing out.

The Global Alliance for Improved Nutrition (Tennyson, 2003) proposes considering partnership as a process composed from 12 phases: scoping; identifying potential partners and motivating them to partnership; building working relationships through agreed objectives and core principles; planning the agenda and particular activities; managing and exploring the optimal long-term structure of partnership; identifying and mobilizing resources; implementing a pre-agreed timetable and work plan; measuring and reporting on outputs, outcome, efficiency, effectiveness, and impact; reviewing the impact of partnership on the partner organizations; revising partnership in light of experience; institutionalizing and building appropriate structures and mechanisms for partnership to ensure longer term commitment and continuity; and sustaining or terminating partnership.

Drawing from the experience of the Community Care Network (CCN), Greenwald (2008) reports on a typology of a series of stages according to which it is expected partnership will develop. CCN is a large, nationwide intervention established in the late 1990s that provided funding for twenty-five intersectoral partnerships across the United States, representing an intense and extensive form of collaborative linkages. Each stage of the multi-sector initiative involves a higher scope of collaboration as moving along the collaboration spectrum, new tasks, challenges and possible outcomes. Table 4 specifies the stages of collaboration and their characteristics.

Table 4. Stages and characteristics of partnerships according to Greenwald (2008)

Stage	**Structure, process, and functioning**
Emergence	Establish initial governance structure Clarify individual partner interests Report and exchange information Define purpose of collaboration Recruit necessary partners
Transition	Build capacity for inclusiveness Establish linkages with key constituencies Review and modify initial structure Broaden view of performance Develop performance assessment capabilities
Maturity	Focus on big picture rather than operational details Initiate action rather than react Increase diversity Deepen involvement in governance Implement measurement system Monitor program and partnership performance
Critical cross-roads	Balance individual and collective interests Balance autonomy and authority Manage membership and leadership transitions Establish future structure and composition Address “wicked” problems Create equitable distribution of benefits Institutionalize partnership

Source: Greenwald (2008)

Considering partnerships from the viewpoint of the voluntary sector, Balloch and Taylor (2001) state that partnership "can offer participants the opportunity to influence other agencies to operate in ways that help them achieve their objectives more effectively and it has the potential to transform radically the culture of public service delivery, through compelling people to think in new ways" (p. 2). They adjust this optimistic vision shortly after by admitting that partnership has not remained integral in prevailing relationships: "as too often dominated by the more powerful partners, has not delivered the promise, especially for the communities and service users who are now a required part of most partnerships" (p. 8).

Austin et al. (2004) propose and explain five main dimensions of the partnering process. The first dimension involves identifying motivations to collaborate, capitalizing on pre-existing relations, acknowledging different institutional capabilities and organizational cultures, and valuing effective communication and overcoming barriers. The second dimension, building alignment, aims at expressing a shared set of expectations. Combining key resources toward a value creation constitutes the third dimension. The fourth dimension focuses on aspects of relationship management, institutionalizing partnership, promoting communication, and building trust. The last dimension, growth and innovation, consists of shared learning and knowledge to improve eventual future joint interventions.

The study of Jackson et al. (2008) investigated integrated governance models to achieve sustainable partnerships between health care organizations. The authors focused on composition of provided health care services, governance structure or contractual relationship between the collaborating parties and enablers and barriers of integrated service delivery. Three approaches for integrated care governance with the ability to sustain at least in medium term were identified. The first model considers a merger of all organizations in cause into one single organization providing since then all services on behalf of these organizations. The second model separates a common business into a new incorporated structure which delivers services to a specific population. The third approach shares only collaborative linkages but not funding, in contrary to the first two. Partnering organizations commit to a common governance arrangement but maintain separate and independent in terms of governance and funding.

Current partnerships appear to be principally concerned with meeting targets and their objectives, and delivering efficiencies, what can lead towards more centralized decision making and aggregated services (Slater et al., 2007). On the other hand, Gilles (1998) demonstrates that partnership for health promotion focuses rather on concrete health outcomes than specific health promotion goals and is "a voluntary agreement between two or more partners to work cooperatively toward a set of health outcomes" (p. 101).

1.2.7. Integration

There has been an extensive discussion on the need of integrating services, specifically health and social care services, followed by multiple empirical studies, demonstrating levels, barriers and facilitators of integrative actions, and a country-context of integration. While it seems then that integration is currently considered a sort of panacea for systemic inefficiency and ineffectiveness, and systems are moving toward integrating some particular services, service areas or, in a lesser extent, the whole sectoral approach toward care needs, a question on whether it actually constitutes a feasible solution for both, the systems and the service users, and, if so, how to achieve it, remains.

Service integration has become a focus of interest and efforts in developed countries in recent years refer to a much higher level of collaboration toward shared targets and include formal agreements and specific legislation. The responsibility for achieving the service goals through joint commissioning is shared among partners, services are planned, organized and audited jointly and, ultimately, joint commissioning may lead to the merger of one or more agencies, into a new shared identity (Horwath & Morrison, 2007). With the focus remaining on service integration, programs emphasize linkages such as shared information, case management, joint planning to change the ways agencies interact without changing the form services are delivered or the organizations themselves.

It is deemed that integration may occur as a result of and within action across sectors and this is to happen on base of collaboration links and networks already established. The better familiarity among the partners and the higher trust, the stronger linkages are established. They all can lead to a better planning and organizing an integrated service.

It is often stated that due to very complex needs it is not possible to integrate all services. The voluntary sector has been historically and culturally irreplaceable for people’s quality of life and possibly transforming it into a totally integrated structure would make it lose its meaning. Additionally, with a frequent opinion that integrated approaches cannot be created at the national level because of separate and competing ministerial budgets, separate ministerial guidelines, lack of encouragement to join an integrated perspective persists.

Distinctions can also be made between levels and degrees of service integration (Waldfogel, 1997). Horwath and Morrison (2007) show that at the simplest, level, the emphasis on collaboration remains around individual service users. That is followed by the level focused around staff working together to deliver local services. The highest degree of integration occurs when the whole system collaborates toward organizing and managing services.

In a recent work, Briassoulis (2004) has presented methodological framework for analyzing integration of policies, proposing for the assessment of the degree of policy integration over forty criteria. After decades of experiences it has become clear that unidimensional, sectoral policies cannot reach the level of coordination necessary for current problems and do not serve the reality. The practice of developing policies individually, ignoring their interrelational character does not produce desirable results. Thus, the author suggests that policy integration is indispensable for holding the system together and guaranteeing effective policy implementation.

1.2.8. Intersectoral partnership

The review of literature reveals that there are several discrepancies in the use of term ‘intersectoral partnership’, what imposes serious implications on its generalizability, applicability and usability. An existing theorem is difficult to reach. The concept of intersectoral linkages emerges from empirical studies and various academic disciplines, such as organizational studies, public policy and economics, among others (Selsky & Parker, 2005) based on different theories and paradigms thus leading to different perspectives into a desired process and outcome of a cross-sectoral action.

Cross-sector collaboration is defined by Bryson, Crosby and Stone (2006) as “partnerships involving government, business, non-profits and philanthropies, communities, and/or the public as a whole” (p. 46) toward mutual goals. Intersectoral collaboration is a term to describe a type of partnership based on the understanding that an issue in cause is determined by multiple, interrelated factors and so, action is required from sectors determining those factors. In case of health, such action would be required from sectors whose work aligns with various health determinants. Intersectoral collaboration is a recognized relationship between a part or parts of the health sector with a part or parts of another sector which have been formed to take action on an issue to achieve immediate or intermediate health outcomes in a way that is more effective, efficient or sustainable than could be achieved by the health sector acting alone (Harris, Wise, & Howe, 1995). Intersectoral action, as defined by the WHO, refers to “actions affecting health outcomes undertaken by sectors outside the health sector, possibly, but not necessarily, in collaboration with the health sector (accessed 20 January 2012). A cross-sector strategy is to attain a wide level of collaboration between community groups and sectors in improving this community through an educational process of organization, collaborative planning, decision making and implementation using available social structures and local resources (Andersson et al., 2005). Limited to one sector, isolated initiatives cannot benefit from core competencies remaining in range of another sector capabilities, restricting the maximum possible to achieve outcome. Several agencies based on local authority boundaries, bringing together public, private, community and voluntary sectors tackle issues requiring joint initiative and proceed through a joint action (Hill, Griffiths, & Gillam, 2007). They can bring particular skills and resources to partnerships, enhancing the environment of open community and common vision. In this context, a role of the public sector in health services delivery should be redefined. Understanding intersectoral collaboration is highly differentiated from other collaboration forms as the rationale for engaging in collaborative action differs among partners. Clearly, the general objective behind is a social issue that requires a joint action. General motives to consider a collaborative approach include public and private agencies perspectives toward that issue but also the current political climate and its changes.

Intersectoral action, as an organized practice, has almost a quarter-of-century tradition. Initiatives, often launched by large scale non-profit institutions have traditionally been applied in underdeveloped counties in order to combat poverty-related issues and set up arrangements for basic needs satisfaction. Operationally, intersectoral linkage can be understood as bonding together agendas, visions and resources and creating a synergy deriving from individual capacities, uniqueness and differences among partners. According to United States Agency for International Development (USAID), intersectoral partnerships strengthen individual organizations within each sector, offer a mechanism to resolve specific development issues and lay a foundation for a broader, systemic change (Charles & McNulty, 1998).

Intersectoral action can be seen as a process, which involves a combination of a broad spectrum of variables and actors toward a socially relevant issue. Some other scholars define ISP as a strategy that allows to achieve a global objective through individual, intentional actions. ISP as a process involves mechanisms, structures and measures to proceed, share information and responsibility, and promote collaborative capacities. On the other hand, a historical, cultural and social context intrinsic in cross-sector partnerships, including *a priori* power asymmetry, must be taken into account.

The Lalonde report (1974) identified four major components of the health field concept: human biology, health care systems, environment and lifestyle. By 1996, as more distinctions and additions were added, these four principal determinants of health described in the Lalonde report increased into twelve. The Lalonde report called attention to the existing fragmentation in terms of responsibility for health of the population and an individual. Glouberman and Millar (2003) published a comprehensive review of conceptualizations of health determinants in Canada since the 1974 publication of the Lalonde report. They call this report as "ahead of its time" in identifying the need for intersectoral collaboration and calling for multiple-source interventions, these combining research, health education, social marketing, community development, and legislative and healthy public policy approaches, to properly address the determinants of health (p. 388).

Hogl (2002) depicts the following aspects of intersectoral coordination from the process perspective: the number of integrated sectors (one = intrasectoral, some, ..., all sectors affected); the time-frame of co-ordination (short-term, medium-term, long-term); the reiterativeness (one-shot event, ..., open-ended iterative); the stage(s) of the concerned policy cycle (formulation, implementation, evaluation or the whole cycle); the applied mode regarding the complexity of overall interaction patterns (hierarchical direction without considering other sectors, negative coordination, only some interaction in the form of positive coordination, but most as negative coordination, most interactions as positive coordination and some as negative, positive coordination among all involved); the mode applied with regard to the exercise of power to constrain coordinated sectors (top-down imposition, …negotiation on an equal basis, …, bottom-up approach to influence decisions of coordinated sectors); the degree of institutionalization (e.g., non-legally/legally; informal/formal, amount of resources devoted to the coordinating institution) (p. 3).

Consequently, according to Hogl (2002), benefits expected from intersectoral approach are: to accomplish objectives which cannot be accomplished alone; to increase the chance that those policy alternatives that have most chances to result in the highest general well-being improvements are opted for; to support prevention general well-being losses due to policies that allow for positive welfare effects for individuals, but cause disadvantages from a global point of view; and to provide legitimacy and recognition to public policy.

Silva and Trevenzoli Rodrigues (2010) conducted a qualitative study aimed at examining practices of intersectoral action by identifying experiences of involved actors, enablers and factors hindering constructing partnerships, interviewing key informants for the topic together with managers and community health agents. The authors suggested that intersectoriality is a strategy "under construction", to which different agents, sectors and social segments are still looking for an appropriate suit (p. 768). The interviews revealed that only some of the actors were able to perceive the complexity of certain issues faced by the population and, therefore, they understood the need of interventions of intersectoral character. In particular, cross-sector partnerships are challenging to structure and to sustain because members are "likely to have noticeably different performance measures, competitive dynamics, organization cultures, decision-making styles, personnel competencies, professional languages, incentive and motivational structures, and emotional content" (Austin, 2000, p. 14).

A variety of issues, including environmental sustainability, education, health or social care can be of interest of such cross-sector initiatives (Selsky & Parker, 2005). It is important, however, to emphasize that the nature of involvement of different bodies and institutions in the intersectoral action as much as their aims vary among countries and systems.

1.3. Public-private partnerships versus intersectoral collaborations

Dawes and Eglene (2004) for their research selected cases based on the existence of a voluntary agreement between two or more distinct public sector agencies or between public and private or non-profit entities, to deliver government services. Altogether, the case studies represent three main types of collaboration arrangements that the authors point out:

a) public-public collaborations: the category including both horizontal agreements between two agencies or departments at the same level of government, and vertical agreements or intergovernmental alliances between or among federal, state, and local levels;

b) public-private collaborations: the most common way for subcontracting and outsourcing between the public and private sectors. The government hands over part of its management responsibilities while retaining enough control to ensure the protection of the public interest;

c) public-non-profit collaborations: the category common for human services delivery at the community level by non-profit service organizations. These relationships are habitually characterized by fee-for-service or annual contracts.

The structural perspective is also visible in Prefontaine et al.'s (2000) work. They state that collaboration can be 'public–public', between two or more government agencies, or 'public-private', between government agencies and private firms/non-profit organizations. Powell and Glendinning (2002) categorize partnerships according to which sectors are involved. The overall options encompass public-private, public-public, public-voluntary and public-community partnerships.

In the public management literature, public-private partnership is described as one of the possible tools of privatization, although the term is often used without an explicit definition. Public–private partnerships for health should be, however, distinguished from the trend to privatization and the for-profit provision of health services by the private sector as only and exclusively government agencies set up rules under which for-profit entities operate.

The motive behind the introduction of public-private partnerships is to have private service providers participating in the provision of supplementary services and to inject private funding and expertise into the NHS (Jackson et al., 2008). To fill the void in resources, governments seek public-private partnerships (Forsyth, 2005), either replacing government support by directly privatizing service or contracting out service delivery.

Partnership between the State and non-State actors has a long history. Wettenhall (2005) compares such partnerships to private shipping of the 16th century. He states that “clear elements of public-private mixing has taken place over many centuries, has often been deeply embedded in society and has produced many positive outcomes” (p. 35). The definition of public-private partnership is elusive and varies among contexts and scholars, generally used to designate a partnering arrangement where parties work together for a mutual benefit involving private financing. Hodge and Greve (2007) argue that “there is a need to re-examine the different meanings and definitions given to PPP to find out whether the concept is worth keeping and using for empirical studies” (p. 545), since a wide range of definitions of PPP are to be found. The WHO defines public-private partnerships as “comprised of many activities, varying with regard to participants, legal status, governance, management, policy-setting choices, contributions, and operational roles, ranging from small, single-product collaborations with industry to large entities hosted in the United Nations agencies or private not-for-profit organizations” (Office of the Auditor-General, 2006, p. 6). Performance audit report (2006) on accomplishing public sector outcomes with relying on partners from the private sector has referred to public-private relationships and adopted the term ‘partnering’ as a generic term to encompass a wide range of mutually beneficial commercial procurement relationships between the public and private sectors that involve a collaborative approach to achieving public sector outcomes (p. 9). These relationships can include ‘partnerships’ in the legal business sense, and other commercial arrangements between the parties where they adopt a collaborative approach.

Deich (2001) claims that public-private partnership exists when the public sector (state, federal, local agencies) meets the private sector (service providers, community-based organizations, employers, civic groups, philanthropic groups) for a common objective. Comon features of public-private partnerships are:

a) the public and the private sector elements are represented in the partnership;

b) all partners provide time, financial, knowledge and other resources to the partnership;

c) partners work together toward common goals;

d) decision-making and management responsibilities are shared among the partners.

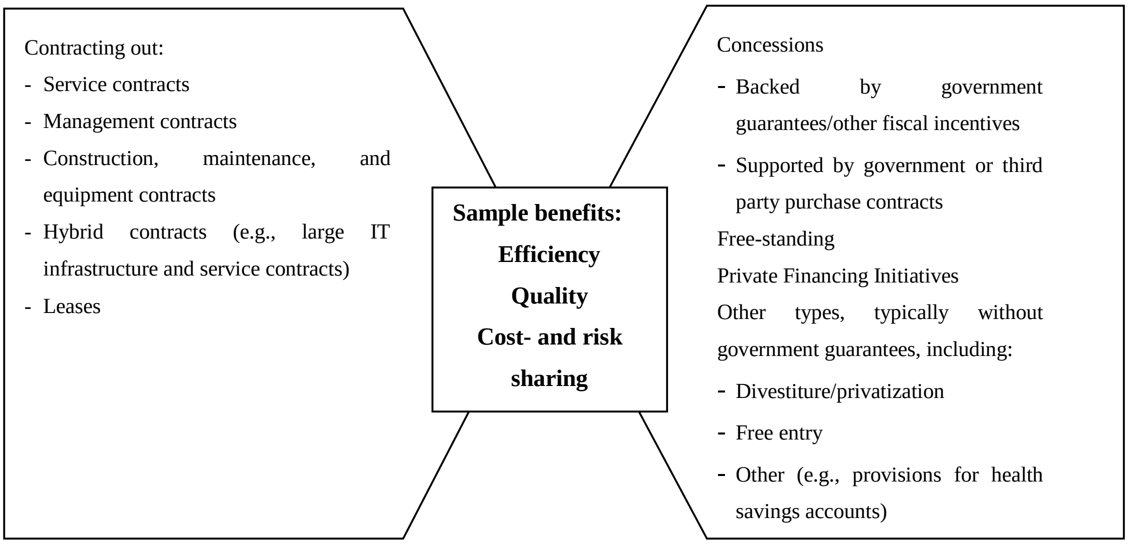
The author deems these four factors vital, while the structure, organization and goals of partnerships diverge broadly (Deich, 2001). The term ‘public-private partnership’, although widely used, remains vague and embraces a range of activities including engagement of private consultants to advisory activities in the governmental agencies, activity of philanthropies, outsourcing government functions to private enterprises and active collaborations (Reich, 2002).

Public-private partnerships are an international phenomenon. Osborne (2000) points out that while in the US they are “central to national and state-government initiatives to regenerate local urban communities”, within the European Union they are “an essential mechanism both to combat social exclusion and to enhance local-community development” (p. 1). In the United States, several projects have adopted partnership initiatives to address community health (Shortell et al., 2002). In Europe, PPP have been widely adopted for disease management projects (Hunter, 2000). In developing countries, partnerships are viewed as one component of efforts aiming to provide public services and public infrastructure. In Australia, the term mainly applies to projects where the private sector partner makes a financial investment to create or improve an asset, and is responsible for designing, building, maintaining and operating a facility. The private sector partner receives payments directly from the public sector partner for services provided and/or income through charges to users. In the UK the expression is used to describe various arrangements, including joint ventures and franchises, among others (Office of the Auditor-General, 2006).

A public-private initiative leads to the creation of conditions for the development of civil society institutions, civil society dialogue, and citizenship forming a variety of social participation forms, and contributes in this way to the dynamic development of the concept of socialized formula for social services. Partnership between public administration organs and non-governmental sector places the participating parties on equal position. Instead of an imperious nature brought by an administrative decision, parties have comparable rights and responsibilities. This status is not visible precisely at the beginning, but planned and organized contacts facilitate the creation of public-private partnerships. Public-private arrangements do not aim to substitute effective governance and to transfer the responsibility into the private sector. The government continues to be accountable for the project in cause in a way that secures the public interest and benefit. The focus of partnering arrangements is usually on specifying the facility or service needed, leaving the private sector party to decide how best to design and construct the facility or provide the service. The main purpose of local government collaborative engagement with NGOs is to develop a democratic social order in the society, in the local community. This goal can be enhanced by supporting non-governmental organizations in implementing relevant social purposes.

Buse and Harmer (2007) investigated habits of global private-public health partnerships that resulted in suboptimal performance and outcomes. The seven habits were: modifying or ignoring national priorities by imposing external ones; denying specific stakeholders the right to take part in the decision-making process; inadequate governance practices; erroneous assumptions of the efficiency of the public and private sector; insufficient resources to implement forecasted partnership activities; wasting resources through inadequate use of systems and poor harmonization of activities; and inappropriate or lacking incentives for staff engaging in partnerships. Naturally, the authors suggested in consequence seven actions that would promote better habits: integration of efforts with national and state planning; a more objective representation of stakeholders; avoiding assumptions of the system efficiency and reconsideration of the assumption that the private sector is necessarily more effective and efficient than the public sector; adequate resources; standard operating procedures; established standards and rules for selecting partners and systems for controlling eventual conflicts of interests; and organizational yearn.

When considering results of collaborations between the public and private sectors, McKinnon (2009) states that those addressing issues such as national defense or space exploration promise, in general, benefits to both sectors, although the same cannot be said about health or education. In general, the author assumes that public-private partnering has produced mixed results. There is a growing level of understanding that, considering respective strengths and weaknesses, neither the public nor the private sector alone can proceed into the best outcomes for the health-related actions. Figure 1 presents the main types of public-private partnerships and collaborations in the health sector as provided by Nikolic and Maikisch (2006).



Source: Nikolic & Maikisch (2006)

Figure 1. Key types of public-private partnerships and collaborations in the health sector of Nikolic and Maikisch (2006)

1.4. Collaboration intensity continuum

The relationships continuum assumes that the more progressive on the collaborative continuum an interorganizational relationship is located, the closer collaboration takes place. There are different levels or intensities of how partners can work together. Partnerships can range from fairly informal associations, to more coordinated efforts of collaboration in which organizations share, plan, pool resources and engage with one another at several levels.

As complex arrangements, some scholars have recommended incremental engagement to partnerships, moving gradually toward highly collaborative models that require intense engagement of all involved parties (Austin, 2000). This not only has allowed for extensive planning, but also for learning about the partner organization, both before and while engaged in the collaborative action. The complexity associated with the concept of working together derives partially from the fact of this term being used to describe a range of different collaborative associations.

Kagan (1991) defines the continuum that encompasses interorganizational collaborative linkages as follows (pp. 2-3):

a) cooperation - personal relationships between management and staff in different organizations, characterized by informality and a lack of formal structure;

b) coordination - multiple organizations work together to coordinate their services, yet remain fundamentally independent from each other;

c) collaboration - a structure in which organizations share resources, staff and rewards;

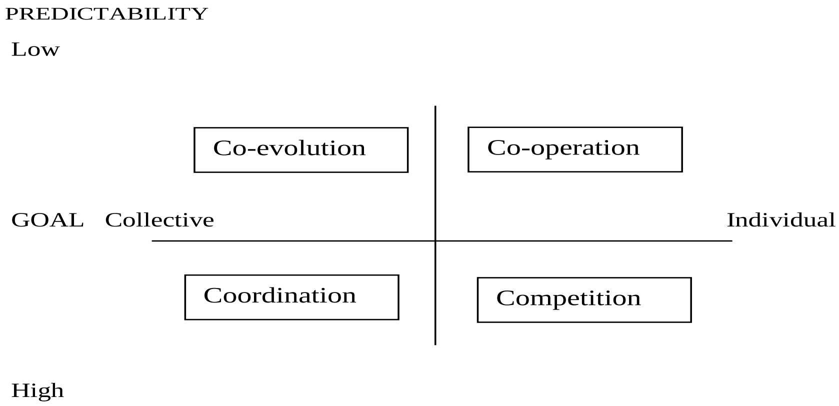
d) service integration - multiple organizations work together to provide a new package of services to their mutual clients.

In their book, Habana-Hafner and Reed (1989) describe three types of partnerships: networks, coordination and collaboration. They note that each type is distinct because of the interaction of member organizations, purposes and operations of partnerships, and the resulting agreements. There is a graduation of complexity in the purposes of partnership, different degree of formality and intensity of linkages. The authors view these types of partnerships as continuum points with varying differences in their purpose.

Early works on collaboration used to emphasize service oriented models (Peterson, 1991) which focus on building and developing strategic alliance through consecutive (possible) collaborative stages. Peterson (1991) proposed a model in which inter-agency initiatives moved along three stages of interaction: cooperation, coordination and collaboration.

Shortly after, Hogue (1993) suggested a slightly more extensive model with five levels of involvement: networking, cooperation (or alliance), coordination (or partnership), coalition and collaboration. These levels are different in several aspects, such as leadership, management, decision making, control, and purpose. Collaboration is identified as the most advanced and highly developed stage of integration continuum.

Pratt, Gordon and Plampling (1999) created a model of partnership behavior (look Figure 2) with a horizontal axis symbolizing different kinds of goals being sought – individual to mutual; and a vertical axis characterizing a so-called ‘predictability’, that is, the extent to which the goal and behavior is known and recognized in advance. At the bottom end, the level of predictability is high and lot is information is known to the organization; at the top end, the organization has only a general view on goals and ways to achieve them. As partnership is a flexible phenomenon, its positioning in a certain quadrant may not be permanent, depending on its development.



Source: Pratt, Gordon, & Plampling (1999)

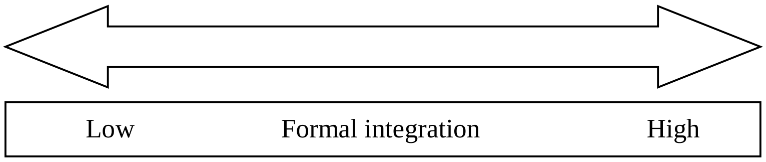
Figure 2. Model of partnership behavior of Pratt, Gordon and Plampling (1999)

Bailey and Koney's (2000) model suggested that the most advanced stage of the collaboration process should be a complete unification of the engaged parties. Their proposal was somehow similar to that of Hogue's and with four phases; it comprised cooperation, coordination, collaboration and the final, coadunation.

Gajda (2004) made an interesting discussion on achievements in defining and modelling phases of partnerships assuming that collaboration is rather "a journey, not a destination" (p. 69) and "is known by many names" (p. 70). The author decided to visually present her conclusions introducing a four-stage continuum of integration with cooperation and coadunation on its ends as an attempt of generalization of previously proposed models and strongly influenced by that of Bailey and Koney's (2000). Figure 3 provides this proposal.

Defining strategic alliances across a continuum of integration

Cooperation	Coordination	Collaboration	Coadunation
Shared information and mutual support	Common tasks and compatible goals	Integrated strategies and collective purpose	Unified structure and combined cultures



Source: Gajda (2004)

Figure 3. Transversal system of partnership evolution classification of Gajda (2004)

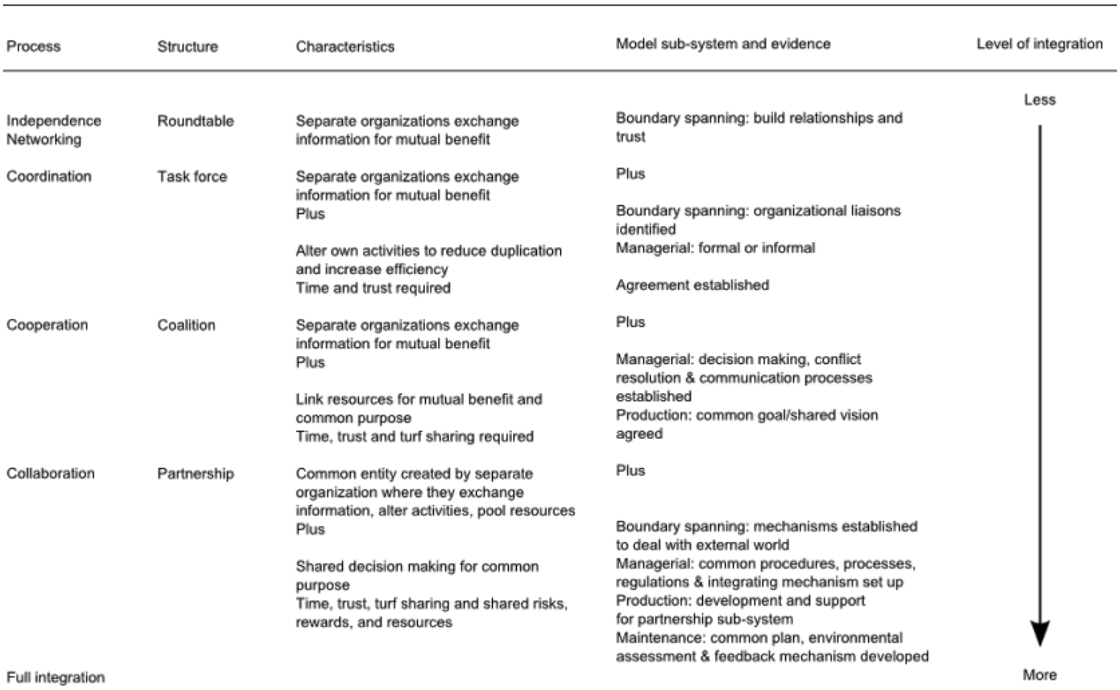
Gajda (2004) suggested later a model composed from five stages, deriving from her awareness of reality, while consistent with the previous approach. The levels included, with an increasing involvement of actors: networking, cooperating, partnering, merging and unifying, and varied between each other on purpose, leadership, control, decision making and communication.

Axelsson and Axelsson (2006) proposed coordination, cooperation, contracting and collaboration as different stages of integration and assumed all these forms as possibly effective, depending on the degree of differentiation. A level of horizontal and vertical integration defined a level of integration. Coordination was understood as a form of integration with a high degree of vertical but a low degree of horizontal integration. Cooperation could be defined as a form of integration with a high degree of both vertical and horizontal integration. Contracting was a form of integration with a low degree of both vertical and horizontal integration, and collaboration represented a high degree of horizontal integration but a low degree of vertical integration, opening door to voluntary agreements and mutual adjustments. The authors admitted that integration in public health was primarily a question of cooperation and collaboration between different organizations, with elements of coordination, while contracting seemed to be more uncommon in the field of public health.

A number of scholars emphasized an importance of a phase of integration in the collaboration process (Hudson et al., 1997; Hudson et al., 1999). They acknowledged integration at one end of a continuum of inter-agency collaboration, which extended from a complete disconnection and autonomy of organizations and organizational functions to a complete and full integration, a level in which organizations did not perceive their individual identities as relevant for their activities. For this stage to happen, organizational relationships should share as much as possible of the following characteristics (Powell, Exworthy, & Berney, 2001): joint commissioning at macro and micro levels; joint arrangements comprising strategic and operational issues; highly connected networks; common goals; little concern about reciprocation reinforced by a shared and diffuse sense of long-term commitment; high degree of mutual trust and respect; and management arrangements.

Leutz (1999) proposed a similar range, a continuum with only three points: linkage, co-ordination and integration. According to the author, the last of these stages gave origin to new units and programs that accumulated resources in order to create new services and additional benefits. Integration could be achieved with at least some of the following characteristics: high level of trust and respect; joint goals; mutual commissioning at micro and macro-levels; joint arrangements on operational and strategic issues; close relationship and networking; and diminutive concern about exchange (Powell, Exworthy, & Berney, 2001).

The continuum of collaborative linkage was also approached by the work of Eilbert and Lafronza (2005) (look Figure 4), who, following previous authors, presented five levels of an increasing engagement strength, from independent networking into full integration. Each phase represented an increasing level of integration that built on each other.



Process	Structure	Characteristics	Model sub-system and evidence	Level of integration
Independence Networking	Roundtable	Separate organizations exchange information for mutual benefit	Boundary spanning: build relationships and trust	Less
Coordination	Task force	Separate organizations exchange information for mutual benefit Plus Alter own activities to reduce duplication and increase efficiency Time and trust required	Plus Boundary spanning: organizational liaisons identified Managerial: formal or informal Agreement established	
Cooperation	Coalition	Separate organizations exchange information for mutual benefit Plus Link resources for mutual benefit and common purpose Time, trust and turf sharing required	Plus Managerial: decision making, conflict resolution & communication processes established Production: common goal/shared vision agreed	
Collaboration	Partnership	Common entity created by separate organization where they exchange information, alter activities, pool resources Plus Shared decision making for common purpose Time, trust, turf sharing and shared risks, rewards, and resources	Plus Boundary spanning: mechanisms established to deal with external world Managerial: common procedures, processes, regulations & integrating mechanism set up Production: development and support for partnership sub-system Maintenance: common plan, environmental assessment & feedback mechanism developed	
Full integration				More

Source: Eilbert & Lafronza (2005)

Figure 4. Organizational affiliation continuum according to Eilbert and Lafronza (2005)

Horwath and Morrison (2007) argued that there were ways of distinguishing one level of collaborative arrangement from another. Collaborative partnerships exist along a continuum from informal and local collaboration to formal and whole agency collaboration illustrated in Figure 5. The authors drew from literature five different levels of endeavor that could be identified, namely: communication, cooperation, coordination, coalition and integration, and began by exploring their distinctive features. In their opinion, the following characteristics of these different levels of multi-agency collaboration could be distinguished:

a) communication: individuals from different disciplines talking together;

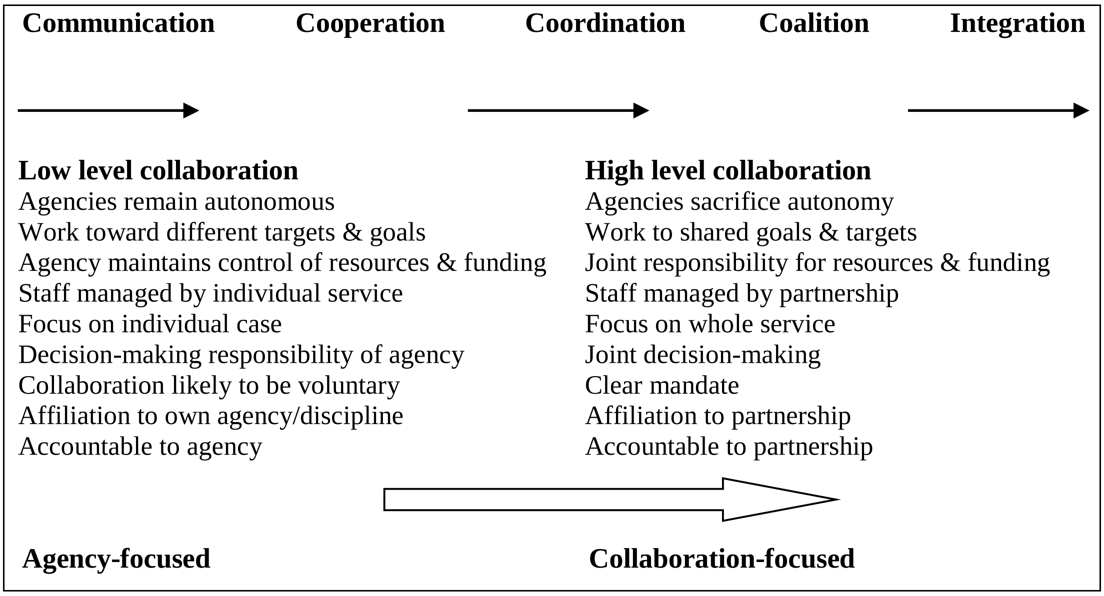
b) cooperation: low key joint working on a case-by-case basis;

c) coordination: more formalized joint working, but no sanctions for non-compliance;

d) coalition: joint structures sacrificing some autonomy;

e) integration: merged organizations with an objective to create a new joint identity.

In their work, Horwath and Morrison (2007) considered cooperation, coordination and coalition as one of the intensity levels of integration thus one of the stages of service integration. Moreover, they admitted the existence of different levels and degrees of integration.



Low level collaboration	**High level collaboration**
Agencies remain autonomous	Agencies sacrifice autonomy
Work toward different targets & goals	Work to shared goals & targets
Agency maintains control of resources & funding	Joint responsibility for resources & funding
Staff managed by individual service	Staff managed by partnership
Focus on individual case	Focus on whole service
Decision-making responsibility of agency	Joint decision-making
Collaboration likely to be voluntary	Clear mandate
Affiliation to own agency/discipline	Affiliation to partnership
Accountable to agency	Accountable to partnership

Source: Adapted from Horwath & Morrison (2007)

Figure 5. Features of collaborative endeavors according to Horwath and Morrison (2007)

In the English context, Discussion Paper no. 8 (2010) following a presentation on "snapshot of integrated working" (p. 2) survey to ADASS Spring Seminar went back to a five-point collaboration intensity scale, this time comprising relative autonomy, coordination, joined appointment, enhanced partnership and structural integration. Relative autonomy meant that local authority and the National Health System met statutory requirements for formal partnership working, but most of coordination remained largely informal. Coordination presented a reasonable level of formal commitment to joint working, coordination around some areas of strategy and/or commissioning depending on circumstances. Joint appointment meant that Primary Care Trusts (PCT) and local authority had some key joint appointments and the teams collaborated but were not integrated or combined. Enhanced partnership encompassed the system-wide commitment, shared vision and integration across the most strategic and commissioning functions, senior and middle-tier joint appointments, formal high-level backing, but separate legal entities remained. Structural integration, the highest level, meant that PCT and local authority care services formed a single integrated legal entity (care trust) or a combined service (joint PCT and social care department).

A notable contribution to the discussion on the collaboration continuum had Austin (2000) who suggested that partnerships consisted of a higher level of interactions, which were classified within the integrative stage of relationships. His vision of collaboration continuum moved from philanthropic relationships between sectors toward an integrative stage through a transactional stage (patronage, cause related marketing, licensing and paid service arrangements). While philanthropic (stage 1), transactional (stage 2), and integrative (stage 3) approaches were seen as progressive points along a continuum, the author pointed out that neither was it necessary to pass through each of them sequentially nor all phases needed to occur. Hence, a relationship could embark on a philanthropic stage and then progress to an integrative stage, without having to pass through a transactional one. According to the scholar, successful linkage built on principles of collaboration would enable participating entities to move from a traditional philanthropic relationship to a more integrative relationship and allow for planning and extensive learning about partners.

The Austin's model (2000) (depicted in Figure 6) is especially functional for the analysis of relationships between business and non-profit organizations, with its weakness of not discriminating between a form of interaction (for instance between sponsorship and donations).

THE COLLABORATION CONTINUUM			
NATURE OF THE RELATIONSHIP	**STAGES**		
	PHILANTROPHIC	**TRANSACTIONAL**	**INTEGRATIVE**
Level of engagement	Low	⇨	High
Importance for the corporate mission	Peripheral	⇨	Central
Size of resources	Small	⇨	Large
Scope of activities	Restricted	⇨	Broad
Frequency of interaction	Reduced	⇨	Intense
Complexity of management	Simple	⇨	Complex
Strategic value	Reduced	⇨	Intense

Source: Adapted from Austin (2000)

Figure 6. The collaboration continuum according to Austin (2000)

According to Peters (1998), the following aspects could be used to describe and measure intersectoral coordination as an end-state:

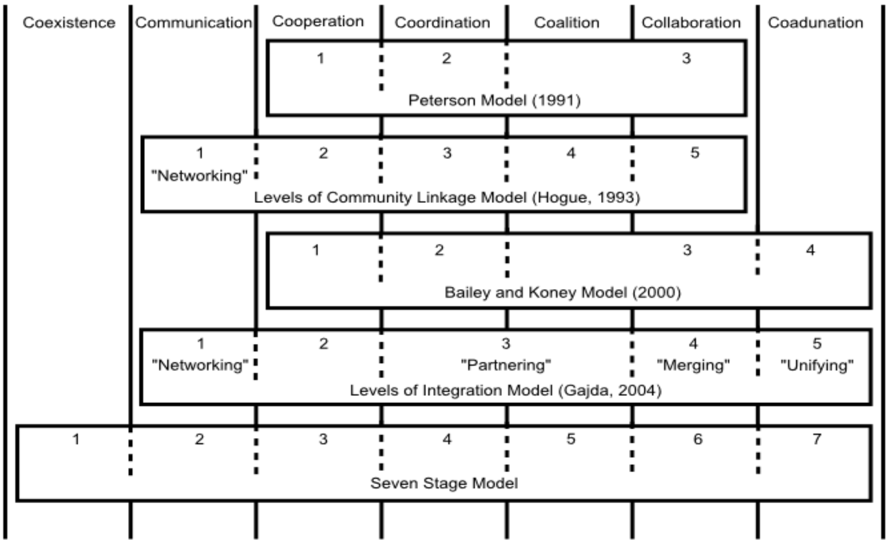
a) degree of redundancy (two or more organizations aim at the same goals without considering each other);

b) degree of incoherence (two or more organizations aim at different goals or are based on different requirements);

c) degree of untackled issues (important issues not included in the agenda).

Following this rationale, Hogl (2002) concluded that intersectoral coordination in its minimum level involved actors from different sectors that were aware of each others' programs and initiatives and attempted not to duplicate efforts (no redundancy) or to interfere (no incoherence). At the other end of the scale, redundancy, incoherence and a number of untackled issues were minimized.

On a basis of these deliberations, Frey et al. (2006) introduced the Levels of Collaborations Scale built upon existing models and instruments which they identified as the most remarkable in literature influenced the most by that of Hogue (1993). Perhaps not in abundance, but surely a variety of present definitions and designations of collaboration intensity, led them to the conclusion that development of models and levels of collaboration was occurring in line with redefining a number of stages and an involved range, and increasing engagement necessary for collaboration to be effective. However, the analyzed models appeared to have much in common (compare Figure 7).



Source: Frey et al. (2006)

Figure 7. Stages of collaboration models according to Frey et al. (2006)

Evidence shows an assortment of phases of collaboration in the theoretical approach. Their classifications differ what origins an interesting discussion on what collaboration in itself actually means. Conversely, the interest of policy makers in recent years has gradually moved from coordination to partnership and to service integration what points into an increasing focus on organizational affiliation and involvement of more equal partners. However, all these three levels: coordination, partnership and service integration, among others mentioned in literature, co-exist in practice. Lessons learnt from experience with one form may provide insights to other forms of relationship, not necessarily to be placed on the continuum line. Nevertheless, for the sustainability of an inter-agency program, a certain level of involvement of the parties will always remain a vital criterion.

1.5. Sectoral approach to the economy

A term ‘sector’ can refer to a field of activity. Society can be broken down into various sectors which play a variety of roles and provide desired services to members of that society. Examples of sectors can include health, social services, finance, education, and agriculture, among others. Although there is a common understanding of types of such sectors, some organizations’ scope of activity does not necessary limit to one of them, placing somewhere in the interface in between. Seitanidi and Ryan (2007) support the opinion which assumes the existence of the profit and non-profit sectors, between of which interactions have intensified over years.

Another distinction takes under consideration governance, purpose and financing. This division encompasses the government, private sector and voluntary sectors. The government sector comprises national, regional, district or county-level bodies. The private sector is built from private for-profit companies, and the voluntary sector include the whole civil society, non-governmental organizations, faith-based organizations and community groups (Helfenbein & Severo, 2004).

Usually, in sectors providing essential services, and health and social care belong to this group, there is a discrepancy between a demand and an offer, what brings a need of the State as a regulatory organism. Health care as a product, from a market perspective, occupies a specific position in a way that a client has an extremely limited choice on whether to purchase a service or not, especially when health condition requires an urgent medical intervention. It is also not a client-patient who individually decides on a set of health services to be acquired, but a health professional, although ethically obliged to recommend the most appropriate treatment.

The public sector comprises institutions financed by the State revenue and functionig under the government budget or control, and it involves local, district, regional and national governments. The government is a body whose actuation covers different levels, from the central, national, through regional to local. Its competencies cover formulation and implementation of legislation with a view to continuously improve quality of life of citizens through improvements of particular questions. The important role of the government is coordinating the interaction between sectors. It is committed to establishing a reliable governance network and provision of public goods. It can regulate the market through accreditation or certification. In case of national governments, partnership provides them with means to draw on others' resources, both human and financial, to fulfill their commitments.

The private sector encompasses entities operating outside of the direct control of the State. In a strict meaning, the private sector covers organizations seeking explicitly a profit. The private sector includes profit-driven entities whose principal objective is to guarantee return on their investments. A traditional vision of a company recognizes its turnabout into guaranteeing and increasing a profit indicating in such a common interest of shareholders. Running profitable business does not exclude social responsibilities besides purely economic ones. Currently, it becomes more and more frequent to include questions such as employee satisfaction, quality of life or global sustainability into the company' corporate mission statement. There has been a shift from the focus on the accounting profit into the social responsibility issues. Corporate social responsibility (CSR) is described in terms of a company considering, managing and balancing the economic, social and environmental impacts of its activities. This interest in social responsibility comes not only from inside but also from outside of a company and an increasing number of activists, labor unions and media puts a pressure to companies to take into account social questions. Numerous reasons, including ethics, improving the company image, complementing the government actions, personal satisfaction or fiscal incentives among others, can drive social investment. Without the focus off the core business, companies can act allocating or donating funds and allowing the construction of a deliberative citizenship through the change in their strategy and policy. To be a socially responsible company is to be responsive to the expectations of the stakeholders, building relationships with them in a democratic and fair manner. Moreover, who decides on a success of a company is a customer and it is important to verify the position of the target market in a matter of social responsibility. A range of factors can influence on whether and how a company's corporate social responsibility activities translate into consumer purchase.

In light of these considerations, some researchers have asked on a relationship between corporate social responsibility and financial performance. Over 40 years ago, Friedman (1970) suggested a negative link as "social responsibility involves costs and therefore worsens a firm's competitive position" and it should "use its resources and engage in activities designed to increase its profits so long as it stays within the rules of the game" (p. 126). The evidence is mixed, in both questions, on type of the relationship and the causality, but suggesting that a relationship between social involvement and financial performance is rather positive independently of the field, and that financial performance, in general terms, precedes social performance (Scholtens, 2008).

In contrary to the strict vision of the public sector, in a broad meaning and as alerted by some commentators, the private sector includes both, for-profit and operating on a non-for-profit basis, entities. In this perspective, the private sector is composed by all others than public entities. Thus, non-profit entities are by some considered part of the private sector and for other scholars a separate sector of the society.

The ‘third sector’ which shall be stressed out as civil society, cannot be omitted in a discussion of sectors and their importance for collaborative linkages. Civil society includes structures of voluntary associations, values and norms that marshal citizen action and modes of independent communication and information sharing that facilitate citizen consciousness and action. Strengths of civil society as a sector include its capacity to be approachable and responsive to various issues through the diversity of organizations that comprise it and the values-driven energy of individuals and organizations (Kalegaonkar & Brown, 2000). The civil sector is comprised of community-based organizations: the not-for-profit providers (Church-based, secular, local government services which provide services to citizens), community organizations (local service clubs, sport clubs, associations, patient organizations), public institutions (schools, child care centers, libraries), and cultural and religious leaders. Religion-based, faith-based entities and religious leaders are important agents of social change especially when they are turned into social issues. The National Health Plan 2004-2010 (Ministério de Saúde, 2004) states clearly that it is less demanding for such organizations to influence behavior of health care providers, professional organizations and public administration of health, in general. The fact that these organizations receive sometimes financial support from the State obliges them, similarly to other public bodies, for public accountability of their activities. It can be argued that the State reaches its goals more easily stimulating collaboration of civil society-based organizations. Local non-governmental organizations enjoy an advantage of extensive local experience and already established networks of collaboration. Community at the local level is able to organize itself to organize partnerships addressing relevant, locally-specific issues and determinants of health.

Civil society is often discussed in contrast to the State and the market. Civil society is concerned with common and not public or private goods, defined by social groups, and it mobilizes resources through social visions and values and not through the State authority or market exchange like in case of the State and the market, respectively.

Scholars from a variety of disciplines have engaged in a much broader long-standing effort to comprehend and define government-non-profit interactions. Public-social partnership is the essence of the constitutional principle of subsidiarity, into which a statement ‘as little State as possible, as much State as necessary’ gives a unique significance. Proceeding from this assumption, one shall look for solutions to social issues at the lowest social level, although organized enough to provide efficiency and quality. A civic initiative involving non-governmental institutions belongs to this group. It leads to creation of conditions for development of civil society institutions, civil dialogue and civic attitudes forming a variety of forms of social participation and, therefore, contributes to dynamic development of the concept of socialized formula for social services.

One of the principal barriers hampering successful collaborations is a lack of appreciation for different roles that the public and private sectors play in the society. The ability of civil society organizations to work with private businesses is shaped by perceptions and attitudes of both sectors. Many in the public health arena distrust business, which is seen as having a blinding commitment to maximizing the profit (Buehler, Whitney, & Berkelman, 2006; McKinnon, 2009). As civil society and the market reflect different core logic, interaction across sectors becomes a challenge for involved parties. Often, values of a variety of stakeholders involved in the policy agenda setting are conflicting in nature (Rudan et al., 2008). McKinnon (2009) points out that the public and private sectors possess “distinct drivers, different frames for how they view the world, different cultures in which they operate, and different languages when referring to the world of partnerships” (p. 2) and that leads to a different organizational behavior.

Nevertheless, there has been a significant shift in a strategic line underlying non-governmental organizations, from a charity orientation into a structured operational course, covering both, a long-term and a task approach, and aiming a social change. Non-profit organizations are increasingly becoming aware of a need to diversify their resource base as well as of the importance of expanding their collaborative linkages to include the private sector. Simultaneously, businesses are aware that their customers and shareholders expect corporations not only to appear but to act like a responsible citizen by providing support for important community issues and events. The challenge for both non-profit and business entities has been to find ways of working together which are mutually beneficial. Companies that recognize opportunities and benefits of working with non-profit organizations want to move beyond traditional charitable activities into a relationship that is more entrepreneurial and business alike. As a result, non-profit organizations need to be capable to find a common position that ties the community needs they believe important with the business interests of corporations. In fact, cooperation with market actors can make desirable to large extent resources available to civil society organizations. Civil society as a sector and a resource confronts a set of challenges which are presented in Table 5.

Table 5. Challenges to civil society according to Brown and Kalegaonkar (1999)

Internal failure	**Source in the sector**	**Implications for civil society**
Restricted focus	Use of social values and visions to focus action on concerns of groups Appeals to narrowly defined social identities and ideologies	Blind to larger problem causes or consequences Difficult to move beyond initial constituencies Duplicate or compete with other CSOs Limited scaling up of successful programs
Amateurism	Mobilize staff by appeals to values and beliefs Expanding activity requires more technical organizational capacity	Low-skilled human resources Limited organizational capacity Ineffective organization and program management
Material scarcity	Mobilizing revenues by values and beliefs limits resources Poor constituents have few surplus resources to support services	CSOs work best on value-driven projects that need volunteers, not material resources Programs hard to replicate/scale up CSOs depend on a few donors so lose autonomy
Sector fragmentation	Low start-up costs enable many diverse organizations Scarcities and narrow focus foster competition Large tasks or opponents require joint action	Duplication of initiatives and failure to coordinate lessens impact and wastes resources Competition with other CSOs reduces influence on large actors (donors, governments) Failure to recognize shared interests/take collective action
Sector parochialism	Heavy emphasis on values and norms as basis for action Negative stereotypes of actors with different values and norms	Stereotyping reduces communication Opportunities for joint gain go unrealized Reduced influence over other sectors, even when they can supplement or widen programs
External Problem		
Legitimacy and accountability	Publics do not recognize or accept key roles of civil society	Little popular support if attacked

	Rights of assembly and speech critical for sector Not accountable to beneficiaries	Little legal protection or enabling context Highly vulnerable to accusations of elitism or foreign control
Relations with the state	State perceives as competitor State supplies financial resources State sensitive to criticism from civil society actors	Problem worse as civil society programs grow Cooptation of civil society to state priorities Reduced political space or repression of civil society actors
Market relations	Business supplies resources Business response to criticism Business sees opportunities in civil society growth	Cooptation of civil society business priorities Reduced political or resource space Business-organized NGOs capture resources
International context	Foreign NGO supplies resources Links to foreign NGOs raise identity questions	Link programs to local values and priorities Build clear identities grounded in local values and roles

Source: Brown & Kalegaonkar (1999)

Independently of the sector, they all function on base on regulations and laws that influence their behavior and impact ISP creation. Despite perceived conflicts of interests, each sector can contribute with its unique competencies, knowledge and experience. The objective is to bring leaders of multiple sectors together to develop a shared vision for a coordinated system in their respective areas.

Sullivan and Skelcher (2002) point out that different forms of partnership: strategic, sectoral and neighborhood, have different implications for public participation, as demonstrated in Table 6. While most of collaborative activities fit into this scheme, there will be some taking place at a number of levels, across two or three of them.

Table 6. Public participation in different types of partnerships according to Sullivan and Skelcher (2002)

Implications for citizens	Strategic partnership	Sectoral partnership	Neighborhood partnership
Role	Representative - focus on community leaders and umbrella groups	Participative - focus on users and beneficiaries	Representative & participative - focus on users and community members

Proximity to community	Distant - infrastructure necessary to secure and support participation	Close	Close
Remit	Wide ranging	Focused on specific service	Focused on local wellbeing
Presence	Citizens one of many stakeholders represented	Users a key stakeholder with providers and commissioners	Citizens one of many stakeholders but with greatest interest and often largest number

Source: Sullivan & Skelcher (2002)

On the other hand, depending on the identity through which a person – a citizen, becomes and remains involved in a participatory action, the technique of participation differs. These participation techniques are illustrated in Table 7.

Table 7. Framing of participation techniques according to Williams et al. (2006)

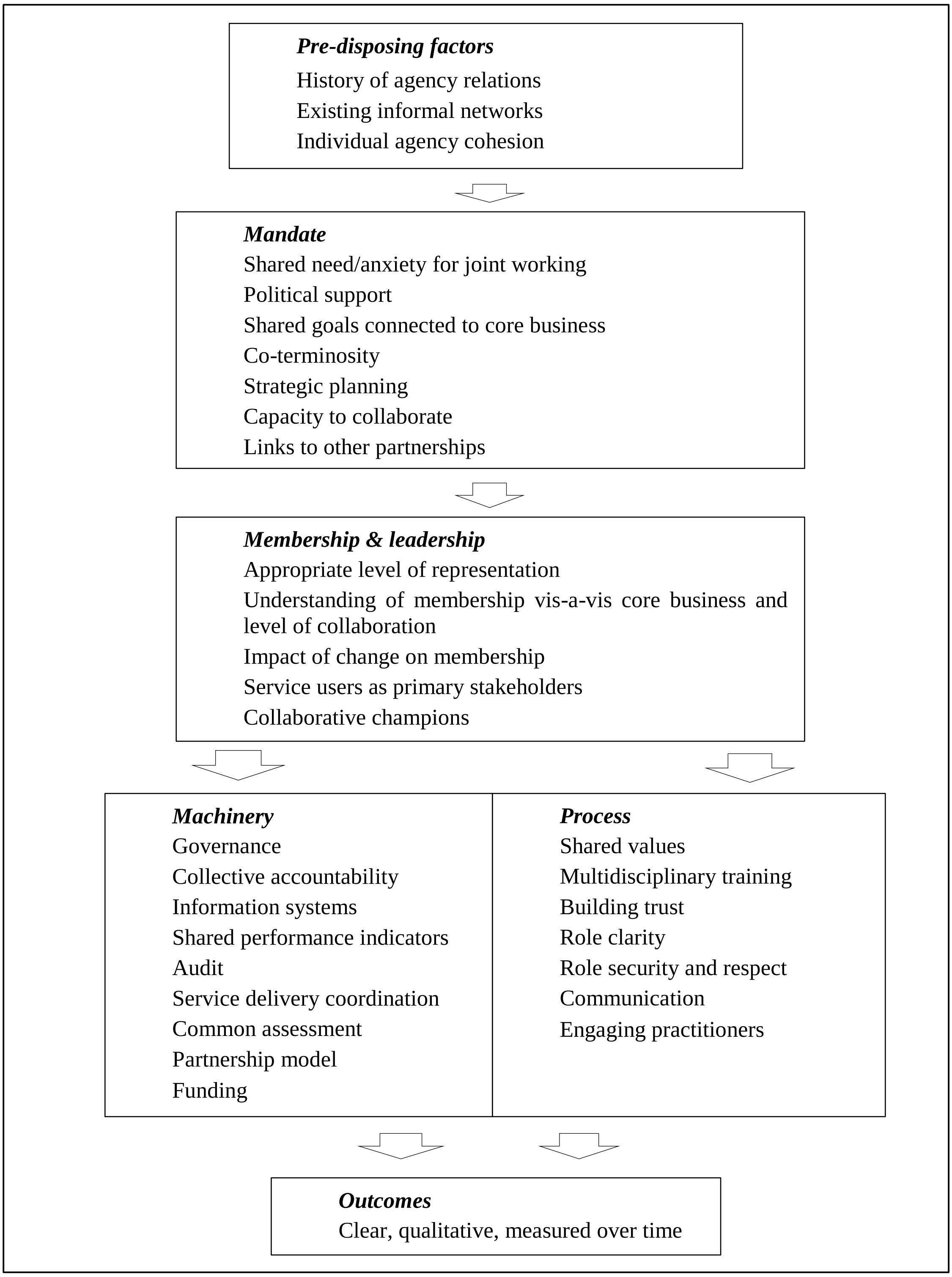
FRAMING OF IDENTITY	PARTICIPATION TECHNIQUE
as individual citizen	Surveys and questionnaires; road shows and exhibitions; newsletters; web sites; vox pop; citizen’s panels
as a member of an area-based community	Public meetings; community and area forums; conferences; open space technology
as a member of a voluntary or special interest group	Focus groups; consultation letters; meetings
as a member of a ‘hard to reach’ group	Festival or Congress; focus group; theatre in the community

Source: Williams et al. (2006)

1.6. Determinants of partnerships

A quantity of publications on collaborative linkages has been growing since the early 1990s. In particular, there have been a number of publications promoting benefits of collaborative approaches. Some of them have claimed benefits include lower costs and inventory, higher efficiency, improved customer service, quicker delivery to the market, improved learning and knowledge exchange, higher profit margins, improved shareholder value and increased competitive advantage over other supply chains. Several authors have provided empirical evidence of these affirmations supporting the view that collaboration can improve customer service, reduce waste and generate mutual benefits by sharing risks and rewards (Horwath &

Morrison, 2007). Figure 8 presents a model proposed by Horwath and Morrison (2007) in which the authors resume the collaboration elements.



Source: Adapted from Horwath & Morrison (2007)

Figure 8. Constituents of collaboration according to Horwath and Morrison (2007)

One of main challenges associated to intersectoral partnership is vast discrepancy between practice and research (Googins & Rochlin, 2000). A collection of frameworks has been developed to increase understanding of what facilitates and what constrains collaborative efforts. Some of these are specific to what happens between individuals, within or across teams, agencies or sectors (Jackson et al., 2008; San Martin-Rodriguez et al., 2005).

Dawes and Eglene (2004) identify six relevant domains that can have an impact, both separately and collectively, on a collaboration process and its effect: political, social, economic and cultural environment; institutional, business and technological environment; partners' objectives and characteristics; collaboration process; modes of collaboration; and project and collaboration performance.

From a theoretical perspective, one of arguments in favor of close collaborative relationships between organizations is presented by a relational view of the company (Dyer & Singh, 1998), also mentioned in literature as a collaborative advantage. The concept states that competitive advantage in a collaborative relationship can be achieved in four different ways: by sharing risk and investment in assets that are specific to the relationship; by improving learning through better knowledge exchange that leads to joint learning; by allowing synergy to take place through the combination of resources and capabilities; and through efficiency, leading to lower transaction costs. This view mentions the ways to obtain a collaborative advantage, although it does not explain circumstances in which collaboration can be effective or not and hence, it does not give directions about when and how close to collaborate.

Pierce (2004) hypotheses that collaboration has a higher likelihood of success if: in general, involved leaders possess minimum amounts of collaborative knowledge skills and values; all relevant stakeholders/actors are convened and included in the decision-making process; a common/shared understanding of the problem, time element, strategies needed, specific roles and available resources is achieved; the strategies formulated and implemented are inclusive in nature; the collaborative process is reflective, critical and iterative (follows the act-reflect-learn-plan-act sequence); credit for results is shared equally among stakeholders and not attributed to any one person or group (pp. 6-7).

A research study conducted in Wales (Bristow et al., 2003) identifies three broadly understood categories of motivations and drivers for partnerships:

1) Increasing efficiency: through improvement in quality, cost-effectiveness and efficiency of public services, and sharing ideas to harness the distinct competencies of diverse agencies;

2) Improving inclusiveness: by increasing civil engagement and developing more inclusive and participatory forms of governance for the delivery of public services; balancing individual organizational goals and collective interests in pursuit of the common good; and achieving a clearer alignment between the provision of services and user’s needs;
3) Integration: in order to reduce duplication of activities between agencies, and to tackle cross cutting issues facing government.

San Martin-Rodriguez et al. (2005) propose a framework for determinants of collaboration that distinguishes between systemic determinants occurring outside the organization, organizational determinants (within the organization) and interactional determinants which encompass interpersonal interactions between team members. The authors of the literature review of collaboration between the primary care and public health (Martin-Misener & Valaitis, 2008) used this framework and identified major barriers and facilitators on the system, organizational and interactional levels. Major barriers for collaboration at a system level included policy, funding, power and control issues, and information infrastructure. Major facilitators for collaboration at a system level included government involvement and fit, funding, and education and training. Major barriers for collaboration at an organizational level included lack of a common agenda, resource limitations, and lack of knowledge and skills. Major facilitators for collaboration at an organizational level included leadership management and accountability issues, geographic proximity of partners, and protocol tool and information sharing. Major barriers for collaboration at an interactional level included attitudes and beliefs, and relationship challenges. Major facilitators for collaboration at an interactional level included role clarity, shared purpose, philosophy and identity, developing and maintaining good relationships, effective communication and decision making strategies.

System barriers can be summarized using Jackson et al.’s framework (2008), classifying three types of barriers identified for successful collaboration: communication barriers, structural barriers and cultural barriers. Communication barriers comprise unclear expectations, lack of essential information, ambiguous roles, incompatible procedures and difficulties in communication deriving from several sources. Structural barriers encompass financial restrictions, inadequate resources, high staff turnover, fundamental difference in aims and conflicting performance targets. Finally, cultural barriers include lack of trust and credibility, lack of shared language, perceived power differences, fear of change and unwillingness to innovate or make in a different way, and tension deriving from in disparity between authority and responsibility, one of the principles of organization.

Gray (1989) argues that “there are many reasons why collaborative attempts fall short of the ideal or are never even initiated” (p. 247). McKinnon (2009) considers the principal among barriers that prohibit successful collaborations a lack of appreciation for different roles that the public and private sectors play in the society. Public organizations frequently mistrust business, as having the profit maximization behind any decision and action undertaken. On the other hand, private sector sees public organizations as against the open market and free competition, requesting rules and decisions that decrease global competitiveness. The author assumes this simplistic though true vision as translating into a general unwillingness to engage in a collaborative action in the first place, and when partnerships are initiated, to charge the process by skepticism of the other’s motives at each step.

To the extent that collaboration requires changes in practice or innovation, perceptions that service providers have regarding similarities and differences between their values and those of providers in other sectors will affect their likelihood to engage in collaborative initiatives. Embedding change takes time and requires an ongoing adaptation. Understanding diversity constitutes their richness and a source of strength.

While establishing collaboration within local partnership structures, setting up the general collaborative system in a way which would coat a protocol of the collaboration practice based on a type of commited organization rather than an individual entity brings a particular challenge. Having reached this phase, a bridge to further operationalize the process involving a wider range of possible partners is established. In their system dynamic model, Black et al. (2002) prove that collaboration is the sum of participants’ engagement. The more engaged the participants, the more the productivity increases. The level to which a participant feels interested to stay commited depends on a sense of progress and trust in other participants. Trust in itself depends on how much a partner knows about other participants’ roles, priorities, needs, objectives and constraints relating to the project and its implementation. As participants do the work, they learn more about the possibilities for their own involvement, as well as more about the others’ involvement in the project. As knowledge of one’s own work in the project increases, the probability of errors in the project implementation decreases. When all participants possess more knowledge about their respective roles in the project, the probability of making mistakes, as they work together, decreases.

Seitanidi and Ryan’s paper (2007) puts forward three propositions conditioning the successful implementation and sustainability of partnerships: to contribute to an increase of institutional trust among organizations and across sectors; to assist in balancing the dynamics across the sectors; and to appreciate a process of interaction as a source. Stewart, Petch and Curtice (2003) propose a sheet of drivers and barriers to integrated working (presented in Table 8) encompassing three global blocks of assessment: the national policy frameworks, the local context and operational factors.

Table 8. Drivers and barriers to integrated working according to Stewart, Petch and Curtice (2003)

	Drivers	**Barriers**
A. National policy frameworks	Joined-up Strategic Realistic	Piecemeal and contradictory Promote "projectitis" Unrealistic change agenda
B. Local planning context	Planning and decision cycles mesh Joint acceptance of unmet need Agreed, comprehensive vision, owned at all levels	Incompatible planning and decision cycles Not needs led Issues seen in isolation
C. Operational factors		
Relations between partners	Trust permits risk taking Open, honest communication	Lack of trust prevents risk-taking Defensive, limited communication
Organizational culture	"Can do" culture Collective responsibility publicly demonstrated	Sees institutional and legal barriers Senior figures devalue/disown common purpose
Enabling staff	Agreed roles and responsibilities Staff valued	Unclear responsibilities, conflict Staff expendable
Professional behavior	Centered on user need Willing to take risks	Tribal, protectionist Covers own back
Attitudes	"We have nothing to lose" "We will find a way"	"We have everything to lose" "No way"
Outcomes	User focused Visible benefits shared	Only seen from agencies' agenda Invisible Winners and losers

Source: Adapted from Stewart, Petch, & Curtice (2003)

Crowley and Karim (1995) comprehend that partnership means two possible manners of interorganizational problem solving. One is related to attributes such as trust, shared vision and a long-term commitment. The second way is a process of approving mission and objectives, and developing agreements on organizing and conducting partnerships.

Trust, knowledge sharing and collaboration are central elements of effective interorganizational relationships (Black et al., 2002). Trust is often isolated as one of the most important factors to influence the course of interorganizational relations. Trust can become a major governance mechanism in a cross-organization setting and can be seen as expectation or hope that another side will not behave opportunistically, even if there are possibilities or incentives to do so. On the other hand, Cousins (2002) argues that trust between organizations does not exist.

Organizations do not trust each other, but they manage risk relying on business case decisions. Various models of trust implicate the concept with faith, risk, predictability, calculation, goodwill and common norms. Following Ring and Van de Ven (1992), a focus on trust is confidence in a partner to work on behalf of partnership, and a reliance on their goodwill. As pointed out by Porter (McAllister, 1995), trust "tends to be somewhat like a combination of weather and motherhood; it is widely talked about, and it is widely assumed to be good for organizations. When it comes to specifying what it means in an organizational context, however, vagueness creeps in" (p. 24). In fact, trust appears to be an important and repeatable concept across fields of economics, organizational behavior, psychology and sociology; nevertheless, there is a little consensus on types or definitions of trust. There is a variety of conceptions of trust which help frame its aspects and they encompass vulnerability, risk, and a role of positive expectations or optimistic belief (Rousseau et al., 1998). In their work, Rousseau et al. (1998) specify three forms of trust as distinct in relationships. Calculus-based trust depends on a trustor's capacity to assess credibility and on the trustee's predisposition to trust. Identity-based trust relies on personal or emotional attachment build on a basis on long-term relation. Institution-based trust is based on institutional factors such as norms, organizational culture and legal systems that alleviate risks and promote trust-based behaviors.

Williams and Sullivan (2007) point out that potential benefits of 'joined-up' government include the "better use of resources, elimination of overlaps, creation of synergies and the delivery of seamless services". However, achieving these benefits is "challenging because of the associated problems of securing accountability and democratic legitimacy, managing complexity and coping with shifting power relationships, higher transaction costs and the difficulties of measuring success" (p. 16). Gray (1989) lists potential benefits of collaborative commitment since broad comprehensive analysis of the problem domain improves quality of the solution; response capability is more diversified; useful in re-opening dead locked negotiation; risk of impasse is minimized; process ensures that each stakeholder's interests are considered in any agreement; parties retain ownership of the solution and are most familiar with the problem inventing solutions; participation enhances acceptance of the solution and willingness to implement it; potential to deliver original, innovative solutions is enhanced; relations between stakeholders improve; costs associated with other methods are avoided; and mechanisms for coordinating future action among the stakeholders can be established. Another proposal of potential benefits is that of Alter and Hage (1993), who considered costs of collaboration, as well. These are provided in Table 9.

Table 9. Calculus of interorganizational collaboration according to Alter and Hage (1993)

Costs	Benefits
Loss of technological superiority; risk of losing competitive position	Opportunities to learn and to adapt; develop competencies; or jointly develop new products
Loss of resources – time, money, information, raw material, legitimacy, status, etc.	Gain of resources – time, money, information, raw material, legitimacy, status, etc.; utilization of unused plant capacity
Being linked with failure; sharing the costs of failing such as loss of reputation, status and financial position	Sharing the cost of product development; and associated risks
Loss of autonomy and ability to unilaterally control outcomes; goal displacement; loss of control	Gain of influence over domain; ability to penetrate new markets; competitive positioning and access to foreign markets
Loss of stability, certainty and known time-tested technology; feeling of dislocation	Ability to manage uncertainty, solve invisible and complex problems; ability to specialize or diversify; ability to fend off competitors
Conflict over domain, goals, methods	Gain of mutual support, group synergy and harmonious working relationships
Delays in solutions due to problems in coordination	Rapid responses to changing market demands; less delay in use of new technologies
Government intrusion, regulation and so on	Gaining acceptance from foreign governments for participation in the country

Source: Alter & Hage (1993)

Mattessich, Murray-Close and Monsey (1994) relate a group of factors they deem influence a collaborative arrangement and its further success (or its lack). These factors refer to the environment, membership characteristics, process or structure, communication, purpose and accessible resources (look Table 10).

Table 10. Factors influencing the success of collaboration as defined by Mattessich, Murray-Close and Monsey (1994)

Factors related to the ENVIRONMENT
History of collaboration or co-operation in the community Collaborative group seen as a leader in the community Political/social climate favourable
Factors related to MEMBERSHIP CHARACTERISTICS
Mutual respect, understanding and trust Appropriate cross section of members Members see collaboration as in their self-interest Ability to compromise

Factors related to PROCESS/STRUCTURE
Members share a stake in both process and outcome
Multiple layers of decision-making
Flexibility
Development of clear roles and policy guidelines
Adaptability

Factors related to COMMUNICATION
Open and frequent communication
Established informal and formal communication links

Factors related to PURPOSE
Concrete, attainable goals and objectives
Shared vision
Unique purpose

Factors related to RESOURCES
Sufficient funds
Skilled convenor

Source: Mattessich, Murray-Close, & Monsey (1994)

Literature does not forget all types of impediments to successful collaborative action, including historical barriers, ideological or emotional barriers, differences in organizational culture or relative power, difficulties in establishing common goals and objectives, among others. Five categories of barriers to coordination identified by Hudson et al. (1997) are displayed in Table 11. Buehler, Whitney and Berkelman (2006) point out that the most frequently cited in literature challenge to collaboration is the difference in cultures, observable between business and government and especially visible in public health.

Table 11. Barriers to coordination according to Hudson et al. (1997)

STRUCTURAL	• Fragmentation of service responsibilities across agency boundaries, both within and between sectors • Inter-organizational complexity • Non-coterminosity of boundaries • Competition-based systems of governance
PROCEDURAL	• Differences in planning horizons and cycles • Differences in accountability arrangements • Differences in information systems and protocols regarding access and confidentiality
FINANCIAL	• Differences in budgetary cycles and accounting procedures • Differences in funding mechanisms and bases • Differences in the stocks and flows of financial resources
PROFESSIONAL/ CULTURAL	• Differences in ideologies and values • Professional self-interest and autonomy • Inter-professional domain dissensus • Threats to job security • Conflicting views about user interests and roles
STATUS AND LEGITIMACY	• Organizational self-interest and autonomy • Inter-organizational domain dissensus

Source: Hudson et al. (1997)

Following their systematic review, Cameron and Lart (2003) classify factors that may support or hamper joint working between organizations from the health and social care arena. These factors are presented in Table 12.

Table 12. Factors supporting or hindering joint working in health and social care according to Cameron and Lart (2003)

Organisational Factors
Aims and objectives
Organisational differences
Roles and responsibilities
Strategic support and commitment
Communication/IT systems
Co-location
Personalities involved
Strong management and professional support
Resources and personnel
Past history of joint working
Cultural and Professional Factors
Negative assessments/professional stereotypes
Trust and respect
Joint training/team building
Different professional philosophies and ideologies
Contextual Factors
Political climate
Constant re-organisation
Co-terminosity
Financial uncertainty

Source: Cameron & Lart (2003)

On basis of a broad and extensive research in the fields of health and social care, Hudson and Hardy (2002) advanced with a set of six principles that they considered to be the key to successful partnerships. These principles were: acknowledgement of the need for partnership; clarity and realism of purpose; commitment and ownership; development and maintenance of trust; establishment of clear and robust partnership arrangements; and monitoring, review and organizational learning. While they cannot guarantee, as the authors admit, the complete success of the collaborative action, ignoring them raises a chance to impede the partnership arrangement.

There are a number of guiding principles that seem fundamental for effective collaboration (Pierce, 2002). A minimum level of essential competencies is necessary, at both, the individual and institutional levels; learning at the organization level should be continuous as learning organizations are proven to better adapt to changes and are more open to dynamic conditions and situations; vital organizational constituents, including leadership, management and information systems have a high degree of interdependence with parallel constituents in partner organizations; individuals within organizations and organizations as a whole exert mutual influence upon each other; changes in one organization lead to changes in partner organizations;

joint planning happening on a regular basis will smoothen the process of change; local reality of each partner taken into account enhances the chance for collaboration success; focus should be held on outcomes and impact rather than a common mission and vision; and each partner must comprehend the organizational culture of all other involved parties: structures, human resources, work culture and attitudes.

Buehler et al. (2006) make an extensive discussion on limitations of partnerships between business and public health organizations, which fall into a number of categories. These encompass: limits of volunteerism, institutional constraints (accountability and procedures within business and governments), timing (time limitation of the speed at which partnerships can take on projects), keeping the focus on the established goal of the partnership (without necessarily quick extending the focus of the project into other related issues).

1.7. Evaluating performance of a partnership

An effective partnership is widely recognized and valued as important for development of the best practice approach. Yet, as McLaughlin (2004) point out, “partnerships have no *a priori* right to be the most effective service delivery method in all situations, the sooner we can learn the simple truth the sooner partnerships can be scrutinized and we will be able to identify when, where and how they can best be used” (p. 112). For this reason, evaluation is regarded as crucial for evidence-based practice.

Leathard (2005) reminds that “only by the 21st century has a quietly increasing number of studies addressed the outcomes of partnership working and collaborative endeavours” (p. 147). Klitgaard (2004) discusses three levels of evaluation question regarding partnerships, corresponding to: evaluating benefits and costs for a specific partner, evaluating partnership as a whole, and evaluating conditions that influence the emergence and functioning of partnerships.

An overall interest in an intersectoral action together with its complexity brings a need to understand mechanisms that underpin operationalizing it. Partnerships are increasingly seeking tools that enable stakeholders to reflect on their own effectiveness, benchmark the status of their partnership and provide a framework for development. Evaluating partnerships is challenging and origins several difficulties as they take long timescales to achieve an impact, require variable and complex interventions, engage different contexts and present different perspectives on what a success means. A regular assessment of performance involves time, effort and resources of various parties. The evaluation should comprise not only quantitative but also qualitative aspects.

Researchers have recognized a need for studies focusing on factors that contribute to effective partnerships. Slater et al. (2007) deem that monitoring and review can give rise to organizational learning, both across partnership and within partners' individual organizations. Monitoring performance against clear objectives is relatively tangible compared to the more tacit partnership process. Partnerships are dynamic arrangements, they need time to develop and grow. The evaluation cannot start and limit into a single point of time, but shall be carried over time in order to verify whether partnership demonstrates the capacity to learn from experience and learn about the surrounding environment (Coulson, 2005).

In available partnering assessment literature, evidence varies when assessing effects and a possible impact of the intersectoral action. Evidence demonstrating that the partnership approach is able to make all involved parties benefiting is extensive. As it obviously cannot be assumed that available reports account for the totality of conducted initiatives, pointing out countries, regions or systems which give a greater chance of success or failure would be erroneous. The same applies to type and specificity of the initiative, whether it concerns education, transportation or health and social sphere.

Dowling, Powell and Glendinning (2004) report systematic literature review of partnerships between the health social care services and note that from 491 articles they could only identify 36 that focused on evaluation and used primary data. The authors recapitulate the general conclusion in relation to evaluation in health and social care partnerships in the following way: "research that brings together rigorous and systematic evidence of the outcomes, causality and costs of partnerships has yet to be conducted. In summary the literature reviewed is heavily skewed towards the process of partnership working and the factors that contribute to success in this respect. Evidence that partnerships produce successful outcomes for staff, users, financial sponsors or other stakeholders is, in comparison, very sparse" (p. 314).

Ling (2000) reflects that partnership is seen, "generally as a good thing although very little empirical work has been done to justify either the claim that policies in the past failed because of a lack of partnership or that new partnership arrangements have demonstrably improved outcomes" (p. 82). Hudson and Hurdy's (2002) analytical framework of partnerships working comprises six principles that the authors claim are generic and applicable across a range of contexts and partnerships types. The six principles making up the framework are:

1) Acknowledgement of the need for partnership;

2) Clarity and realism of purpose;

3) Commitment and ownership;
4) Development and maintenance of trust;
5) Establishment of clear and robust partnership arrangements;
6) Monitoring, review and organizational learning.

A number of working papers and reports indicate that there is an interest in collaborative action and it has been becoming a recognized instrument and process, but monitoring instruments are still lacking. Literature does not provide much of instruments which would assess core aspects of a collaborative plan, opportunities in the process and pitfalls. Successful collaboration has been conceptualized in different ways but its assessment provides two types of measures that can be used. Most studies make a distinction between two types of measures: process and outcome measures of success. Process measures focus on the way partnerships work, the relationship between partners and the quality of the collaborative activity itself. Outcome-focused measurement examines whether partnerships lead to actual benefits for service users such as improved health and well-being.

Process measures provide an ongoing feedback on the views of the participants and stakeholders regarding processes used to implement the program. Process evaluation can be implemented throughout the course of the initiative and it can then offer an enduring feedback that can be used to continuously modify and improve the initiative. Process evaluation that is done at the end of the program can provide useful information on what worked well and less well, and what modifications can be proposed for another, similar program. Outcome measures provide researchers with information on what has changed as a result of the initiative. Data used to measure outcomes can be gathered throughout the program for an ongoing feedback as well as at its conclusion. Information gathered before the initiative begins - ‘baseline data’- can be compared to information gathered at one of the stages of the program to observe the scope and quality of occurred changes.

Dowling, Powell and Glendinning (2004) indicate that collaborative success from the viewpoint of the process involves measurements for the level of engagement and commitment of partners, suitable legal structures, favorable financial environments, satisfactory accountability arrangements, adequate leadership and management of the partnership and agreement of the purpose of and need for the partnership. For the outcome-perceived success, two potential dimensions can be distinguished:

1) Dimension resulting in changes of levels, organization or delivery of services (such as improving accessibility of service, improving quality of provided service, improving efficiency);
2) Improvements or the absence of deterioration in health, quality of life, well-being and social inclusion of service users.

In order to broadly assess the effectiveness of partnership working, Hudson (2006) proposes a framework of 'components of a holistic perspective' (look Table 13). The construct is to be used in two phases. In the first phase, the current state of partnership is summarized regarding each of eight dimensions. These are judged by their relative progress as high, medium or low. The second phase allows for the judgment of the relationship between the variables.

Table 13. Components of a holistic perspective for partnership evaluation according to Hudson (2006)

COMPONENT	DESCRIPTION
Ideological consensus	The extent to which there is agreement regarding the nature of the tasks facing the partnership
Domain consensus	The extent to which there is agreement regarding the role and scope of each partner's contribution to the task
Positive evaluation	The extent to which those in one part of the partnership have a positive view of the contribution of those in another
Work co-ordination	The extent to which autonomous partners are prepared to align working patterns
Fulfillment of programme requirements	The degree of compatibility between the goals of the partnership, and the goals of the individual stakeholders
Maintenance of a clear domain of high social importance	The extent to which there is support for the objectives of the social importance of partnership from the range of affected constituencies
Maintenance of resource flows	The extent to which there is adequate funding for the objectives of the partnership
Defence of the organisational paradigm	The extent to which stakeholders see themselves as working for the partnership rather than representing their constituency

Source: Hudson (2006)

Conducting broad and valuable evaluation of collaborative efforts is necessary to contribute to the evidence-based practice. Developing effective partnerships is demanding and acts as a barrier to effective evaluation in a key health area for some community health practitioners. Results indicate that evaluating such interventions is challenging for practitioners due to a broad nature of the subject and currently available measurement tools (DHS, 2004).

Partnership is not a goal in itself; partnerships are established to "achieve other goals, with the implicit or explicit recognition that by acting together partners can accomplish more than by acting alone" (Caplan & Jones, 2002, p. 1). Establishing partnering arrangement is thus means to achieving a set of objectives rather than an end, and different bodies interested and affected by partnership functioning have different perspectives on how to measure its results. Different interested and affected groups will measure the success of the initiative according to different sets of criteria due to their backgrounds, organizational culture and visions of the collaboration. Monitoring and evaluating partnership becomes hence an important component of the arrangement without which partners cannot measure their impact on the outcome. Setting up indicators assessing mutual and individual goals is challenging but necessary. For mutual goals, these indicators should be established and jointly agreed before the first evaluation phase, ideally, on the partnership design phase. Additionally, individual indicators can be set up allowing for verification how partnership responds to particular objectives of each of the entities involved. While general partnership indicators should rather be stable across the partnership arrangement, individual indicators may vary over time as priorities and viewpoints of organizations change. This stability is relative to the point in which partnership is a dynamic settlement. Its structure needs to ensure adaptation to the changing dynamics of partnerships and actors involved. Caplan and Jones (2002) argue that cross-sector partnerships are “living, breathing organisms” and methods to “determine a baseline, measure achievements along a given axis and then use those measurements for future planning must somehow capture this dynamism” (p. 2).

The complexity of gauging partnership outcomes is highlighted by Rein et al. (2005), who suggest that the value of partnerships “lies not just in their ability to deliver tangible improvements in social services or economic goods: it can also reside in the vantage point a partnership can give to relatively weak or disadvantaged sections of the community, to enable them to express their needs, draw attention to pressing problems and build dialogue with other groups and institutions” (p. 125).

One approach regarding the assessment of partnership could use the Report of the Working Group promoted by the WHO (1998), which established four aspects that should necessarily be part of project evaluations in initiatives that promote health:

1) Participation: engage all interested in the conducted initiative bodies in all stages of its realization;
2) Multiple methods: use sources from several disciplines, search for elements and procedures of collecting data;
3) Capacity: enhance the capacity of individuals, organizations and governments to consider issues relevant to health promotion;

4) Adequacy: foster planning that takes into account the complex nature of the intervention and its long-term impact.

The coalition theory can be employed to approach the analysis of intersectoral collaboration. One of the most important figures in the coalition theory, Gamson (1961), defined coalition as temporary alliances between individuals and groups that differ in goals. According to Gamson (1961), four parameters determine the establishment and development of coalition. The first parameter, initial distribution of resources, encompasses all characteristics and aspects of the parties that act as predictors of further collaboration, such as contacts, prestige or size. The second parameter comprises rewards that participating actors expect to receive from their participation in coalition, pay-offs expected and hoped to generate within coalition. As the author describes, the pay-off for joining coalition is the expected value of future decisions multiplied by the probability that coalition actually works in practice. The third parameter is named ‘non-utilitarian preferences’ and relates to the tendency of one participant to join any other participant in coalition independently of resources that the participant represents. These relations and ties can be of a positive or a negative type. The fourth parameter, effective decision point, specifies the amount and type of resources necessary to control decisions and aims at reaching a consensus in coalition.

A specific framework developed for partnerships comes from the USAID and the New Partnership Initiative. In 1999, the USAID experts, Charles and McNulty, developed a framework specifically directed into assessing the impact of intersectoral partnering. The framework stressed out the role of three domains of intersectoral collaboration: the values and capacity of partnership, the process of partnering, and the impact of the partnership. The first domain of partnership, values and capacity, focuses on partnership itself. It contains three dimensions: organizational capacity, organizational culture and external environment. Organizational capacity refers to the capacity of partnership to stick to its pre-defined objectives. Organizational culture relates with a joint conviction for establishing partnership, sharing objectives and common consensus that this partnership is a suitable strategy to address a given issue. External environment comprises political, legal, social and economic context within a country, factors that affect the process of formation and conduct partnership. The second domain of the framework, the process of partnering, is, according to the authors, the most difficult to appraise. It obliges evaluating two dimensions of the process of partnering: mechanisms for communication and collaboration in partnership, and mechanisms for communication and collaboration outside partnership. The last domain of the framework, the impact of partnership, needs to be assessed at three different levels: as an impact on the common issue addressed by partnership, as an impact on the partner members, and as an impact on the society. The framework, overall, can be used to assess any development activity that involves intersectoral partnering as a process or a result (Charles & McNulty, 1998). The authors further confirm that indicators of collaboration tend to be rather qualitative and subjective than quantitative and objective.

Provan and Milward (2001) developed a rationale for a need to evaluate publicly funded, community-based networks. Their framework proposes evaluation of a public sector network at three levels: the community, the network and the organization/participant. They all need to be considered, although not necessarily equally. These levels are of concern of three broadly understood categories of the network constituents: principals, who fund and further monitor the network; agents, who work within the network; and clients, who receive the actual services provided by the network. The aim of the authors was to find a rationale for evaluating whether the network performed at the level that justified a continued public support. At the community level, networks are analyzed from the point of view of contribution they make to the community they are aimed to serve. They provide value that would not be delivered through fragmented agencies and uncoordinated efforts. The key stakeholder groups comprise principals and clients (regulators, politicians, funders and clients groups). The effectiveness criteria to be employed consider cost to the community, capacity to build social capital, changes in the incidence of the problem, public perception of the problem, and comprehensive indicators of clients' well-being. At the network level, mainly structural targets of analysis are suggested (such as a number of partners or a number of connections between partners), together with outcomes of the network (for instance, measured in a range and quantity of provided services). The principal stakeholder groups at this level are principals and agents. The effectiveness criteria include (Provan & Milward, 2001) network membership growth, variety of provided services, absence of service replication, relationship strength, creation and maintenance of the network administrative organization, integration/coordination of services, cost of the network maintenance. At the organization/participant level, Provan and Milward (2001) recognize that individual agencies remain motivated by self-interest toward the network membership. At this level, clients and agents play the key role. While the network can significantly contribute to individual agencies success, this success is in most cases indispensable to guarantee the network effectiveness. The effectiveness criteria encompass agency survival, cost of services, access to services and acquisition of resources, among others.

Another framework for assessing partnerships relations and outcomes was proposed by Brinkerhoff (2002a) who starts from the assumption that from all possible arrangements, intersectoral partnership is the most capable to produce an ‘added value’. The author clearly defines five areas on which to base the framework:

1) Compliance with prerequisites and success factors in partnership relationships (partners’ tolerance for sharing power, keenness to adjust their operations, and procedures to smooth the progress of partnership performance);
2) The degree of partnership principle (mutuality and organizational identity);
3) Outcomes of the partnership practice (qualitative or quantitative synergistic outcomes of the program itself; linkages with other programs and actors; enhanced capacity);
4) Partners’ performance (following the prescribed by partnership roles or changes made as a result of strategic adaptation);
5) Efficiency (existence of environmental unfriendliness towards the program and the extent to which this resentment is proactively managed).

According to Brinkerhoff (2002a), the key role in assessing the outcomes of partnership relations plays the analysis of the degree of partnership. It encompasses two unique partnership dimensions: organizational identity and mutuality, which the author deems represent ‘the nature of partnership’. Adding these dimensions to the assessment model provides a link between the relationship and the project outcomes, and constitutes the key enhancement in respect to traditional partnership assessment frameworks focused on causal change. Organizational identity encompasses everything what is unique and distinctive for the organization, without which any assessment of intersectoral partnerships is believed to be incomplete. Organizational identity is the degree to which an organization remains reliable and faithful to its mission and values. In this way, assessing organizational identity involves identifying and evaluating its mission, vision, values, culture, strengths and weaknesses, and how the participation in partnership has shaped its competitive advantage. A dimension of mutuality enables an organization to act within and influence the other actors in partnership equally. It encompasses mutual respect, horizontal coordination, resource exchange, accountability, and equity in decision-making. Assessing mutuality involves measuring regularity of contacts and reporting between partners, participation in planning and organization meetings, balance of resource exchange and satisfaction on benefits allocation (Brinkerhoff, 2002a).

Bryson, Crosby and Stone (2006) developed an inventory of 22 propositions comprising a model of five central dimensions of intersectoral collaboration. For each dimension, relevant concepts were discussed and relative propositions presented. The first dimension, initial conditions, relates to the general environment in which collaboration is entrenched, the notion of sector failure as a disregarded prerequisite for collaboration, and other direct and immediate preconditions affecting specific development of the collaboration. The authors propose:

Proposition 1. Creation and sustainable endurance of intersectoral relations are affected by unstable environmental forces and institutional environments.

Proposition 2. The probability that public policy makers become interested in intersectoral action increases when one-sector efforts to solve problems have been unsuccessful and/or potential or actual failures cannot be solve by sectors working separately.

Proposition 3. If, at the initial phase of the formation of a cross-sector relation, one or more from the mechanisms, such as common agreement on the purpose, influential supporters, or already existing networks exist, it is more likely to succeed.

The second dimension draws attention to diverse aspects of a process within collaboration, focusing on forging initial agreements, building leadership, legitimacy, trust, managing conflict, and planning. Bryson, Crosby and Stone (2006) admit this dimension may somehow overlap with some features of the research on initial conditions and structure. The authors state:

Proposition 4. The preliminary process leading to formulation of collaboration agreement and a structure of its agreement constitute factors affecting outcomes of further collaboration.

Proposition 5. Intersectoral collaborations have more chances to achieve success if they have sponsors and supporters at several levels dedicated to the cause providing both, formal and informal guidance.

Proposition 6. Intersectoral collaborations have more chances to achieve success if they establish a separate, legal entity with internal and external stakeholders as a form of further activity.

Proposition 7. Intersectoral collaborations have more chances to achieve success if they set up foundations for continuous and long-lasting trust building activities.

Proposition 8. Cross-sector collaborations are more likely to be successful if partners manage to learn solving conflicts effectively, using resources and tactics available for them.

Proposition 9. A success of intersectoral collaboration is more likely to occur when combining deliberate and emergent planning.

Proposition 10. Intersectoral collaborations have more chances to achieve success if the planning process springs from all stakeholders' analysis, emphasizing their responsibilities, and is built on distinctive competencies of the collaborators using their resources, capacities and skills.

The third dimension focuses on structure and governance mechanisms that affect stability and impact strategy. Structure concerns horizontal and vertical components and partnership appears to influence structure. As a group of coordinating and monitoring activities, governance must take place in order to make collaboration be created, service and function. The authors affirm the following:

Proposition 11. Collaborative structure is influenced by its external environment, in which some environmental factors can be considered more general and some more specific to a given linkage.

Proposition 12. Collaborative structure is likely to suffer modifications over time as a natural consequence of complexity of environments and uncertainty of membership.

Proposition 13. Collaboration structure and the nature of responsibilities assumed by the stakeholders influence general effectiveness of collaboration.

Proposition 14. Formal leading mechanisms are as likely to influence the collaboration effectiveness as the informal ones.

The fourth dimension looks at contingencies and constraints affecting process, structure and governance. It draws the attention on three factors that have been proven to affect collaboration as a whole, with its sustainability: a type of collaboration, power imbalances and competing institutional logics within the collaboration. In this regard, Bryson, Crosby and Stone (2006) advance with:

Proposition 15. Collaborations that involve planning activities on the system-level are the most likely to include negotiation, followed by collaborations that involve planning activities on the administrative-level and on the service delivery-level.

Proposition 16. Intersectoral collaborations have more chances to achieve success if they use their existing resources, knowledge and competencies in order to deal with imbalances.

Proposition 17. Conflicting rationalities of the stakeholders are very likely within the cross-sector collaborations and are able to considerably impact the degree to which the partners agree on the structure, process, leadership, control and outcomes.

The last dimension approaches long-term aspects of intersectoral collaboration, such as outcomes and accountabilities. Outcomes can be discussed in three categories: public value, first-, second- and third-order effects, and resilience and reassessment. Accountability turns to be an intricate issue in terms of collaborative engagement as it may not necessarily remain clear to whom it is accountable and for what. Accountability encompasses inputs, process and outputs, results and management system, and relationships with political and professional constituencies. Regarding outcomes and accountabilities, the authors propose:

Proposition 18. Intersectoral collaborations are most likely to generate value for the society when they base on own interests of individuals and organizations and each sector distinctive assets while seeking ways to minimize their weaknesses.

Proposition 19. Intersectoral collaborations are most likely to generate value for the society when they produce positive first-, second-, and third-order effects.

Proposition 20. Intersectoral collaborations are most likely to generate value for the society when they involve regular re-examinations and evaluations, and are robust.

Proposition 21. Cross-sector collaborations have more chances to achieve success if they have and use an accountability system that follows inputs, processes and outputs; they use methods for interpreting and evaluating the information and results, and use the results management system built on strong relationships with relevant political and professional publics.

Bryson, Crosby and Stone’s final proposition (2006) affirms that it is expectable to perceive cross-sector collaborations as complicated to build and sustain, and their success is difficult to achieve.

Jorgensen’s (2006) framework covers both, partnership process and outcome measures, and focuses on the field of social development. In order to assess partnership processes, participating parties’ strategies and collaborative advantage are taken into account and under a close review. For the assessment partnership outcomes, the framework proposes parameters relating to developmental outcomes - their contribution to development goals, and to ‘business outcomes’ - contributions to objectives of each organization. Jorgensen (2006) proposes a variety of evaluation parameters adapted to different specificities. Measures employed by the framework are broad rather than specific so that the framework could be practically applied into a wide range of settings and situations.

The outcomes-based performance model of the multi-stakeholder arrangements represents a permanent, iterative process and is composed, according to Atkinson and Maxwell (2007), from the following components:

a) identification of outcomes;

b) definition of associated life factors and measurable indicators;

c) data collection, analysis and reporting;

d) review of achievements against outcomes, identification of areas for improvement and action planning.

A logical framework helps guide development of project design, and subsequent monitoring and evaluation system. CARE (the Cooperative for Assistance and Relief Everywhere) has developed a simplistic 'healthy partnership' objective assessment tool allowing for defining in advance how partners establish, monitor and evaluate individual objectives within a larger project (Bartel, Igras, & Chamberlain, 2007). The authors point out that naming the objective and determining its predicted output, involved activities and the leader responsible for its achieving, verification method and indicators are vital elements of the methodology. An example of such 'healthy partnership' is presented in Table 14.

Table 14. An illustration of 'healthy partnership'

Objective	Outputs	Activities	Lead person	Indicators	Verification
Conduct an annual 'check-up' of the partnership	The health of the partnership is affirmed (or not) and commitments made to resolve outstanding issues. Renewal of trust in and commitment to partnership	In a 'safe' setting held offsite, selected staff meets to talk about how 'healthy' the partnership is. Partners analyze issues in their relationship, discuss problems and their causes, and identify actions/ solutions	Senior staff from each organization	Staff from different levels of each organization participates in the partner reflection Partners' rating of adequacy of each other's attitudes, behaviors, and adherence to partnership principles	Commitments to resolve remaining issues are written up and actions are determined

Source: Adapted from Bartel, Igras, & Chamberlain (2007)

For the purpose of assessment, the Canadian Institute for Environmental Law and Policy (2005) proposes a checklist with a number of detailed issues to be verified over the course of partnership (pp. 6-7):

1) The partnership has a solid base of joint commitment and understanding:
   - partners either have common backgrounds or mandates, or go through a process involving extensive face-to-face contact to define problems or opportunities being addressed, and to understand each other's concerns;
   - partners clearly define vision;
   - partners clearly define goal;
   - partners clearly define general methodology/strategies; and
   - partners clearly define relationship to one another.

2) There is a clear and appropriately detailed plan for achieving the goals of the partnership:
   - a plan exists;
   - the activities planned will lead to realization of goal;
   - the plan defines who will undertake each action;
   - the plan defines what resources they will use;
   - the plan defines a timeline for completing action;
   - the plan defines how action will be evaluated;
   - the plan includes reflection on the processes of the partnership; and
   - the plan addresses further continuation or ending of partnership.

3) Each partner clearly benefits from the partnership:
   - the activities of the partnership help each participant to achieve part of their mandate.

4) Sufficient and appropriate resources are committed from all partners for achieving the goals of the partnerships:
   - each partner contributes to the partnership;
   - all partners acknowledge that resources necessary to the partnership include more than financial resources;
   - there are enough resources available to achieve the aims of the partnership in the short term and long term;
   - there is a clear agreement as to who will provide specific resources, and when those resources will be provided;
   - the provision of resources is planned in a timely manner; and

- if resources are acquired for the partnership, there is a plan for what to do with them after the partnership.

5) The partnership has an appropriate level of formality:
   - if the partnership has begun action, the partners have thought about formality and consciously decided how formal it should be; and
   - if the partnership is just being initiated, partners are discussing different structures.

6) The partnership has good leadership:
   - the partnership's leadership is defined;
   - there is openness in communication with the leadership;
   - the leadership has strong abilities in the areas of negotiation, team building, planning, evaluation, time management, financial management, conflict resolution, and stress management;
   - the leadership clearly supports and understands the vision and goals of the partnership;
   - the partners trust the leadership and are supportive of it; and
   - the leadership is open to change and improvement.

7) The partnership has clear and enforceable lines of accountability:
   - each partner understands their responsibilities;
   - each partner reports thoroughly on their actions to other partners, leadership and to their organizations;
   - there are mechanisms for addressing non-fulfillment of responsibilities; and
   - there are mechanisms for monitoring each partner's progress.

8) Partners communicate in productive and supportive ways:
   - there is a plan for communicating within the partnership;
   - there is a plan for communicating with the public;
   - each partner has a plan for communicating internally about the partnership;
   - all plans outline the frequency of communication;
   - all plans outline the general content of the communication;
   - all plans describe how information will be transmitted;
   - there are general ground rules and/or principles that guide the partnership's communication; and
   - potential conflict is addressed in the communication plan.

9) There is trust in the function of the partnership:

- partners are willing to share resources, success, and risk with one another to the extent that the partnership's actions demand it;
- partners are able to fulfil the commitments that they make; and
- partners are open with one another.

10) Accurate and appropriate indicators are used to monitor and improve the success and progress of the partnership:
    - there are indicators of what the partnership will look like if it is successful;
    - there are indicators of what successful completion of each action of the partnership will look like;
    - the indicators are reflective of actual success;
    - the indicators are, in some way, measurable;
    - partners agree on the methods of measurement; and
    - there is a system in place to continuously improve the partnership based on the indicators.

A self-assessment tool, deriving from common factors and characteristics influencing a collaborative process is also offered. From research of Borden and Perkins (1999) emerge key factors included into the collaboration checklist for the Self Evaluation Tool. These fundamental factors are: communication; sustainability; evaluation; political climate; resources; catalysts; policies/laws/regulations; history; connectedness; leadership; community development; and understanding community. Each of these factors is identified and defined, allowing the evaluator for scoring it from 1 to 5 according to the agreement achieving the particular factor within the collaborative arrangement.

Ahgren, Axelsson and Axelsson (2009) developed and validated a model that can be used to assess intersectoral collaboration between welfare services from a perspective of service users. Their DELTA model follows Donabedian's (1996) classical model for evaluating quality in medical care that considers structure, process and outcome of care. A structure includes aspects related to access to services, information about service users, perceptions and needs, resources necessary for adequate provision of service, professional qualifications, and division of duties and responsibilities. A process comprises a variety of activities across provided services with continuity and coordination between them, communication and relation between service users and professionals, between professionals and between organizations. An outcome is a sum of successful satisfactory structural conditions and processes involved, and it draws attention into different, setting-oriented possible measures, such as level of satisfaction, financial effects or increment of professional capacities. These three dimensions were a starting point to model integration of services from a viewpoint of service users. The DELTA model questionnaire contains altogether 32 questions about structure, process and outcome of integration. The authors admit that cross-sector collaboration is the most complex form of collaboration since it includes interprofessional as well as interorganizational collaboration between different sectors of the society (Ahgren, Axelsson, & Axelsson, 2009).

1.8. Intersectoral partnerships in international documents

The multi-sector approach to address sustainable advancements in health has been acknowledged on the European, national, regional and local levels. The need to incorporate many sectors of the society in addition to the traditionally acknowledged health sector in the process of design and implementing of public policies for improving quality of life is rooted in the recognition of a wide net of interrelated determinants of health. The WHO has explicitly promoted such approaches since the 1978 Alma Ata Declaration, and many resolutions, decisions and reports have included those strategies, including the Ottawa Charter for Health Promotion in 1986 and the 2005 Bangkok Charter for Health Promotion.

In its early years, the WHO focused primarily on combating transmissible diseases. In the 1960s, reflecting wider changes in the international health policy community, these activities were extended to include improving an access to health services in poor or rural populations, combating childhood diseases through a progress in use of technologies, and expanded immunization campaign. A general concern to provide core health services and attain a level of health which would allow living an economically productive and socially active life conducted to the Health for All (HFA) definition, which led into a declaration of primary health care (PHC). Health for All was first defined in 1977, when the 30th World Health Assembly decided that governments and the WHO should focus primarily on attaining by the year 2000 a level of health that would permit every individual leading a socially and economically productive life. Following the 1978 joint WHO/UNICEF[3] conference in Alma Ata, Health for All strategy was approved and later endorsed by the UN[4] General Assembly in 1981. Primary health care was considered the key to attaining the Health for All and primary solution for serious structural limitations of an access to basic health care needs satisfaction. The Alma Ata declaration (1978) stated that PHC, in addition to the health sector, involved all related sectors and aspects of national and community development, in particular agriculture, food, industry, education, housing, public works, communication and other sectors, and required harmonized efforts toward all of them. Marking a shift towards advocacy, as well as analysis, the Health for All

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[3] UNICEF – the United Nations Children’s Fund

[4] UN - the United Nations

was to be delivered through a radical commitment to social justice, equity, self-reliance, appropriate technology, community involvement, intersectoral collaboration but still bearing in mind affordable costs. Apart from these central themes, some common topics such as equality, community action for health and intersectoral action for health were present in all the HFA documents. However, while the content of the HFA policy has not been altered, the emphasis given to different themes has changed over time.

Of course, a country-specific context deriving from economic, social, political and cultural conditions would require a different implementation of the Health for All strategy at the operational level and could be confronted with a need to set up a different system configuration. PHC in this understanding included among its pillars an intersectoral action to address social and environmental health determinants. Art. 7 of the Alma Ata Declaration pointed out that primary health services should be supported by “integrated, functional and mutually supportive reference systems”. The Declaration highlighted a need to formulate national policies, strategies and plans to sustain primary health care and in cooperation with other sectors. There was no country which would, in fact, adopt this program entirely, but the Alma Ata agreement both, reflected and helped to frame the international public health agenda for the following decades.

From the Declaration of Alma Ata, the HFA movement gained drive in primary health care. In 1986, the Ottawa Charter pledged to advocate political commitment to health matters and alerted to benefits from cooperation between governments at all levels, linking non-governmental and voluntary organizations and the commercial sector. It was originated by current, at the time, debate on intersectoral action at the World Health Assembly and in line with shifts in public health needs in industrialized countries. The Ottawa Charter leading theme was health promotion. It called for and promoted new forms of intervention that were guided by values of empowerment and community participation. The Ottawa Charter identified five key strategy areas for action in promotion of health: to build healthy public policy (the need for health promoting policies to be developed in all sectors of society); to create supportive environments; to strengthen community action (collective efforts by communities directed toward improving health and increasing community control over determinants of health); to develop personal skills in order to empower citizens to take more charge of their own health and promote healthy lifestyle and behavior; and to reorient health services pointing an emphasis on health promotion and prevention.

A call for intersectoriality was stated in the Ljubljana Charter on Reforming Health Care (1996b), highlighting that health services, although relevant for human health, are not an exclusive factor influencing it. Other sectors have their contribution on health as well and to bear population health in mind cross-sectoral approach needs to be a fundamental feature of health care reforms.

The Jakarta Declaration came from the 4th International Conference on Health Promotion: New Players for a New Era - Leading Health Promotion into the 21st Century, meeting in Jakarta in 1997. It aimed to promote social responsibility for health and increasing investment for health development through a truly multi-sectoral approach. The consolidation and expansion of partnerships for health were emphasized, along with increasing community capacity and empowering both, communities and individuals. For health promotion in the 21st century the Jakarta Declaration identified five priorities: promoting social responsibility for health; increasing investments for health development; increasing community capacity and empowering an individual citizen; expanding partnerships for health promotion; and securing a sufficient and an adequate infrastructure for health promotion.

Almost 20 years later, facing challenges of a globalized world, the 6th Global Conference on Health Promotion reconfirmed in Bangkok, Thailand, the need to persist in health advocacy to address determinants of health. Participants of the conference, through the Bangkok Charter for Health Promotion in a Globalized World (WHO, 2005) advocated: building capacity for policy development; health based on human rights and solidarity; investing in sustainable policies; actions and infrastructure; regulation and legislation to ensure protection; and on setting up alliances between all sectors and subjects (public, private, civil society) for sustainable actions.

During the 19th World Conference on Health Promotion and Health Education initiated together with the Canadian Consortium for Health Promotion Research in Vancouver, Canada, in 2007, the focus remained on the mission of promoting global health and contributing to the achievement of equity in health between and within countries of the world. Participants followed the concept of ‘thinking global while acting local’ in order to implement intersectoral activities and mechanisms for global health promotion for a healthy future in the globalized world.

In conjunction with the 19th World Conference on Health Promotion and Health Education (2007), Crossing sectors: Dialogue on intersectoral action was held in Vancouver, British Columbia, Canada. Its purpose was to share experience in intersectoral action for health and to consider implications for future cross-sectoral approaches. The expected Dialogue outcomes included creation of an informal network of both, individuals and organizations involved in intersectoral approaches to address social determinants of health, sharing knowledge on reported cases with an objective to report on intersectoral action to the WHO Commission on Social Determinants of Health and basis for further collaborative approaches. Cross-sector methodologies were used as strategies in policy frameworks by Ministries of Health to address a variety of health inequalities. The Dialogue admitted that engagement across sectors could occur more simply at local levels and that additional attention should be given into incentives and budgetary tools in order to encourage intersectoral linkages at higher levels of government. Participants of the Dialogue referred also to a working definition of intersectoral action and stated that it could be then seen differently than as defined by the WHO in 1997 and understood as “a subset of multisectoral or cross sectoral action - work by multiple sectors toward broader social and or economic goals, but not necessarily working together” (Crossing sectors: dialogue on intersectoral action 2007, p. 6).

Intersectoral approach was a fundamental tenet of the Alma Ata Declaration, and consequently, one the four pillars of Primary Health Care as laid out in the 2008 World Health Report (WHO, 2008). The current World Health Report (WHO, 2010b) assumes that many of the changes will require intersectoral action, with health ministry staff working with other ministries.

A health promotion movement stresses out that intersectoral collaboration will be necessary if policies are to deal with several determinants of health. Intersectoral approach forms also a basic premise of the WHO Commission on Social Determinants of Health. In 2008, the final report of the Commission insisted on action across different sectors of the society to “tackle the inequitable distribution of power, money, and resources” (CSDH, 2008, p. 109). Specifically for urban settings consultation with experts was carried in June 2009 and the following key aspects were identified for successful cross-sector interventions: (a) health equity and health impact assessment; (b) monitoring and assessment of interventions; and (c) involvement and participation of the community. A number of additional recommendations for policy makers were prepared, including a need for supporting governance structures and taking advantage of multiple levels of government. For all these issues, a strong political commitment was recognized as a crucial component.

A commitment for intersectoral health policies has been expressed in numerous documents, resolutions and conclusions of the Council of the European Union. The European Union is required by its founding treaty to ensure that human health is protected as part of all its policies, and to work with the EU member countries to improve public health, prevent human illness and eliminate sources of danger possibly threatening physical and mental health. Through the health strategy, the EU plays its part in improving public health in Europe, and in doing so, it provides an added value to its member states’ actions while fully respecting responsibilities of the member states for the organization and delivery of health care and services. The EU health strategy focuses mainly on strengthening cooperation and coordination, supporting the exchange of evidence-based information and knowledge, and assisting with national decision-making. To this end, the EU is developing a comprehensive health information system to provide the EU-wide access to reliable and updated information on key health-related topics, and hence a basis for a common analysis of factors affecting public health. Secondly, the EU aspires to enhance the capability to respond rapidly to health threats. That is why it is strengthening epidemiological surveillance and control of infectious diseases.

Within the European Union legislation, among the founding[5] and other treaties and protocols, the intersectoral action as such is not directly affirmed. However, a number of documents address health and social care, acknowledging the European interest in health and social matters, referring areas of concern and contributing to a common understanding on issues to be tackled and directions to be undertaken. Article 2 of the Treaty establishing the European Community makes a special reference to well-being, considering quality of life and standard of living areas to be promoted and sustainably developed. Article 3 brings for that purpose establishment and development of trans-European networks. In article 152, cooperation, quality, safety and health protection remain the principal and recurrent concerns and these should be ensured by all policies and activities. It indicates health information, research and education as means to improve public health and disease prevention. These commitments support the Health in All logic.

Article 9 of the Treaty on the Functioning of the European Union (TFEU) emphasizes the problem of social exclusion, the need for social protection, education and training. In fact, all these issues are irreversibly linked to health and inclusion of promotion of health and health-related behavior within them may bring significant savings for other sectors and the economy as a whole. Article 9 of the TFEU includes a ‘social clause’ which states that the EU must respect social objectives, including promoting a high standard of health, in all its policies, while Article 11 of the Treaty addresses involvement of the civil society.

The Council Resolution on Action on Health Determinants of 29 June 2000 considered that increasing differences in health status and health outcomes between and within the member

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[5] The Treaty of Rome of the European Economic Community (EEC), the original full name of which was the Treaty establishing the European Economic Community has been amended by successive treaties significantly changing its content. The 1992, with an entry into force in 1993, the Treaty of Maastricht established the European Union with the EEC becoming the European Community. For this reason, the Treaty was renamed the Treaty establishing the European Community (TEC). The Lisbon Treaty which came into force in 2009 led this Treaty to be amended, consolidated and renamed into the Treaty on the Functioning of the European Union.

states of the European Union called for renewed and coordinated efforts at the national and community level.

In 2006, the European Union introduced Health in All Policies (HiAP), a broad-reaching directive with implications for intersectoral policy development, implementation and evaluation. Health in All Policies was one of the principal and the main public health theme of the Finnish EU Presidency. HiAP logic meant in practice that all sectors would take advanced account of all possible health impacts in their decision making and in the preparation of proposals. The approach highlights that population health is largely influenced by measures - health determinants - often managed by sectors other than health care, emphasizing the importance of policy options that may contribute to improving health outcomes by relating the health care sector with others. These health determinants play a key role in the implementation of HiAP and thus, it requires cross-sectoral and multi-level action for health (Stahl et al., 2006). After the conference on Health in All Policies on 20-21 September 2006 in Kuopio, Finland, the Council Conclusions of 30 November and 1 December 2006 on Health in All Policies stated that intersectoral action is an effective approach into policies, particularly those of transport, employment, environmental, health and social, which share health objectives and may in that way complement specific missions undertaken individually by the health sector.

With the declaration approved in the conference ‘Health in All Policies: Achievements and challenges’ organized in 2007 in Rome, the 27 European Union members (EU-27) expressed their commitment to strengthen intersectoral approach at a scope of Europe, country, region and local making all policies visible in public health. Collaborative linkages were to be intensified on and among all levels engaging also the European Commission and the WHO in order to contribute to a quicker and more effective elaboration and implementation of health-conductive policies in other sectors. The signatures recognized a need to improve research and information base for projects and sharing experience with other countries, including the EU candidates.

Over 30 years after the Alma Ata resolution for expansion of primary care, progress has been made in what public health and the most burning health and social issues concern. In fact, PHC acts as a gatekeeper in many health care systems, but nowadays attention needs to be given to secondary and tertiary care as well, in a global, systemic context. As Dowling, Powell and Glendinning (2004) state: “it is difficult to find a contemporary policy document or set of good practice guidelines that does not have collaboration as the central strategy for the delivery of welfare” (p. 309).

1.9. Intersectoriality in health and social care in Portugal

The Portuguese State has constitutional obligation to ensure access to health care, with effective coverage of the country, and justice in the financial contributions. It also has to guarantee the adequacy of entrepreneurial and private provision of health care and regulate the utilization of health products.

Equity in health care in Portugal is the object of the second paragraph of the Health Comprehensive Law (*Lei de Bases da Saúde*). Citing this law, “it is a major objective to reach equality among citizens in access to health care independently of their economic condition and place of living, as to achieve equity in the distribution of resources and the use of services” (*Lei de Bases da Saúde,* Base II). In other words, inequity is understood as an unacceptable difference related to a socio-economic status, and several groups are specifically quoted as requiring particular attention: children, teenagers, pregnant women, the elderly, disabled persons, and drug addicts.

The Health Plan, founded on sustainability of the health system, has as its principal objective providing an adequate health and social care to citizens in situations of dependency improving their well-being in a process of continuous and integrated rehabilitation. The National Health Plan 2004-2010 calls for setting up intersectoral policies and administrative cooperation between ministries for global improvement in health. Among main strategic objectives one can find “to ensure mechanisms appropriate for activating the Plan, through capturing adequate resources, promoting intersectoral dialogue, adapting the legal framework and creating mechanisms for monitoring and updating the Plan” (Ministério de Saúde, 2004, p. 1). The Ministry of Health has not only to coordinate and promote an intersectoral action, but to take an active role in policy advocacy.

An integrated scope of care remains the priority for health and is covered in cross-cutting strategies in the National Health Plan 2011-2016 (Ministério de Saúde, 2011) through health sustainability, resource allocation and continuity of care delivery. This step ensures the convergence and strengthening of measures for the sustainability of the NHS and for health equity (Guerreiro, 2010). The principles and strategies of the National Health Plan 2011-2016 defend a consensus for the need of a simple practice to operationalize, monitor and evaluate the Health Plan, and of establishing an intersectoral approach allowing for the implementation of strategies and action for the recognition of more value in health. It also identifies cross-sectoral activities in course as well as potential areas for intersectoral work to be developed within the next Plan. Specifically, local authorities, civil society, the third sector are identified as having responsibilities for health promotion, health management, treatment or rehabilitation in case of illness.

An unquestionable need for intersectoral articulation to develop rehabilitation and social participation strands integrated with the community and beyond the traditional boundaries of the health care sector is emphasized by the National Plan for Mental Health 2007-2016 (Caldas de Almeida, 2009). This, of course, implies new methodologies in order to share the responsibility for a patient between sectors. As the document states, "the responses of the integrated, continuous care are an important instrument to regulate the joint participation of the areas of health and social security, allowing to ensure the residential and occupational support for patients with serious illness that origin disability or dependency" (p. 28). The recommendations focus on mental care services however, could well apply to other health conditions that may cause complex needs requiring services and support far beyond on what the health care system can provide on its own.

The year 2002 inaugurated a political cycle, especially marked by a concentrated legislative activity. That period of time brought a construction of ten new hospitals under private-public partnerships and a revolutionary transformation of 34 out of 97 hospitals into 31 public enterprises under the logic of autonomous hospital management. New reality and new managerial challenges brought to life the independent Health Regulation Authority as a new entity with specific regulatory functions. Current government policies emphasize collaboration, particularly between health and social care services.

In Portugal, urbanization, economic factors and cultural shift have had a very quick and dramatic impact on weakening family bonds and human relations and leading to social disintegration. This disruption of the traditional family-caregiver support will additionally pressure the already overburdened social system. Intersectoral partnership is a fundamental task of modern public health. More attention is necessary to be placed at a human factor, the one typically forgotten by policy makers when considering reforms. In order to change behavioral attitudes and practice, perceptions on collaboration among sectors of health and social professionals and the whole society in general need to follow the reasoning. Jurisdictional division maintains activities separated from the patient viewpoint whilst enduring a complex decision-making process. There are fundamental differences in governance and financing. Initiatives toward a collaborative approach to health do exist, although the most frequently not as effect of a structured and planned governmental strategy. The RNCCI, as a formal organizational model, assures, indeed, integrated health and welfare services in a situation of dependency and autonomy failure. One might argue that other, disease-specific or issue-specific programs, of a more limited scope, such as the PAII (the Integrated Support Program for the Elderly) have also been implemented. Nevertheless, an individual initiative cannot be considered a substitute to a consistent and reliable policy with long-term objectives in consideration, but rather means to a steady construction of the system. In several cases, a partnership is a fruit of personal involvement of individual professionals, their orientation across the system and a sense of emphatic solidarity with a patient. Such arrangements, however, do not transfer knowledge and experience to other entities and settings and subsequently, do not permit a collaborative approach to become a natural solution for health outcomes and promotion.

With such a complex nature, effective provision of health and social services in Portugal requires improvement of the systems individually, but also modifications of the way they work with other sectors of the economy, as well as with the community. In Portugal, intersectoral collaboration has been formally acknowledged as a concept thank to its visibility in multiple action agendas, programs, and documents, yet, at the practical level, there is still a lack of appreciation that a stronger linkage with other parties could result in better health outcomes, provide better quality of care and enhance patient satisfaction. While the need and potential outcomes are underlined in empirical context, a few manage to explain how to proceed in order to establish and conduct an intersectoral action in practice through an appropriate theoretical background.

1.9.1. Systematic review of the Portuguese legislation on intersectoral action

The systematic review of the Portuguese legislation comprised a search for separated keywords associated to collaborative linkages, as well as their combination with intersectoriality together with a search for respective laws and other regulatory acts.

The keywords were those related to types of collaborative bounds described previously in this work, namely ‘coalition’, ‘alliance’, ‘cooperation’, ‘coordination’, ‘collaboration’, ‘partnership’ and ‘integration’, with two additional, ‘articulation’ and ‘strategic program, and combined with the term ‘intersectoral’ (with an exception for the combination with the phase ‘integration’). Results are provided in Table 15.

Table 15. Results of the search for keywords associated with collaboration in *Diário da República*[6]

Keyword	Number of appearances in the 1st Series of *Diário da República*	Number of appearances in the 2nd Series of *Diário da República*
coalition	0	0

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[6] The official gazette of the Republic of Portugal, called *Diário de Governo* before 1976

alliance	159	375
cooperation	9302	22029
coordination	11174	38384
collaboration	7913	20825
partnership	961	3145
integration	9543	17236
articulation	7354	11501
intersectoral	271	350

The most numerous use of collaboration-related terms in the 1st Series of *Diário da República* was that of ‘coordination’ with 11174 entries, ‘integration’ with 9543 entries and ‘cooperation’ with 9302 entries. The word ‘intersectoral’ appeared separately 271 times. In the 2nd Series of *Diário da República*, the most used phrase from the sought was ‘coordination’ (38384 times), ‘cooperation’ (22029 times) and ‘collaboration’ (20825 times). In the next step, the terms either associated with collaboration or considered by some scholars as its synonyms, or placed on the continuum of the collaboration intensity were linked with the expression ‘intersectoral’ and the results of that systematic search in *Diário da República* are presented in Table 16.

Table 16. Results of the search for keywords associated with collaboration and the expression ‘intersectoral’ in *Diário da República*

Keyword	Number of appearances in the 1st Series of *Diário da República*	Number of appearances in the 2nd Series of *Diário da República*
intersectoral coalition	0	0
intersectoral alliance	0	0
intersectoral cooperation	15	37
intersectoral coordination	63	167
intersectoral collaboration	6	4
intersectoral partnership	3	1
intersectoral articulation	28	9
intersectoral strategic program	2	2

The results clearly demonstrate that the amount of occurrences decreased considerably in the legislation if collaboration-related expressions were contextualized to an intersectorial action. The term most frequently arising was ‘intersectoral coordination’ which appeared 63 times in the 1st Series and 167 times in the 2nd Series, and ‘intersectoral cooperation’ with 15 records in the 1st Series and 37 records in the 2nd Series.

With an intention of determining entities issuing the above laws and regulatory acts, and the sectors these acts concerned, an in-depth analysis of the legislation was conducted. The first outcome, somewhat surprising, revealed that the term ‘intersectoral’ appeared in the Portuguese legislation for the first time already in 1974.

The results of the analysis of the contextualized expressions indicated that no ‘intersectoral coalition’ phrase in any context was detected in the legislation; neither was it ‘intersectoral alliance’. The term ‘intersectoral cooperation’ appeared 15 times in the 1st Series and 37 times in the 2nd Series of *Diário da República*. Detailed results of the search for the term ‘intersectoral cooperation’ are presented in Table 17.

Table 17. Results of the search for the expression ‘intersectoral cooperation’ in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral cooperation	
1st Series	**2nd Series**
Regional Regulate Decree no. 23/90/A of the Autonomous Region of Azores – Regional Government	Notice no. 2839/2000 (2nd Series) of the City Council of Felgueiras
Resolution of the Cabinet of Ministers no. 29/92 of the Presidency of the Cabinet of Ministers	Notice no. 9254/2000 (2nd Series) of the City Council of Marinha Grande
Decree Law no. 184/94 of the Ministry of Trade and Tourism	Notice no. 2519/2002 (2nd Series) of the City Council of Sesimbra
Decree Law no. 193/96 of the Presidency of the Cabinet of Ministers	Notice no. 3903/2002 (2nd Series) of the City Council of Vila Nova de Gaia
Law no. 127-A/97 of the Assembly of the Republic	Dispatch no. 1916/2004 (2nd Series) of the Ministry of Health – Ministry Office
Resolution of the Cabinet of Ministers no. 124/98 of the Presidency of the Cabinet of Ministers	Notice no. 5577/2004 (2nd Series) of the City Council of Mogadouro
Law no. 87-A/98 of the Assembly of the Republic	Notice no. 6180/2004 (2nd Series) of the City Council of Rio Maior
Decree Law no. 15/99 of the Ministry of Culture	Dispatch no. 25399/2004 (2nd Series) of the Ministry of Economic Activities and Labor
Decree Law no. 135/99 of the Presidency of the Cabinet of Ministers	Notice no. 8534/2006 of the City Council of Barreiro
Regional Regulate Decree no. 10/2000/A of the Autonomous Region of Azores – Regional Secretary of Education and Social Issues	Dispatch no. 12166/2007 of the Ministry of Environment, Spatial Planning and Regional Development – Coordination and Regional Development Commission of Lisbon and Vale do Tejo
Regional Legislative Decree no. 18/2008/A of the Autonomous Region of Azores - Legislative Assembly	Dispatch no. 14534/2007 of the Ministry of Health – General Directorate of Health
Decree Law no. 130/2012 of the Ministry of Agriculture, Sea, Environment and Spatial Planning	Dispatch no. 381/2008 of the Ministry of the Ministry of Environment, Spatial Planning and Regional Development – Coordination and Regional Development Commission of Lisbon and Vale do Tejo
Regional Regulate Decree no. 2/2014/A of the Autonomous Region of Azores – Presidency of the Government	Ordinance no. 224/2008 of the City Council of Vila Nova de Gaia
Resolution of the Cabinet of Ministers no. 12/2014 of the Presidency of the Cabinet of Ministers	Dispatch no. 6623/2009 of the Ministry of Health – General Directorate of Health

Decree Law no. 73/2014 of the Presidency of the Cabinet of Ministers	Notice no. 22300/2009 of the Municipality of Vila Nova de Gaia
	Notice no. 21232/2010 of the Municipality of Grândola
	Notice no. 24886/2010 of the Municipality of Grândola
	Dispatch no. 19391/2010 of the Municipality of Barreiro
	Dispatch no. 19409/2010 of the Municipality of Vendas Novas
	Dispatch no. 47-D/2011 of the Municipality of Óbidos
	Dispatch no. 467/2011 of the Municipality of Tomar
	Dispatch no. 1082/2011 of the Municipality of Tomar
	Dispatch no. 1221/2011 of the Municipality of Ansião
	Dispatch no. 1229/2011 of the Municipality of Esposende
	Dispatch no. 1603/2011 of the Municipality of Golegã
	Dispatch no. 1699/2011 of the Municipality of Portel
	Notice no. 13812/2012 of the Municipality of Amares
	Dispatch no. 95-B/2013 of the Municipality of Cabeceiras de Basto
	Dispatch no. 739/2013 of the Municipality of Grândola
	Dispatch no. 1447/2013 of the Municipality of Óbidos
	Dispatch no. 2530/2013 of the Municipality of Tomar
	Notice no. 4313/2013 of the Municipality of Amares
	Notice no. 4353/2013 of the Municipality of Amares
	Dispatch no. 13593/2013 of the Municipality of Amares
	Dispatch no. 16691/2013 of the Municipality of Barreiro
	Dispatch no. 4205/2013 of the Municipality of Tomar
	Dispatch no. 6604/2013 of the Municipality of Grândola

In the 1st Series, legislation associated with the health and social care concerns intersectoral character of activities and actions of the Institute of Social Action (Regional Regulate Decree no. 23/90/A of the Autonomous Region of Azores; Regional Regulate Decree no. 10/2000/A of the Autonomous Region of Azores), relevance of intersectoral approach for the National Program of Drug Prevention – VIDA Project (Decree Law no. 193/96 of the Presidency of the Cabinet of Ministers), health protection and health advocacy (Law no. 127-A/97 of the

Assembly of the Republic), intersectoral cooperation of which importance was emphasized after the referendum of decriminalization of abortion in Portugal and integrated action of sexual education and family planning in schools followed that result by the decision of the government (Resolution of the Cabinet of Ministers no. 124/98 of the Presidency of the Cabinet of Ministers), promotion of intersectoral projects for the development of continuous care and integrated homecare (Law no. 87-A/98 of the Assembly of the Republic), priorities for health promotion and well-being for the youth in the Autonomous Region of Azores which accomplishment would require involvement of public administration and intersectoral cooperation actions to be developed (Regional Legislative Decree no. 18/2008/A of the Autonomous Region of Azores), and intersectoral cooperation of the Institute of Social Security of Azores with other entities intervening in the same domain or related with it (Regional Regulate Decree no. 2/2014/A of the Autonomous Region of Azores).

Among legislation from the 2nd Series, legislative acts focus predominantly on structuring local services and in that context the term ‘intersectoriality’ is found in use. Among them, one act is especially interesting, namely Dispatch no. 1916/2004 of the Ministry of Health. This act emphasizes the importance of strong intersectoral strategies based on linkages between sectors of health, education, labor, economy, social solidarity, agriculture and transportation, among others, in order to face and combat chronic and non-transmittable diseases, the principal cause of mortality in Europe.

Table 18 presents results of detailed search for the term ‘intersectoral coordination’.

Table 18. Results of the search for the expression ‘intersectoral coordination’ in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral coordination	
1st Series	**2nd Series***
Decree Law no. 549/77 of the Ministry of Social Affairs – Secretary of State of Social Security	Ordinance no. 325/2010 of the Ministry of Health – Regional Health Administration of Lisbon and Vale do Tejo, I.P.
Resolution no. 72/79 of the Presidency of the Cabinet of Ministers	Declaration of rectification no. 873/2010 of the Ministry of Health – Regional Health Administration of Lisbon and Vale do Tejo, I.P.
Resolution no. 7/80/A of the Autonomous Region of Azores – Regional Assembly	
Decree Law no. 304/82 of the Ministries of Finance and Planning, of Social Affairs and Administrative Reform	
Decree Law no. 398/82 of the Ministry of Social Affairs	
Decree Law no. 293/93 of the Ministry of Health	
Decree Law no. 335/93 of the Ministry of Health	
Decree Law no. 122/97 of the Ministry of Health	

Regional Regulate Decree no. 20/2003/M of the Autonomous Region of Madera – Presidency of the Government	
Decree Law no. 212/2006 of the Ministry of Health	
Decree Law no. 222/2007 of the Ministry of Health	
Decree Law no. 234/2008 of the Ministry of Health	
Decree Law no. 124/2011 of the Ministry of Health	
Decree Law no. 22/2012 of the Ministry of Health	

* Due to the quantity of legislative acts found in this specific search and space restrictions, the ones presented in the 2nd Series of the above table regard merely legislation related to cross-sectoral action in the health and social care sectors

In the 1st Series, intersectoral coordination applies to permanent or temporary commissions that may be created in order to coordinate social security and related areas (Decree Law no. 549/77 of the Ministry of Social Affairs; Resolution no. 72/79 of the Presidency of the Cabinet of Ministers), to the recognition of health improvement of the population as the principal objective of the health care sector and interdependence of the achievement of this goal from intersectoral action comprising education, dwelling, culture, etc. (Resolution no. 7/80/A of the Autonomous Region of Azores), to intersectoral policies with familiar incidence between adequate structures and cooperation between private institutions of support to families (Decree Law no. 304/82 of the Ministries of Finance and Planning, of Social Affairs and Administrative Reform), to participating in intersectoral action planning with a health basis as one of objectives of the Department of Studies and Health Planning with its organizational units (Decree Law no. 398/82 of the Ministry of Social Affairs; Decree Law no. 293/93 of the Ministry of Health), to an intersectoral specificity of activities of Regional Administrations of Health (Decree Law no. 335/93 of the Ministry of Health; Decree Law no. 212/2006 of the Ministry of Health; Decree Law no. 222/2007 of the Ministry of Health; Decree Law no. 234/2008 of the Ministry of Health; Decree Law no. 124/2011 of the Ministry of Health; Decree Law no. 22/2012 of the Ministry of Health) and the Division of Planning and Normalization as a part of the Direction of Planning Services within the General Directorate of Health (Decree Law no. 122/97 of the Ministry of Health), and, finally, to intersectoral coordination of measurements planning in the health sector as one of the objectives of the Direction of Planning Services functioning within the Regional Direction of the Planning and Public Health (Regional Regulate Decree no. 20/2003/M of the Autonomous Region of Madera).

In the 2nd Series, from 167 identified regulatory acts only two specifically relate as directly concerning intersectoral action in health or social care. Ordinance no. 325/2010 of the Ministry of Health – Regional Health Administration of Lisbon and Vale do Tejo, I.P. underlines a relevance of multidisciplinary and intersectoral work processes. Importantly, Ordinance mentions two intersectoral, already created teams: (a) ERA – Regional Support Team to the primary health care reform (*Equipa Regional de Apoio à reforma dos cuidados de saúde primários*); and (b) ECRCCI – Regional Coordinating Team of Continuous Integrated Care (*Equipa Coordenadora Regional dos Cuidados Continuados Integrados*). Declaration of rectification no. 873/2010 of the Ministry of Health readjusts the above ordinance.

Results of the detailed search for the term 'intersectoral collaboration' are presented in Table 19.

Table 19. Results of the search for the expression 'intersectoral collaboration' in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral collaboration	
1st Series	**2nd Series**
Dispatch DG 260/74 of the Ministry of Economy – Ministry Office	Dispatch no. 4158/2000 (2nd Series) of the Ministry of Foreign Affairs - Ministry Office
Decree Law no. 294/91 of the Ministry of Environment and Natural Resources	Notice no. 2654/2002 (2nd Series), appendice 36/2002 of the District Assembly of Faro
Law no. 3-A/2000 of the Assembly of the Republic	Dispatch no. 7144/2002 (2nd Series) of the Ministry of Health – Ministry Office
Law no. 109-A/2001 (2nd part) of the Assembly of the Republic	Notice no. 14011/2010 of the Municipality of Cascais
Resolution of the Cabinet of Ministers no. 49/2008	
Ordinance no. 95/2009 of the Ministry of Finance and Public Administration	

In the 1st Series, the phrase 'intersectoral collaboration' was found six times, of which two applied directly to issues of health and/or social care. Law no. 109-A/2001 (2nd part) of the Assembly of the Republic acknowledges that health is a multidisciplinary concept and health determinants exceed the strict scope of the health sector requiring systematic structural reconfiguration of the system and regular close collaboration among sectors. The National Plan of Mental Health mentions mental health services together with intersectoral articulation between them in the Resolution of the Cabinet of Ministers no. 49/2008 as an object of special attention.

In the 2nd Series, the requirement to working above sectoral limits is indicated in Notice no. 2654/2002, stating that different sectors should ensure mutual collaboration if that is deemed beneficial or indicated by a higher purpose. The health or social sector is not directly specified, however, a broad meaning of the act may be applied to both of them. That is not the case of Dispatch no. 7144/2002 which relates clearly to health and information systems, emphasizing their importance for monitoring population health, identifying risk situations in prompt time and defining strategic programs to develop intersectoral and interinstitutional mechanisms adequate to guarantee health management in the country.

Table 20 provides results of the detailed search for the expression ‘intersectoral partnership’.

Table 20. Results of the search for the expression ‘intersectoral partnership’ in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral partnership	
1st Series	**2nd Series**
Regional Legislative Decree no. 9/2006/M of the Autonomous Region of Madera – Legislative Assembly	Dispatch no. 3269/2000 (2nd Series) of the Ministry of Labor and of Solidarity – Cabinet of the Secretary of Adjunct State
Resolution of the Cabinet of Ministers no. 53/2010 of the Presidency of the Cabinet of Ministers	Dispatch no. 16338/2012 of the Municipality of Cascais
Declaration of Rectification no. 30-A/2010 of the Presidency of the Cabinet of Ministers – Juridical Centre	Dispatch no. 353/2014 of the Municipality of Cascais

Regional Legislative Decree of the Legislative Assembly of Madera approved the status of the social action of the Social Security in the Autonomous Region of Madera. The second and the third of these legislative acts from the 1st Series, with numerous recalls to intersectoriality, consider a need to conclude implementation of the integrated care network recognizing a cross-sectoral approach.

In the legislation of the 2nd Series, the program directed to protection of children and the youth in risk goes in line with a multisectoral strategy, evoking an action of social protection for the youngest in risk, visible in Dispatch no. 3269/2000. Dispatches no. 16338/2012 and no. 353/2014, both from the Municipality of Cascais, establish and confirm the status of the Division of Health Advocacy, attributing it (among others) competencies of health promotion at the local level, adopting strategies and platforms for intersectoral partnerships, knowledge management systems and practices in the areas of health promotion, social communication and social marketing, while confirming their impact on health.

Results of the detailed search for the term ‘intersectoral articulation’ are provided in Table 21.

Table 21. Results of the search for the expression 'intersectoral articulation' in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral articulation	
1st Series	**2nd Series**
Regional Regulate Decree no. 3/86/A of the Autonomous Region of Azores – Regional Government	Dispatch no. 12972/2001 (2nd Series) of the Ministry of Labor and Solidarity – Institute of Solidarity and Social Security
Regional Legislative Decree no. 11/87/A of the Autonomous Region of Azores - Regional Assembly	Deliberation no. 100/2002 of the Ministry of Labor and Solidarity – Institute of Solidarity and Social Security
Decree Law no. 260/89 of the Ministry of Spatial and Administration Planning	Dispatch no. 6705/2002 (2nd Series) of the Ministry of Labor and Solidarity – Institute of Solidarity and Social Security
Regional Regulate Decree no. 23/90/A of the Autonomous Region of Azores – Regional Government	Notice no. 1242-A/2004 (2nd Series) of the City Council of Vila Franca de Xira
Decree Law no. 260/93 of the Ministry of Labor and Social Security	Protocol no. 115/2005 of the Ministry of Labor and Social Solidarity - Ministry Office
Law no. 52-B/96 of the Assembly of the Republic	Protocol no. 116/2005 of the Ministry of Labor and Social Solidarity - Ministry Office
Decree Law no. 393/98 of the Ministry of Culture	Protocol no. 117/2005 of the Ministry of Labor and Social Solidarity - Ministry Office
Regional Legislative Decree no. 28/99/A of the Autonomous Region of Azores - Regional Legislative Assembly	Dispatch no. 10464/2008 of the Ministry of Health - Ministry Office
Regional Regulate Decree no. 10/2000/A of the Autonomous Region of Azores – Regional Secretary of Education and Social Affairs	Dispatch no. 12866/2008 of the Ministry of Environment, Spatial Planning and Regional Development – Coordination and Regional Development Commission of the North
Decree Law no. 323-D/2000 of the Ministry of Justice	
Ordinance no. 543-A/2001 of the Ministry of Labor and Solidarity	
Decree Law no. 224/2001 of the Ministry of Planning	
Law no. 109-A/2001 of the Assembly of the Republic	
Regional Legislative Decree no. 39/2002/A of the Autonomous Region of Azores - Regional Legislative Assembly	
Resolution of the Cabinet of Ministers no. 112/2005 of the Presidency of the Cabinet of Ministers	
Decree Law no. 207/2006 of the Ministry of Environment, Spatial Planning and Regional Development	
Regional Legislative Decree no. 2/2007/A of the Autonomous Region of Azores - Legislative Assembly	
Decree Law no. 134/2007 of the Ministry of Environment, Spatial Planning and Regional Development	
Ordinance no. 1584/2007 of the Ministry of Health	

Resolution of the Cabinet of Ministers no. 49/2008 of the Presidency of the Cabinet of Ministers	
Decree Law no. 304/2009 of the Ministry of Health	
Regional Legislative Decree no. 1/2010/A of the Autonomous Region of Azores - Legislative Assembly	
Resolution of the Cabinet of Ministers no. 53/2010 of the Presidency of the Cabinet of Ministers	
Declaration of Rectification no. 30-A/2010 of the Presidency of the Cabinet of Ministers	
Decree Law no. 7/2012 of the Ministry of Agriculture, Sea, Environment and Spatial Planning	
Decree Law no. 228/2012 of the Ministry of Agriculture, Sea and Spatial Planning	
Resolution of the Cabinet of Ministers no. 11/2013 of the Presidency of the Cabinet of Ministers	
Resolution of the Cabinet of Ministers no. 37/2013 of the Presidency of the Cabinet of Ministers	

Legislation in the 1st Series of *Diário da República* referring to health and social care point into articulation of health centers with other relevant for patients entities, such as the Social Security (Regional Regulate Decree no. 3/86/A of the Autonomous Region of Azores), to intersectoral articulation of the Institute of Social Action with other entities (Regional Legislative Decrees no. 11/87/A, no. 39/2002/A, no. 1/2010/A of the Autonomous Region of Azores, Regional Regulate Decrees no. 23/90/A, no. 10/2000/A of the Autonomous Region of Azores), to questions of human resources management and cost efficiency of the Social Security which led to restructuring of the institution and allowed for a better intersectoral articulation (Decree Law no. 260/93 of the Ministry of Labor and Social Security), to importance of intersectoral articulation in prevention and control of HIV/AIDS (Ordinance no. 1584/2007 of the Ministry of Health), to articulation between areas targeting social policies, namely health, education, formation, solidarity, dwelling, and employment (Law no. 52-B/96 of the Assembly of the Republic), to local needs for ensuring and concluding integrated continuous care in the intersectoral perspective (Resolution of the Cabinet of Ministers no. 53/2010 of the Presidency of the Cabinet of Ministers; Declaration of Rectification no. 30-A/2010 of the Presidency of the Cabinet of Ministers), and to the regional health plan in Azores built on health programs and designed from the perspective of intersectoral articulation (Regional Legislative Decrees no. 28/99/A, no. 2/2007/A of the Autonomous Region of Azores). Resolution of the Cabinet of Ministers no. 49/2008 is identified again, while previously for the use of the phrase ‘intersectoral collaboration’, here appears once more, due to the use of the expression of ‘intersectoral articulation' in the body of the regulatory act. Intersectoral articulation in the perspective of mental health care and professional integration of patients is mentioned in Decree Law no. 304/2009 of the Ministry of Health. Law no. 109-A/2001 mentioned before as it was identified to have used the expression 'intersectoral collaboration' applies the term 'intersectoral articulation', as well. Also in the context of this work, intersectoriality appears in Ordinance no. 543-A/2001 of the Ministry of Labor and Solidarity in a sense to approve proposals submitted by IPSS regarding modification of projects and to foster intersectoral articulation between entities targeting an integrated action.

Regulatory acts in the 2nd Series relate to attributing a set of competencies to a certain person, among which stands intersectoral articulation with a long-term vision integrating diverse entities, including IPSS (Dispatches no. 12972/2001 and no. 6705/2002; Deliberation no. 100/2002). Protocols no. 115/2005; 116/2005 and 117/2005 are established between the Ministry of Labor and Social Solidarity and the National Confederation of Institutions of Solidarity. The acts evidently state they shall not prejudice cooperation or mechanisms of intersectoral articulation to be eventually launched for integrated social support services. Dispatch no. 10464/2008 of the Ministry of Health - Ministry Office, refers to intersectoral action in mental health services for children and the youth, emphasizing the relevance of articulation between health care entities providing services for this specific target group with primary health care, to be ensured by the National Network of Continuous Integrated Mental Care (*Rede Nacional de Cuidados Continuados Integrados de Saúde Mental*).

Table 22 provides results of the detailed search for the expression 'intersectoral strategic program' *in Diário da República*.

Table 22. Results of the search for the expression 'intersectoral strategic program' in *Diário da República* in the 1st and the 2nd Series

Keyword: intersectoral strategic program	
1st Series	**2nd Series**
Decree Law no. 257/2001 of the Ministry of Health	Dispatch no. 25197/2005 (2nd Series) of the Ministry of Health – Ministry Office
Statutory Decree no. 7/2005 of the Ministry of Health	Dispatch no. 766/2006 (2nd Series) of the Ministry of Health – High Commissariat for Health

Interestingly, in the search for the expression 'intersectoral strategic program' two results found in the 1st Series and two in the 2nd Series relate to health – they were issued by the Ministry of Health. In the 1st Series, Decree Law no. 257/2001 creates a role of the High Commissary for Health who shall propose, develop and coordinate (among a number of other responsibilities) intersectoral strategic programs in health. Statutory Decree no. 7/2005 creates the High Commissariat for Health, an entity consisting of the High Commissary for Health and four national coordinators. As a continuation of an individual activity of the High Commissary for Health, the High Commissariat for Health promotes intersectoral strategic programs and their execution at a regional level, as well as evaluates their implementation.

In legislative acts of the 2nd Series, for a special attention in terms of cross-sectoral initiative in health and social care calls Dispatch no. 25197/2005 (2nd Series) which reflects the High Commissariat for Health as committed to implementation of the National Health Plan 2004-2010, and for the intersectoral strategic program in health, in particular. Dispatch no. 766/2006 endorses alterations in the National Program of Prevention and Control of Cardiovascular Diseases.

From the additional search, a number of other regulatory acts were identified.

Conjoint Dispatch no. 407/98 of the Ministry of Health and the Ministry of Labor and Social Solidarity proposes new units and teams deriving from social and business sectors, encompassing public and private for-profit bodies. This goes in line with conventions endorsed by Portugal internationally within the EU and with the recommendations of the WHO aiming at building more efficient human and clinical public and private structures.

Decree Law no. 156/99 of the Ministry of Health launches SLS (Local Health Systems), and constitutes the national commission aiming at supervising their development, which consists of representatives of the Ministry of Equipment, the Ministry of Planning and of Territorial Administration, the Ministry of Justice, the Ministry of Health, the Ministry of Labor, Solidarity and Environment, the National Association of Portuguese Municipalities, the National Association of Portuguese Parishes, the Union of Portuguese Charities, the Union of Reciprocities, the National Federation of Health Care Providers, the General Union of Employees and the General Confederation of Portuguese Employees. Decree Law no. 284/99 of the Ministry of Health indicates a set of competencies of a coordinator of a group of hospitals. Among them, we find promoting articulation and cooperation with health centers and other, public or private, health services and institutions which activities are related to health or may have an impact on health; promoting articulation with education, training and research institutions; and promoting community participation.

Resolution of the Cabinet of Ministers no. 84/2005 forms the Commission for the Development of Health to the Elderly and Citizens in Situation of Dependency that was appointed to identify unmet health and social needs of the population, retract and organize information on contribution of diverse social and institutional partners relevant for community services and propose a model of intervention maximizing the likelihood of reaching the objectives. The proposed model laid on articulation between entities of health and social solidarity, local government and private sector in order to respond health and social needs.

In Decree Law no. 101/2006 an integrated model which would allow a smooth articulation between entities of health and social care sectors, of preventive, convalescent and palliative nature is deemed vital for the future of the system and formally established, counting on participation of diverse social groups, civil society and the State, as the principal encouragement body, and cooperating on basis of a network. The term ‘intersectoral’ does not appear evidently in the document; nevertheless, its manifestation is clear. As a consequence of Decree Law no. 101/2006, Dispatch no. 19 040/ 2006 creates Regional Coordinating Teams which shall ensure the coordination of the RNCCI at the local level by a specific team composed by representatives from health (at least one doctor and one nurse), social (preferentially, a social assistant) and, always when necessary, a technician of a local government. Again, the term ‘intersectoral’ remains implicit.

Intersectoral action for health promotion, prevention and disease treatment is very clearly visible, yet alleged, in Decree Law no. 186/2006 which determines a system of financial support by the State through the central and regional levels of the Ministry of Health to private non-profit entities. Such support has, among others, an objective to develop a social dimension of health interventions through direct participation of private non-profit entities, form partnerships with public entities, for instance local governments and education institutions at different levels, and form partnerships with private entities.

Decree Law no. 28/2008 points out an importance of education and promotion of health, more specifically to be proposed by the community council to ACES and taken into action by ACES in partnership with other bodies from the municipality and represented in the community council. Dispatch no. 31292/2008 of the Ministry of Health calls for action the monitoring committee for children and the youth in risk of which one of responsibilities is promoting establishing intersectoral protocols in this respective field.

Law no. 81/2009 of the Assembly of the Republic, which in part concerns intersectoral collaboration, organizes the system of public health surveillance as an integrated network of entities communicating and cooperating among their sectors of origin, and imposes accreditation of those entities. Decree Law no. 81/2009 of the Ministry of Health recognizes the importance of public health for other sectors of the economy turning, automatically, public health services catalysts of intersectoral partnerships and strategies for health promotion and advocacy. Dispatch no. 10143/2009 of the Cabinet of the Secretary of State for Health defines the scope of intervention of a Community Care Unit, which activity is developed on a basis of inter-cooperation, inter-institution and intersectoral articulation with other functional units of ACES.

Coordination and articulation in mental health at the national, regional and local levels with partners that may come to contribute in continuous health services delivery is stated in Decree Law no. 8/2010 of the Ministry of Health, together with cooperation and collaboration between diverse units and teams of continuous integrated mental care, here, however, with intersectoriality remaining implicit. This Decree is then altered by Decree Law no. 22/2011 leading to creating new typologies of units and teams, and broadening the scope of promoting entities from social non- and for-profit and public sectors. Ordinance no. 149/2011 of the Ministry of Labor and Social Solidarity and the Ministry of Health points out coordination of continuous integrated mental care providers at all levels.

Resolution of the Cabinet of Ministers no. 37/2010 recognizes an increase of the average life expectancy, gradual aging of the population together with an upsurge of persons with chronic conditions. These aspects were on base of creating the RNCCI, leading to a systemic change and with an intersectoral approach in view of providing health and social care services to persons who are not independent in ADL. Ordinance no. 196-A/2010 of the Ministry of Health and the Ministry of Education respective to health education, more specifically sexual health education for the youth, envisages actions and projects with the collaboration of the General Directorate of Health, the Portuguese Institute of the Youth (*IPJ - Instituto Português da Juventude, I.P.*), institutions of higher education, as well as other accredited organizations. Further partnerships may be established by the General Directorate of Innovation and Curricular Development in the area of health and sexual education. Dispatch no. 17595/2010 changing Dispatch no. 9872/2010 underlines that above members of USF (*Unidade de Saúde Familiar*), other professionals representing the National Health System, business or social sector may also participate in the work of USF.

Ordinance no. 159/2012 passes to the Direction of Services of Prevention of Illness and Promotion of Health, among others, responsibility for ensuring collaboration with suitable governmental and non-governmental entities and establishing partnerships in health promotion and protection.

Law no. 67/2013 of the Assembly of the Republic specifically stipulates an obligation of collaboration in art. 44, where representatives of enterprises or other consignee entities are obliged to demonstrate a collaborative attitude toward the regulating entity in what information and documentation provision concerns. Decree Law no. 137/2013 republishing Decree Law no. 81/2009 indicates a responsibility of a health unit by a coordinator and an executive director to establish partnership agreements with municipalities and parishes in the respective area, and active participation in developments in the field of public health of local commissions. Intersectorial programs are stated as means for health prevention and promotion for chronic and infectious diseases, as well as for promotion of healthy lifestyles. Ordinance no. 168/2013 considers demographic, epidemiologic and social changes which have given origin to new health needs and family structure, and urges a strategy involving social non and for-profit and public sectors. Ordinance no. 258/2013 presents a tendency to embrace partnerships in legislation in a more firm and pronounced way. Not only are they promoted, between public and private entities, but a strong appeal for a formal way of cooperation and articulation between partners is emphasized. Dispatch no. 1393/2013 of the Ministry of Health mentions the importance of collaboration between intensive neonatal and pediatric services and units of the NHS and the INEM (*Instituto Nacional de Emergência Médica, I.P.*).

Dispatch no. 5561/2014 of the Ministry of Health indicates the importance of collaboration between the emergency services and the INEM.

1.10. Summary and conclusions

At the moment, organizations representing three principal society sectors are increasingly working together in partnership in order to address common issues. As a result of intensive promotion of this mechanism by international organizations, governments at all levels and private entities a number of intersectoral partnerships has grown rapidly in recent years, and has become a functional means to address challenges such as economic development, education, health and social care or sustainable development. It has been noticed more in some world regions, some countries and some systems more than others.

The consensus on a need of intersectoral engagement to promote health in populations seems to be clear. This is because what has a direct and long-term impact on health has its origin outside the realm of curative and preventive health services. There is also an evident agreement on what key elements of an intersectoral action should be and what factors influence collaboration across sectors and decide on its success. Finally, there is a high level of accordance on how to proceed and work intersectorally – at least in terms of recommendations. Still, while empirical evidence exists on what has worked in a certain context and in a given setting, a body of literature on general cross-sectoral procedures is limited as it is theoretical basis supporting intersectoral logic.

This chapter has discussed the collaborative engagement rationale. It has brought closer definitions and forms of collaborative bounds, together with available frameworks for a collaborative action. The potential underlying collaboration, especially the one crossing system boundaries, has been continuously recognized since the 1970s, but its popularity has reached a peak in the last years. Collaboration between health and social services has been considered by policy makers in many countries and care systems a fundamental solution for shifting systemic exigencies. Intersectoral partnerships are proposed as particularly well suited to addressing complex social problems that cannot be solved by single sectors and organizations acting alone.

The systematic review of the Portuguese legislation reveals that indication of an intersectoral action has been present in mind of policy makers for long. Legislative acts of diverse types and in different fields, including health and social care area, have been launched over decades with an intention to mobilize material and human resourses to collaborate in order to achieve what one sector cannot accomplish on its own. Consistent feedback from the field proves, however, that legislation lacks its capacity to pursue the reality taking into consideration the amount of legislature regarding intersectoriality and the dimension of laws effectively implemented attaining concrete intended outcomes.

CHAPTER TWO:

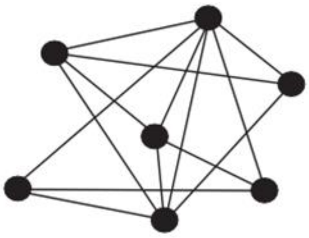
APPROACHING INTERSECTORAL PARTNERSHIPS THROUGH THE LENS OF THE NETWORK THEORY

One of the most compelling and potent ideas in the social sciences is a belief that individuals are embedded in broad linkages of social relations and interactions. Nowadays organizations operate in the interconnected and interrelated business world and a strategic success of an organization depends on its linkages with the surrounding environment. In a society where personal and organizational relationships are increasingly valued, analysis of networks has gained its importance as an analytic and strategic tool.

This chapter aims at discussing the concept, development and relevance of network analysis as health and social care organizations can be successfully approached through networks to pursue with their activities. It begins with presenting the theoretical framework of networks, a concept of a network in itself and the network theory, all in Section 2.1. Section 2.2 discusses network analysis and social network analysis. Next, historical evolution of the network theory is shortly portrayed in Section 2.3. Section 2.4 brings closer characteristics of networks, while forms and types of networks, and participating actors are depicted in Section 2.5. The last part of this chapter presents advances in development and evolution of the network theory over time and its application into organizational contexts, with a special emphasis on health and social care organizational arena.

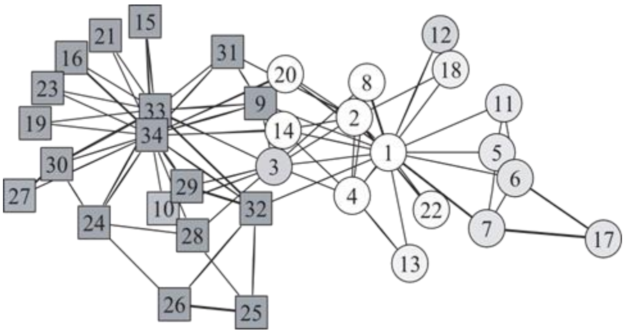
2.1. Network concept and the network theory

A network, in the understanding of the graph theory, is “a finite set of points linked, or partly linked, by a set of lines (called arcs)…called a net, there being no restriction on the number of lines linking any pair of points or on the direction of those lines. A relation is a restricted sort of net in which there can only be one line linking one point to another in the same direction, i.e. there are no parallel arcs” (Mitchell, 1969, pp. 2-3). The basic sociological concept of a network was given by Mitchell (1969), who understood it as a specific type of relationship (ties) that links a group of people, objects or events (actors or nodes). In this way, a network is composed of ties and nodes and aims to depict some relationships between the nodes. The author conceptualizes a ‘total network’ of the society as “the general, ever-ramifying, ever-reticulating set of linkages that stretches within and beyond the confines of any community or organization" (p. 12). He argues that from the total network, always particular aspects are to be taken under consideration, which he denominates 'partial networks'. Gamm (1981) defines a network as a system or a field compound of organizations and interorganizational linkages and relationships. Figure 9 presents a simple construction of a network. Figure 10 depicts a more structured network example, with a higher number of nodes and ties between members. In Figure 11 an example of a very complex network is provided.



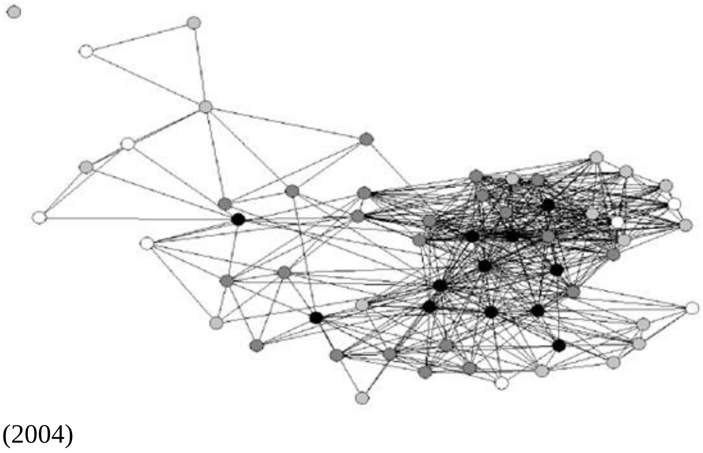
Source: Boccalettia et al. (2006)

Figure 9. A simple configuration of a network



Source: Boccalettia et al. (2006)

Figure 10. A group of relationships in a network



Source: Molina (2004)

Figure 11. A complex network of relationships

A social network is a theoretical construct which is used to study relationships between individuals, groups of individuals, organizations and also between greater communities, such as societies. The social network perspective stresses a relevance of relationships among interacting units to uncover hidden pressures that exist within the network (Hatala, 2006). The smallest element of analysis in a social network is an individual in the social setting and with an individual social network analysis at the micro level typically begins. At the meso level, low density networks begin with a population size that falls between micro and macro levels. Macro level networks trace outcomes of interactions over large populations rather than interpersonal interactions.

Network as a construct can be analyzed at different levels of which compilation is presented in Table 23.

Table 23. Network levels according to Hill (2002)

Level	Definition	Authors/conceptions
Vision	Why the network exists	Mays et al. (1998) – "strategic orientation", Boland and Wilson (1994) – planning
Structure	How the network exists	Mays et al. (1998) – structural; Boland and Wilson (1994) – administration; Gray and Wood (1991) – 'collaborative alliance'
Process	What the network does to fulfill its vision/existence	Mays et al. (1998) – functional; Gray and Wood (1991) – "collaborating"
Service delivery	What activities the network performs related to process, for the purpose of its vision, via its structure	Boland and Wilson (1994) – service delivery

Source: Hill (2002)

The network theory is a formal theory that enjoys many substantive theoretical applications. Hatala (2006) argues that there are many problems across different disciplines that may benefit from the use of similar formal concepts to understand their 'network' (linkage and context) component, although substantive interpretations will vary as to the role played by a given formal concept in differing phenomena. Second, to the extent that similarly defined concepts are mobilized in "puzzle solving" in different disciplines and problem areas, we can pose comparative questions not just between different cases of the same phenomenon but between different phenomena, where we can ask whether or how some of the same types of processes may be operative (p. 49 cited in White, 1997).

Wasserman and Faust (1994) identify a number of basic assumptions to the network theory: (a) actors are perceived as interdependent rather than independent units; (b) linkages between actors are means to transfer material or non-material resources; (c) individuals recognize the structural environment of the network they are part of as a source of barriers and opportunities to their own action; and (d) network models conceptualize structure as long-term patterns of relations among actors.

The network theory is based on the hypothesis that organizations operate in the market through interdependence and coordination of action built upon mutual relationships. Neither a central plan nor a bureaucratic organizational hierarchy give origin to such coordination. Pooling resources is a starting point for dependency between organizations as they depend on resources of each other, and a possible source of gains (Johanson & Mattsson, 1988). Pfeffer and Salancik (1978) indicate that interdependence focuses on considerations regarding resource procurement and uncertainty reduction. Organizations enter into interorganizational relations to access resources necessary to proceed with their activities while partly controlled by other actors (Hoang & Antoncic, 2003). Symbiotic interdependence arises between organizations representing different fields and domains, and may motivate collaboration aimed at taking advantage of complementary differences (Hawley, 1950). Competitive interdependence arises between organizations from similar or related domains and may lead to creating collaborative arrangements as a substitute of existing competition (Pfeffer & Salancik, 1978).

The network approach is based on the social exchange perspective (Cook, 1977; Emerson, 1972), which points into two relevant features. Firstly, a relationship between parties is only possible when all find it profitable at any level. Second, in business relationships, cooperation is an informal process of coordinated actions between organizations (Blankenburg Holm, Eriksson, & Johanson, 1996).

The network approach relies on understanding the social structure as patterns of relations between social units or actors (Marsden, 1990). The contemporary network approach points out actual flows, social ties and linkages, relatively more than it happens with social psychological constructs, such as affect, interpersonal charisma and appeal, with which sociometry used to be concerned (Borgatti, 2005).

The focus of network analysis is based on relations between agents and how pattern of such relations can be used to value system processes and performance. An underlying supposition is the inter-connection between actions of individual actors and social structures. As social structures impact actions, actions perform influence on social structures. Systematic network analysis allows therefore for describing and clarifying opportunities and barriers that social structures compel at individual action (Marsden, 1990).

2.2. Network analysis and social network analysis

Network analysis is a set of techniques developed to study how individuals, groups, organizations and communities connect and interact with each other (Wasserman & Faust, 1994). It focuses on the analysis of patterns of relationships between such entities. Social network analysis provides both, a visual and mathematical analysis of human relationships.

Network analysis approaches social systems as networks of dependency relationships resulting from a differential possession of scarce resources at the nodes and a structured allocation of these resources at the ties. Basic to this approach is the assumption that actors, also organizational actors, are embedded within a network of relationships that provide opportunities and constraints to different behaviors (Brass et al., 2004).

The embeddedness construct is central to the network perspective. Uzzi (1996) defines embeddedness as “the process by which social relations shape economic action in ways that some mainstream economic schemes overlook or misspecify when they assume that social ties affect economic behavior only minimally or, in some stringent accounts, reduce the efficiency of the price system” (p. 674). Coleman (1988) adds to this that embeddedness is “an attempt to introduce into the analysis of economic systems, social organizations and social relations not merely as a structure that springs into place to fulfill an economic function but as a structure with history and continuity that give it an independent effect on the functioning of economic systems” (p. S97). In its initial formulation stage, embeddedness was a notion that all economic behavior was essentially and unavoidably embedded in a larger social context, while a more recent empirical work has been focusing on embedded linkages and their performance benefits as embedded ties are frequently associated with more intense and more restricted business relationships (Uzzi, 1997). Table 24 presents network analysis principles and assumptions with corresponding and deriving from them methodological issues faced in studies on networks.

Table 24. Network analysis principles, assumptions and methodological issues

Principles	Assumptions	Methodological issues
Behavior is interpreted in terms of structural constraints on activity rather than in terms of inner forces within units. Analyses focus on the relations between units. A central consideration is how the patterns of relationships among multiple (actors) jointly affects network members' behavior. Analytical methods deal directly with the patterned relational nature of social structure.	Actors and their actions are viewed as independent units. Relational ties (linkages) between actors are channels for transfer of "flow" of resources. Network models focusing on individuals view the network structure environment as providing opportunities for and constraints on individual actions. Network models conceptualize structure (whether social, economic, political, and so forth) as enduring patterns of relations among actors.	What are the boundaries of the network under study? What type(s) of relations will be measured? Do the relations measured represent the range of relevant components of the construct? Will binary or value data be collected? Does the operationalization of the relationship construct(s) require assessing the strength of the ties? Are the ties directional or nondirectional? Are the exchange ties between network partners reciprocal?

Source: Wellman (1988) and Galaskiewicz & Wassermann (1984) cited in Rowley (1997)

The social network approach origins from the understanding that a social phenomenon should be firstly perceived and investigated through the properties of relations within and between units of analysis, instead of the properties of these units. "To discover how A, who is in touch with B and C, is affected by the relation between B and C…demands the use of the [social] network concept" (Barnes, 1972, p. 3). It employs, therefore, necessarily relational constructs. Social network analysis perspective suggests that the power of individual actors is not an individual feature, but arises from their relations with others. In other words, the strength of the network relationship and communications may come from the synergy of connections (Palazzolo et al., 2011).

Social network analysis is a group of procedures that uses a catalogue of relatedness indicators which represent social positions and social structures inbuilt in dyads and groups. These representations play a significant role in describing the surrounding environment and its nature, and depict an impact it exerts on individuals who form relationships (Hatala, 2006). Stokowski (1992) defines the analysis of social networks as a set of methods utilized to portray relationships and interactions between groups of social actors with an objective to evaluate types and modes in which patterns influence structural behavior of actors. Wetherell, Plakans and Wellman (1994) describe social network analysis as follows: "Most broadly, social network analysis (1) conceptualizes social structure as a network with ties connecting members and channeling resources; (2) focuses on the characteristics of ties rather than on the characteristics of the individual members; and (3) views communities as 'personal communities', that is, as networks of individual relations that people foster, maintain, and use in the course of their daily lives" (p. 645).

Social network analysis perceives social relationships in terms of the network theory, consisting of nodes (representing individual actors within the network) and ties (which represent relationships between individuals, such as friendship, kinship, organizational position, etc.). Freeman (2004, cited in Luke & Harris, 2007) indicates four relevant characteristics of the network paradigm: (a) network analysis is a structural approach that concentrates on patterns of relationships; (b) it is based on empirical data; (c) it employs mathematical and computational models; and (d) it is highly graphical.

Network analysis approaches social systems as networks of dependency relationships resulting from differential possession of scarce resources at the nodes and a structured allocation of these resources at the ties (Wellman, 1983). McIllwain (1999) demonstrates that there is a variety of ranges and types of ties, in which the most common are (p. 305):

a) evaluation of one person of another (e.g., friendship, liking, respect);
b) transfers of material resources (e.g., business transactions, lending or borrowing things);
c) association or affiliation (e.g., jointly attending a social event or belonging to the same formal or informal organization);
d) behavioral interaction (e.g., talking together, sending letters and e-mails);
e) movement between places or statuses (e.g., migration, social, economic, or physical mobility);
f) physical connections (e.g., a road, river, or bridge connecting two points);
g) formal relations (e.g., authority);
h) biological relationship (e.g., kinship, clan, or descent).

From an analytical viewpoint, social network analysis in social sciences is a proof of a shift from a traditional individuality towards a structural analysis (Garton, Haythornwaite, & Wellman, 1999). From typical units, such as persons and their relative attributes, the analysis focuses on type and structure of a relation between them (look Table 25).

Table 25. A typology of ties studied in social network analysis

Similarities			**Interactions**	**Flows**
Location	**Membership**	**Attribute**		
e.g., Same spatial and temporal space	e.g., Same clubs Same events etc.	e.g., Same gender Same attitude etc.	e.g., Talked to Advice Helped Harmed	e.g., Information Beliefs Personnel Resources
Social relations				
Kinship	**Other role**	**Affective**	**Cognitive**	
e.g., Mother of Sibling of	e.g., Friend of Boss of Competitor of	Likes Hates etc.	e.g., Knows Knows about etc.	

Source: Adapted from Borgatti et al. (2009)

For studies and tests on theories, social network analysis employs a quite characteristic and distinctive from other perspectives measurement approach, and uses for these purposes structural or relational information (Wasserman & Faust, 1994). This quantifiable approach provides information on patterns of interactions between actors and observable patterns of information flow between them. Wasserman and Faust (1994) state that “these methods translate core concepts in social and behavioral theories into formal definitions expressed in relational terms” (p. 21).

Another perspective on analytical element of social network analysis provide Sih, Hasner and McHugh (2009) who note four important aspects of social network analysis that, as they argue, are rather observed than quantified: (a) differences between individuals and their individual experiences influence individual and group outcomes; (b) an indirect connection of an individual of the network are as important as a direct connection, however from different rationales; (c) individuals are judged to have different experiences from the point of view of the network; and (d) social network frequently goes along different contexts.

2.3. Historical evolution of the network theory

As Scott (2000) refers, strands in the development of network analysis have been overlapping and crossing each other over time and so, it is hard, not to say, impossible, to delineate a clear pathway in the theoretical development of this concept. Three principal lines of research that contributed to the current shape of the theory originated from:

a) the sociometric analysts (contributed with technical advances to the science through employing the graph theory);

b) the Harvard researchers of the 1930s (exploring patterns of interpersonal relations); and
c) the Manchester anthropologists who used the previous strands to proceed the research on relations among tribal and village communities.

Major developments in the field of social network analysis can be seen in the 1930s by several groups in psychology, anthropology and mathematics working independently from other groups, followed by the 1980s and a prosperous development of the social network theory and blooming interest of researchers from several research areas.

As a result of the II World War, a number of scholars went into exile from Nazi Germany to the United States, among other destinations, and conducted their research on cognitive and social psychology. Their work was strongly influenced by the Köhler's 'gestalt' theory and motivated considerable amount of research in group dynamics and sociometry.

The concept and theory of networks originated from work of one of those émigrés, Jacob Moreno, a psychiatrist who studied relationships of a small network of individuals in network diagrams (Freeman, 2004). Moreno is believed to have developed the first sociogram in the 1930s to study interpersonal relationships as structures in which people were considered points and the relationships between them were drawn as connecting lines. The sociometry introduced by Moreno was the first attempt toward social network analysis, a method for analyzing and measuring social networks. Moreno argued that by constructing sociograms researchers gained an access to map inter-relations, identify leaders and isolated individuals and trace relationships between individuals. Scott (1997) indicated one of the principal sociometric concepts, the sociometric star, which could be described as an individual on a position of a leader, who was a recipient of frequent and numerous choices of the others from the network.

At the same time, researchers at the Harvard University were developing their work basing on the theoretical and ethnographic foundation for social network of Malinowski, Radcliffe-Brown and Lévi-Strauss. A number of studies were based on the concept of interdependence in social systems and underlined the importance of interpersonal relations in any type of social systems, including informal relations (Scott, 1997). Radcliffe-Brown's ideas were especially influential for Mayo and Warner's empirical work, who perceived their investigation of factory and community life in the United States as direct application of the structural Radcliffe-Brown's concerns (Scott, 2000).

The third strand of research in social network analysis focused around the Manchester University and applied, somehow in parallel with their Harvard colleagues, Radcliffe-Brown's work to analyze conflict and contradiction in social systems. A group of social anthropologists investigated first African tribal societies and advanced into a study of a British rural small town (Scott, 2000). The primary figure in the group, Gluckman, argued that conflict and power which the research group focused on, were integral elements of social structures, and social integration required coercion and negotiation. Only in the 1960s the breakthrough in methodological issues, related to work of White at the Harvard University, occurred.

From 1940s to 1960s social network analysis lost partially its visibility, albeit still developed by a group of scholars working in different academic and institutional settings. In 1954, Barnes started using the term ‘social network’ systematically to designate patterns of ties, encircling concepts traditionally used by public in general and those used by social scientists.

Further advances of network analysis were accomplished thank to Cartwright and Harary (1956), who related the concept to mathematical theory and pioneered an application of the graph theory to group behavior. According to the authors, sociograms could be analyzed using the graph theory, what added a significant contribution to link the qualitative approach to sociograms in social sciences with quantitative analysis of the graph theory. Worth to mention that until that time, social scientists used exclusively descriptive methods in work with sociograms. In mathematics, the graph theory began to be developed in the 18th century by Euler, the author of the resolution to the problem of bridges of Königsberg. Euler used a visual representation of a network of bridges and rivers to solve now famous the Königsberg bridge problem. In fact, a number of publications followed Euler’s work, but only in 1936 a formal setting of this theory was presented. Even that one, as many works from Nazi Germany, did not cause the immediate impact on the scientific community.

Since the 1970s, empirical studies of networks have played a central role in social sciences, and many of mathematical and statistical tools used for studying networks have been first developed in sociology. In late 1960s and the 1970s, social network analysis became a generalized paradigm for research, until high extent thank to White’s work, who used structural perspective and transmitted it to his students. Granovetter and Wellman have become those from former White’s students who elaborated and mastered the analysis of social networks.

The field of network analysis used to be composed of two principal groups, distinct from each other regarding their origin of research. One group included anthropologists, historians, social psychologists, geographers, political scientists, communication scientists and mathematicians, and the second almost exclusively of sociologists (Freeman, 2004). In the 1980s, all researchers joined a common, integrated community of researchers in network analysis and won consideration of a still growing number of scholars from different research fields. In this way, in literature, network analysis started to emerge in the 1980s gaining much attention in the following decade, both, in academic research and its application in a non-academic world (Scott, Baggio, & Cooper, 2008). An interest in the network approach has increased since the 1980s. This approach has been widely used in a large number of disciplines, including political science, marketing, social policy and innovation studies (Araujo & Easton, 1996). Table 26 provides a compilation of topics studied within social network analysis with respective academics.

Table 26. Topics studied within social network analysis and involved researchers

Topic	Researcher
Occupational mobility	Breiger, 1981, 1990
Performance	Sparrowe, Liden, Wayne, & Kraimer, 2001; Doving & Elstad, 2003
Social support	Gottlieb, 1981; Lin, Woelfel, & Light, 1986; Kadushin, 1966
Group problem solving	Bavelas, 1950; Bavelas & Barret, 1951; Leavitt, 1951
Diffusion and adoption of innovations	Coleman, Katz, & Menzel, 1957; Agapitova, 2003; Hargadon, 2005
Corporate interlocking	Levine, 1972; Mintz & Schwartz, 1981a, 1981b; Mizruchi & Schwartz, 1987
Collaboration	Cross, Borgatti, & Parker, 2002; Joshi, Labianca,,& Caligiuri, 2002; Parker, Cross, & Walsh, 2001
Learning	Borgatti & Cross, 2003; Cross, Parker, Prusak, & Borgatti, 2001; Reffay & Chanier, 2000
Exchange and power	Cook & Emerson, 1978; Cook, Emerson, Gillmore, & Toshio, 1983; Cook, 1987; Markovsky, Willer, & Patton, 1988
Consensus and social influence	Friedkin, 1986; Friedkin & Cook, 1990; Doreian, 1981; Marsden, 1990

Source: Wasserman & Faust (1994) cited in Hatala (2006)

At present, Scott (2000) stresses out that analysis of social networks, with its separate origins and a number of interim consolidations, derives from one of two approaches: (a) social sciences perspective, with an application of qualitative techniques, emphasizing structural relations and the influence of social arrangements on individual behavior and attitudes of actors; and (b) mathematical perspective, with a use of quantitative methods to study features of a given network.

2.4. Characteristics of networks

Analysis of networks allows for creating descriptive indices of a social structure. There have been various attempts to measure social networks using different approaches and available research indicates that there might be some, albeit imperfect, measures for this purpose. Some important issues are still to be systematized, but contemporary network analysis is more forward in its advances and more conscious of its limitations (Marsden, 1990). A variety of measures, drawn from network analysis literature have been utilized to uncover patterns within the social structure. Some of formal theoretical properties in the network perspective include centrality (betweenness, closeness and degree), strength of ties (strong/weak, weighted/discrete), cohesion (groups, cliques), density, structural (network range) and division (for instance, existence of structural holes).

Network density is the average strength of connections among units in a network or a proportion of ties which are present relatively to those which are possible in a certain setting, and is one of the most common indices of a network structure. It permits to assess how solid the network is and to verify a presence of subgroups (Palazzolo et al., 2011). Density is measured by the extent to which an actor’s contacts are interconnected and is reflected by the connectedness of the nodes. It is a characteristic of the whole network. As the number of ties that link various dyads of actors within the network increases, the density of the network increases (Rowley, 1997). As density increases, communication across the network becomes more efficient and a diffusion of norms across the network occurs in a more dynamic and efficient way (Meyer & Rowan, 1977). Friedkin (1981) shows that in case a network composed of subgroups, density turns to be a problematic index, and that comparisons of density measures across networks that differ in size can likewise be misleading.

The second dimension on the network properties is that of centrality. Perhaps the focal point of the greatest amount of recent research has been measurement of centrality in networks. While this measure is conceptually quite analogous to size, it unequivocally includes an ability to access (or control) resources through indirect as well as direct linkages (Hoanga & Antoncic, 2003). Centrality measures a focus on relative positions of units within a network and reflects variability in centrality scores among units. Freeman (1979) concentrates on different types of centrality data and presents a relevant conceptual review of degree-based measures, betweenness and closeness. The basic approach to degree-based measures is a network size and focuses on communication activity. Degree centrality is centrality-based on a number of direct ties an individual has. Betweenness measures point the capacity to control the network or disrupt communication. Betweenness centrality is an indication of the strategic importance of actors within the network. A higher percentage of betweenness centrality indicates that fewer actors provide bridging roles across the network, while a lower percentage means that more actors are performing this task (Lewis, 2005). Closeness measures reveal individual autonomy and freedom from the control of others. Closeness centrality refers to the extent to which an individual part of the network can reach all other members of the network in the fewest number of direct and indirect linkages, while direct links are considered 'closer' than indirect links (Brass, Butterfield, & Skaggs, 1998). In contrast, a centrality measure referred by Stephenson and Zelen (1989) is based on information and employs all direct and indirect ties between pairs of units.

Density and centralization are important complementary measures. Density illustrates a broad level of cohesion in a sociogram, while centralization points into the extent to which this cohesion is organized around particular focal and central points that can be one node or a cluster of nodes (Palazzolo et al., 2011).

Another question to be studied within networks is strength of ties. An interesting perspective is a wage and a value of a given link and how it diversifies from other linkages from the same network. Network studies often seek to deepen the knowledge of the tie type and attributes while it is unfeasible and impractical to expect respondents exemplify specific characteristics of every tie. The amount of time actors spend together, frequency of contact, reciprocity or sharing, emotional intensity and intimacy between actors all describe the strength of ties. Several authors have studied multiple measures of properties of individual dyads in an effort to obtain indices of a tie strength (Marsden, 1990). Lund (1985), for instance, offers scales for love, commitment, and investments in close personal relationships. Wegener (1989), in consequence of his studies on job procurement, argues that questions of closeness, duration and frequency of a linkage are all positively related to a level of intimacy which appears to be the most consequential property of social ties for explaining the outcomes of the studied job searches. He proposes isolated facets of a tie strength which are intimacy, formality and leisure.

While centrality and network size make the approach to measuring an amount (quantity) of resources with a direct access of an agent, other patterns of the network structure question the diversity of resources that can be accessed by this agent. A relevant contribution to discussion on a strength of ties within a network is a notion of a 'strength of weak ties' introduced by Granovetter (1973). It describes the extent to which actors can gain access to new ideas and new information through ties that are located outside of their immediate cluster of contacts ('weak ties'). Strong ties occur in situation in which there is a great linkage between the parties of the network, what allows a member to access information and gain knowledge from other sources. Nonetheless, this great proximity between members of the network does not remain without risks. While strong ties serve for keeping or improving the status, they represent a risk of surplus information and little innovation. Weak ties open a network into its extremes and may bring new ideas and new information. They allow an access to diverse perspectives, other skills and resources, new and unknown for actors technologies and it is assumed that they stimulate creativity and learning skills. Granovetter (1973) argues that weak ties, people loosely connected to others in the network, are necessary for diffusion to occur across subgroups within a system.

A complementary discussion to the one on advantages offered by weak ties brings benefits of bridging structural holes: a term introduced by Burt (1992). As network analysis takes into consideration not only a presence of relationships, but an absence of relationships as well, it can be assumed that organizational network members exist without requesting their direct connection (Brass, Butterfield, & Skaggs, 1998). Structural holes can be defined as deficiency and non-existence of ties between actors. These are weak connections between clusters of tightly connected individuals. Holes in the social structure of a network can be filled by linking one or more nodes to tie other additional nodes. A bridging actor can profit from establishing ties between otherwise separated actors, exerting influence on these actors, increase its relative power and position in the network, open access to new contacts and new relevant information.

Analysis of a network can also aim at measuring a network range. Burt (1983) defines the concept of a network range as the extent to which an actor’s network links it to diverse other parties. A range can be measured by a network size or, inversely, by a network density, in which less dense networks are considered of a higher range. Campbell, Marsden and Hurlbert (1986) have found that different measures of the network range are weakly correlated between each other and emphasized that size, density, and diversity are empirically distinct aspects of the network range. Table 27 provides description of elementary network properties.

Table 27. Essential network properties

Structural characteristic	Explanation
Size	The number of individuals participating in the network
Density (connectedness)	The number of actual links in the network as a ratio of the number of possible links
Clustering	The number of dense regions in the network
Openness	The number of actual external links of a social unit as a ratio of the number of possible external links

Stability	The degree to which a network pattern changes over time
Reachability	The average number of links between any two individuals in the network
Centrality	The degree to which relations are guided by the formal hierarchy
Star	The individual with the highest number of nominations
Liaison	An individual who is not a member of a cluster but links two or more clusters.
Bridge	An individual who is a member of multiple clusters in the network (linking pin)
Gatekeeper	A star who also links the social unit with external domains
Isolate	An individual who has uncoupled from the network

Source: Adapted from Tichy, Tushman, & Fombrun (1979)

A network can be analyzed regarding several other dimensions. Some scholars (see Scott, Baggio, & Cooper (2008) and Murdoch (2000) for a more comprehensive discussion) indicate betweenness as a position of an individual between groups; vertical differentiation as a degree to which different organizational levels are presented in and by a network; horizontal differentiation as a degree to which professional areas are represented in a network; and reciprocity as a level of a two-sided communication between the actors of a network. On the other hand, Haythornwaite (1996) specifies cohesion as a term describing a grouping within a network according to strong common relationships with each other, brokerage as an indicator to bridging connection to other networks, and the most active membership denominated prominence as network properties.

2.5. Typology of networks and types of actors

The network approach has been widely employed within a large number of disciplines and, as a consequence, a notion of network is used to describe different types of phenomena (Achrol, 1997). In general, network studies universally depict interdependencies of relationships between actors. Lynch (2000) demonstrates that these relationships vary and can be classified as social or business relationships. According to Mitchell (1973) social relationships can be classified into structural, categorical and personal.

If considering networks in their interorganizational dimension, collaborative networks can be perceived as variations of social networks, where relationships between actors are of collaborative nature. While the basic task of a network in a business relationship is to manage economic transactions between different parties of the network, one cannot forget that social entities belong to the organizational typology as well, and dynamics of relationships between them derives from interpersonal relationships between individuals composing them (Granovetter, 1973; Uzzi, 1997). Therefore, it remains equally valid to apply a micro level approach to networks, examining patterns of connections, shared norms and personal emotions between individuals, besides the macro level, commonly assumed (Leek & Canning, 2011). Otte and Rousseau (2002) demonstrate that there are two main forms of social network analysis, ego network analysis and global network analysis. The starting point for ego network analysis is an individual, and network studies on the ego level focus on one actor and relationships with others, while global network analysis encompasses the macro level.

Networks can be viewed and analyzed in different ways. Regardless of attempts to categorize them, no unique and distinctive manner of a network classification has been developed. One common feature for all networks is their composition. As comprising two principal elements, nodes and ties, several approaches to network analysis have arisen in literature. Social network analysis involves three basic units of analysis, dyadic (tie-level), monadic (actor-level), and network (group-level). In dyadic units, each case is represented as a pair of actors and variables are attributes of the relationship among the pairs. Monadic units involve cases of actors with variables understood as aggregation that count a number of ties a node has or the sum of distances to others. A network unit of analysis comprises cases of whole groups of actors along with relationships that exist among them. Variable aggregations point to elements such as an extent of centralization, an average distance or a number of ties in the network (Hatala, 2006).

Literature demonstrates several typologies of networks. They vary along a number of dimensions which give them specific characteristics. Hawe, Webster and Shiell (2004) demonstrate that there are one mode and two mode networks. One mode networks cover linkages among a single set of alike and related actors. Two mode networks focus on researching relationships between two sets of network actors. They are used to investigate existing relationships between a set of actors and a series of events as network members may be related with each other by attending the same or similar events or perform similar activities.

Networks can be classified as open or close regarding their extension of accessible linkages (Saxena & Ilbery, 2008). Open networks allow for an easy access to a broad spectrum of services as they are more dispersed geographically. They encompass a wide choice of different actors who can easily enter in contact with each other to obtain information and capture knowledge. Close networks comprise usually fewer members whose relation is typically more personal and socially secure. Through deeper personal linkages, members of such networks have access to tacit knowledge.

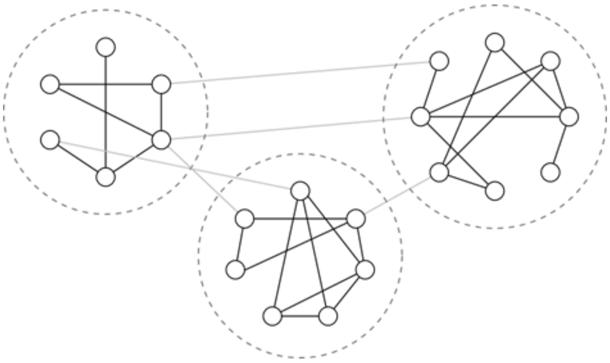
Another classification divides networks into hard or soft (Saxena & Ilbery, 2008). Hard networks are considered to be more official, involving formal agreements between their members, and are usually formed to achieve well-defined business objectives. Thus, they are mostly economic and profit-oriented. Soft networks are characterized by a broader spectrum of action, not necessarily profit-related. They have an open membership policy, involving diverse groups of actors, including governmental agencies, non-governmental organizations, groups, individual actors and enterprises, as well. In soft networks, standards of reciprocity are of high value.

Networks can be also socio-centric and ego-centric (Hawe, Webster, & Shiell, 2004). Socio-centric networks, also called complete networks, are focused on relational linkages of a single, bounded community. Ego-centric, personal networks are analyzed from one actor viewpoint. From one actor’s perspective, ties connecting this actor (ego) to other actors (ego’s alters) are considered together with the ego’s opinion about the ties connecting all ego’s alters between each other.

As networks embrace a wide range of formal and informal arrangements, from this standpoint they can be analyzed as formal and informal (Fuller-Love, 2009). Informal networks members typically come from the same tightly-related groups, what suggests a pre-existence of social ties between them. These groups are characterized by a long-term commitment and can, but do not have to, evolve into a more structured, organizationally-based network. Formal networks are typically time-limited, however the time boundary can be extended into a medium and long-term, and involve planned, organized structures within organizations.

2.6. Networks in organizational context and their potential for health and social care

In the globalized and interconnected world of organizational relations, much discussion has been placed to policy-making and governing in the interrelated setting, what indicates a significant shift into the model of governance across different sectors of the society based on inter-agency coordination, collaboration and networking. Figure 12 provides a representation of such intrasectoral and intersectoral collaboration within the network approach. The emphasis relies (or should rely) not exclusively in establishing and improving collaboration within a group and then a sector but going beyond and looking ahead for predicting future needs and seeking potential solutions and advantages.



Source: Boccalettia et al. (2006)

Figure 12. Collaboration within and between sectoral boundaries on a basis of the network approach

Organizational objectives are increasingly accomplished cooperatively through networks of collaboration. Existing literature, however, has mainly ignored the network theory perspective and has focused principally on networks in the organizational perspective (Rampersad, Quester, & Troshani, 2010).

An early debate in this research field was based on questions whether networked organizations were standing for some organizational form somehow transitional from markets to hierarchies (Williamson, 1991) or whether they were representing a completely new organizational form. During the 1980s and 1990s, the concept focused on exchange relationships between semi and self-governing, independent organizational setting, which based on embedded social linkages to protect their activities (Jarillo, 1988). More research has preserved some confusion and uncertainty on sources and processes regarded by networks as organizations can both, remain already formed networks in their internal structure and transform into a network with other organizations (Palmer & Richards, 1999). Nohria and Eccles (1992, cited in Pryke, 2005) have enriched this discussion pointing out that all organizations are social networks and need to be analyzed from the network perspective, and the same organizations operate in the environment composed of networks of other organizations.

In the organizational standpoint, a network can be defined as "more or less stable patterns of social relations among different actors (people, groups, organizations) who depend on each other to reach their goals without the existence of a dominant actor" (Minkman, Ahaus, & Huijsman, 2009). Another viewpoint is that of a network as patterns of relationships between interdependent actors "who cannot attain their goals by themselves, but need the resources of other actors to do so" (Kickert, Klijn, & Koppenjan, 1997, p. 6) and "structures of interdependence involving multiple organizations or parts thereof, where one unit is not merely the formal subordinate of the others in some larger hierarchical arrangement" (O'Toole, 1997,

p. 45). A network comprises “those organizations that in the aggregate constitute a recognized area of institutional life: key suppliers, resource and product consumers, regulatory agencies, and other organizations that produce similar services or products” (DiMaggio & Powell, 1991, p. 64). Provan and Kenis (2007) in their work about modes of network governance, perceive a network as “a group of three or more legally autonomous organizations that work together to achieve not only their own goals but also a collective goal” (p. 231). Jessop (1997) considers that networks are entrenched and can be analyzed at three levels: the interpersonal level between individual actors; the institutional level between organizations; and, the societal level between functionally differentiated institutional orders.

A network of local actors who join a supportive initiative is called a multi-sector network. A multi-sector network is based on social capital to solve a future-oriented problem. It is formed by participating bodies from the public, private and non-profit sectors, therefore a broad range of organizations with different backgrounds, capacities and skills, from different working environments. It means that the actors from civil society, business and governmental institutions come together in order to find a common resolution of a problem that affects them all (Roloff, 2008).

A network can be designed as an entity on top of entities, and thus to become a new entity, which may take the form of a joint venture. The latter joins infrastructure, resources, processes and relationships that support a shared effort and follow its own strategy, possessing its own information and communication systems and governance structure.

Networked organizations have a different operating mode than a traditional organization in a way that they look outward rather than inward. They operate as equal partners in an interorganizational setting, where their objective is not to become a central node that dictates strategic decisions and further directions. Proper organizations as individual actors go behind the mission and vision of the network and the governance is based on trust and joint decision-making rather than top-down controls (Wei-Skillern, 2010).

This interdependency context allows for exchanging tangible and intangible resources, including knowledge in its ample meaning, providing means and basis for organizational learning for all participating entities and is a result of strategic, deliberate and cautious choices (Rutten & Boekema, 2004). With limitations in resources, organizational learning constitutes a potential to identify homogeneous yet sometimes not sufficient portions of knowledge offering the network members a potential to share them in order to either seek complementary pieces of knowledge, constructing more comprehensive and robust knowledge for the use of all members, or sharing knowledge fully with other partners. Hence, it is crucial within any network to be aware of sort of capacities and knowledge each of its members can contribute with. For networks seeking perspectives for maintenance and future developments organizational learning becomes not only important but vital.

While network analysis is considered to be a well-established concept, its usefulness has not reached its peak in health and social care yet (Luke & Harris, 2007). Currently, complexity and uncertainty of the environment, and the surrounding dynamics make health and social care sectors not very much different from other sectors from the economy. While Rutten and Boekema (2004) argue that large enterprises need to enter into the collaborative environment in order to share their knowledge and get partners' knowledge and skills in return, the same applies to organizations involved in health and social care provision and the prospective to exchange knowledge and build synergies resorting to external contexts. Due to their interdependency, actors from the health and social care arena have been pressured to interact with other entities, having the interaction broadened from between two or a number of organizations from either health or the social care, to more widespread contacts, in some cases happening on a daily basis, jointly with private or voluntary sector entities also participating in care and support services delivery. That situation has arisen to provide a response to comprehensive care needs of the population.

Some networks in health and social care focusing on interventions addressing public health matters have been described in literature. Those have addressed common issues as determinants of health - compliant factors that are part of the social, economic, physical or geographic environment, which can be influenced by policies and programs and make significant contribution to general health condition and health care standards of a population. Conducted and concluded studies on interorganizational relations within networks in the health field can be employed for mapping general collaboration, referral, and formal agreement relations (Valente et al., 2008).

2.7. Summary and conclusions

This chapter brought closer the concept of networks and its roots, with current tremendous popularity and application in a variety of disciplines rising dynamically from 1930s of the 20th century. In fact, network analysis has a long and complex history drawing on traditions in many different research disciplines. Social network analysis is nowadays considered one of the major paradigms in contemporary sociology and is also employed in a number of other fields.

A network, understood as a group of units – actors – together with relationships between them has been a source of interest of academics over last years and can be approached from different perspectives, as different are backgrounds of the nodes. Actors of a network may represent individuals, groups of individuals, organizations and greater communities. Social network analysis is a theoretical paradigm that is employed to study actors involved within the network from the perspective of relationships that bound them. Similarly, examples of network relations comprise personal connections, business relationships between enterprises, cooperation relationships and any other relations based on mutual gains. In an organizational perspective, networks between organizations in health and social care may take a variety of forms and turn into cooperation, alliance, or collaboration, among others (for a wider discussion on possible forms of collaborative linkages, refer to Chapter 1 of this work).

According to the network theory and its application to economic organizations reality, a market can be regarded as a network composed of a number of agents - organizational entities, and relations between them. In fact, as literature indicates, the entire economy can be understood as a network of organizations, as well as every single organization itself represents a network of relationships.

In the today's networked society and economy, health and social care organizations seem to be by nature embedded in the network perspective as they represent economic and individual relationships between a broad range and diversity of entities providing mostly fragmented care services to the society. Health and social care nowadays involve different types of organizations, from different sectors, of different structures and sizes, different visions and organizational cultures, and different operational policies and philosophies. The network theory allows for analyzing and visualizing these organizations and linkages existing between them from the perspective of a variety of network indicators and characteristics. Network characteristics, such as density, network range, centrality or the strength of ties permit to characterize general types of relationships and enter into a deeper analysis of the problem. In health and social care, such network agreements have proven to already be established in issues addressing public health matters, however, perspectives for their applications are broad and bring a promise to advance toward better health outcomes for the society.

CHAPTER THREE:

PERCEIVED SERVICE QUALITY AND USER SATISFACTION

Services have persistently been gaining their fundamental position as sector of the economy in today's world. Their distinctive characteristics differentiate them from other sectors requiring another approach to their analysis and research. It is vital, both for managers and researchers, to fully comprehend the concept of service quality, especially given that it is thought to be a way to guarantee its satisfactory level with its improvement over time, and to differentiate the service together with the enterprise delivering it onto the market. Given an escalating significance of services in the economy, it is suggested that service quality and satisfaction should be a concern to both, consumers and businesses.

This chapter aims to discuss constructs of service quality and satisfaction. Section 3.1 provides conceptualization of services in the economy and identifies their unique characteristics. In Section 3.2 concepts of service quality and satisfaction are presented, together with a discussion on a relationship between them. This Section conceptualizes service quality (in Subsection 3.2.1), presenting models (Subsection 3.2.2) and measurement instruments (Subsection 3.2.3) of service quality. Furthermore, in Subsection 3.2.4, the notion of satisfaction is presented, followed by a debate on a relation between service quality and satisfaction, in Subsection 3.2.5. The last Subsection, 3.2.6, discusses how service quality construct can be applied to health care services.

3.1. Conceptualization of services

Differentiating physical goods from services has been well documented in literature (Bateson et al., 1978; Shostack, 1977). There is a common consensus that services encompass distinctive characteristics, which differentiate them from physical goods.

A term 'product' refers to both, a good and a service. Grönroos (1990) describes a service as a process which consists of a series of activities to a lower or higher extent intangible that usually, but not necessarily, occurs during an interaction between a provider and customer, and/or physical resources or goods and/or service provider systems that are supplied as solutions to a customer. A service is therefore an economic activity that creates value and provides benefits to customer in a specific time and place. It may arise as part of a product offering support to core product characteristics or to be, as it happens globally, supplied in an isolated manner. Eiglier and Langeard (1977) define a service as an outcome of an interaction between the client, the service personnel and the physical environment. For Hill and Neeley (1988), a service is a "broad class of products characterized by intangibility, inseparability of production and consumption, difficulty of standardization and perishability" (p. 17). These are four unique features that for the above authors remain specific, making the evaluation of customer satisfaction with services different from the evaluation of satisfaction with goods.

Still, a definition of a service remains uncertain and is challenging (Grönroos, 2000). Especially in marketing, since the 1960s, concepts of a product and a service have been calling unquestionable interest and research has been seeking to deepen knowledge on what defines and how to achieve a satisfactory level of service provision.

In fact, a number of certain characteristics distinguish services from typical consumption goods. Grönroos (2000) presents a comparison between physical goods and services (look Table 28).

Table 28. Characteristics of physical goods and services according to Grönroos (2000)

Physical goods	Services
Tangible	Intangible
Homogenous	Heterogeneous
Production and distribution separated in time from consumption	Production, distribution and consumption simultaneous
A thing	An activity or a process
Value produced in a factory	Value produced in interactions between a client and a provider
Client does not participate in the production process	Client participates in the production process
Can be stowed	Cannot be stowed
Transferable from the owner	Not transferable from the owner

Source: Grönroos (2000)

The fundamental difference between a good and a service is a property of intangibility, a lack of physical substance, and this property is a key determinant of the offer. As service is characterized by intangibility, it cannot be touched, felt, tasted or even seen before the moment of its consumption (Grönroos, 2000). Bateson et al. (1978) argue that services are impalpable. As they cannot be touched by a consumer, the vision of their future and final result is confusing. In addition, services generally cannot be counted, measured, tested, or thoroughly evaluated before consumption. The level of standardization is significantly lower than comparing to a product, what results in the heterogeneity. In this way, while describing an experience with a service, a sense of confidence and safety may come to be mentioned. Consumption of a service turns to be a unique experience as a service cannot be provided in the same way in different periods of time. A service is not separated, that is, it is produced and consumed at the same moment of time. It cannot be stowed and transferred from one proprietary to another. Furthermore, customer is directly involved in the process of production of a service, hence, the final value of a service is derived from the interaction between the service provider and the customer (Grönroos, 2000; Philip & Hazlett, 1997). Other scholars (Eiglier, 1977; Zeithaml, 1981) argue that a service is characterized by complexity of its nature, a higher level of perceived risk and a higher cost when switching brands. It is challenging to differentiate a service from its direct competitors as customers tend to group them into categories rather than according to brands (Eiglier & Langeard, 1977).

Supporting these viewpoints, Grönroos (2007) mentions three particular characteristics of a service: it is a process consisting of an activity or a series of activities; to some extent its production and consumption are simultaneous; and a customer plays an active role in the production process.

3.2. Concepts of service quality and satisfaction

Since the 1970s there has been a significant rise of interest in investigating concepts and dimensions of service quality (Grönroos, 2000) and satisfaction. At first, both of these concepts seem and are frequently thought to represent the same construct deriving from the service performance assessment. Little attention by resorting available body of literature allows to comprehend these are two distinctive albeit interrelated constructs and ought to be well defined before any discussion regarding them may take place.

3.2.1. Service quality notion

A concept of quality brings in itself a definition partiality derived from a subjective opinion of an evaluator. Perceived quality is defined as a consumer’s judgment about an entity’s overall experience or superiority (Zeithaml, 1987). In the service area, measuring service quality is more complex due to characteristics of a service (Parasuraman, Zeithaml, & Berry, 1985) and, as quality is very superficial and subjective, it is difficult to evaluate precisely or take a direct control over a service (Yoo, 1996). Perceived service quality could be a product of evaluations of a number of service encounters. An organization that regularly and clearly provides service at a level that surpasses consumer expectation is evaluated as the one of high quality. On the other hand, if an organization fails to meet consumer's expectations, a service will be judged as of poor quality (Zammuto, Keaveney, & O'Connor, 1996).

Webster (1989) comprehends service quality as a measure of how well a provided service matches customers' expectations on a reliable foundation. Parasuraman, Zeithaml and Berry (1985) write: "service quality as perceived by consumers stems from a comparison of what they feel service firms should offer (…) with their perception of the performance of firm providing the services. Perceived service quality is therefore viewed as the degree and direction of discrepancy between consumer's perceptions and expectations" (pp. 16-17). Perceived quality is a global judgment or attitude related to the service. It involves a subjective reaction and is therefore highly relativistic. It is a form of attitude and results from a comparison of prospects with insights of performance (Parasuraman, Berry, & Zeithaml, 1988). Bitner and Hubbert (1994) propose that service quality is "the consumer's overall impression of the relative inferiority/superiority of the organization and its services" (p. 77). Grönroos (1984) holds that perceived quality of a given service as the result of an evaluation process, [in which] the consumer compares his expectations with his perception of the service received; in other words, he places the perceived service and the expected service opposite one another (p. 37).

Parasuraman, Zeithaml and Berry (1985, p. 42) suggested three underlying themes after having reviewed the previous writings on services:

a) service quality is more difficult for the consumer to evaluate than goods quality;

b) service quality perceptions result from a comparison of consumer expectations with actual service performance; and

c) quality evaluations are not made solely on the outcome of service; they also involve evaluations of the process of service delivery.

Literature review and empirical findings suggest that service quality is a construct that should be approached and measured as an attitude (Cronin & Taylor, 1992) related to, but not the same as satisfaction, and resulting from a comparison of expectations with perceptions of occurred performance (Rowley, 1996).

Sasser, Olsen and Wyckoff (1978) list seven service attributes which they believe adequately embrace the concept of service quality. These attributes encompass security – confidence as well as physical safety; consistency – receiving the same each time; attitude – politeness and social manners; completeness – ancillary services available; condition – status of facilities; availability – access, location and frequency; and training (Philip & Hazlett, 1997).

Zeithaml, Parasuraman and Berry (1990) make an interesting discussion on leadership and service quality. Leadership plays a fundamental role in delivering an excellent service and strong management commitment to service quality stimulates an organization to an improved service performance. There are some features of service leadership that are worth to generalize:

a) Service vision. Service leaders "see service quality as a success key" (p. 5). Service excellence is a process of a constant improvement and there is no stage that makes the process slow down. Service is a tool toward a profit strategy and an integral rather than a peripheral part of an organization;

b) High standards. An interest driven into small actions and details of a service, and achieving the objective at the first attempt are always profitable. High standards of a service create true customers, happy to use the service again in the future and speak to others about the positive experience;

c) In-the field leadership style. Service leaders are visible to people they cooperate with, they take an active role in approaching decisions and actions emphasizing communication. Teamwork climate within an organization creates an excellent unit rather than an excellent employee, and quality of work and quantity of employees engaged actively in the excellence of process delivery are a premise to consumer satisfaction;

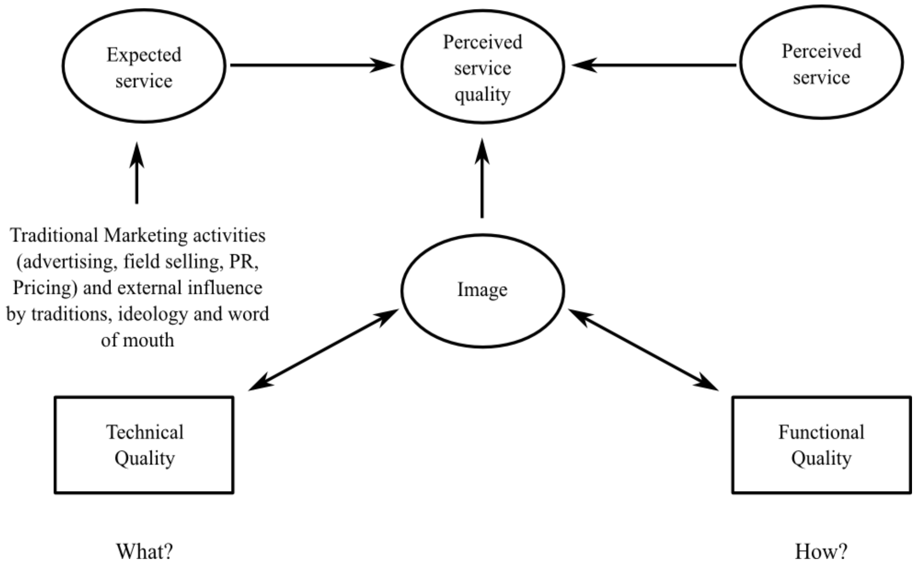
d) Integrity. Personal integrity of leaders in service organizations allows them to follow right choices and decisions even bearing in mind their inconvenience.

Literature is predominantly goods-oriented and contributions toward services have been arising in a larger number in recent years. There are distinctive characteristics applied into studies on goods and services what makes an analysis obligatorily separate. Services are perceived by customers as more difficult to evaluate what makes them more challenging to approach by researchers. Customers do not evaluate service quality uniquely on basis of outcome of a service. In case of services, a process of service delivery plays a remarkably significant role and should be considered in the conception phase. The only criteria that count in the service quality assessment are the ones defined relatively by customers and only customers may judge quality. Other judgments pointing at service quality are for all intents and purposes irrelevant (Zeithaml, Parasuraman, & Berry, 1990).

3.2.2. Models of service quality

A concept of perceived service quality was introduced by Grönroos in 1982 (Grönroos, 2000) together with a subsequent model of perceived service quality (Grönroos, 1984). The basic premise of this model is that total perceived quality is satisfied when quality experienced by a customer equals expected quality.

Grönroos (1984) holds that service quality is made up of three dimensions 'the technical quality of the outcome', 'the functional quality of the encounter' and 'the company corporate image'. The model assumes that expected quality is derived from several sources, including communication and marketing, image of a company, price of a product, word-of-mouth communication, and needs and values of a client. It is vital to manage the difference between what a client hopes and expects to receive and what is actually provided in order to make this difference as small as possible and create a positive experience. Grönroos model is presented in Figure 13.



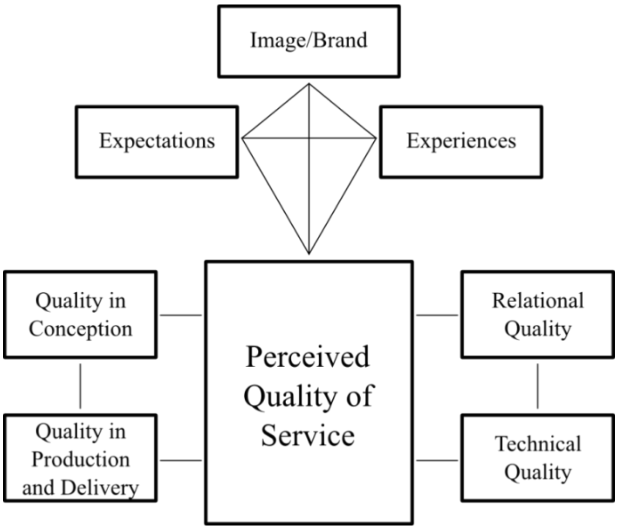
Source: Grönroos (1984)

Figure 13. Grönroos's (1984) model of service quality

Experienced quality encompasses two dimensions: technical quality and functional quality. Technical quality relates to a result, which is an effect that a customer obtains through the service. Functional quality is related to a process, a way through which the service has been delivered to a customer. Both of these dimensions have the same weight in the model since what a client obtains through the service is as important for the final evaluation as a manner of service provision. Usually, the technical dimension of service delivery is deemed to be more objective than the functional dimension (Grönroos, 1984).

Grönroos (2000) considers also a strong impact of an image of a company on perceived quality, which is the third component of service quality. While a good image may raise higher expectations toward further experience with a company, it limits customer's acceptability of possible errors. A customer will unlikely accept failures from a company with a good image. In contrast, a negative image will not have such a strong impact on perception of quality. Image is then of great importance for all service companies.

4Q model of offering quality was developed subsequently by Gummesson (1987). This model puts expectations and experiences of a customer in its base and adds a brand and image as additional variables. The model is depicted in Figure 14.



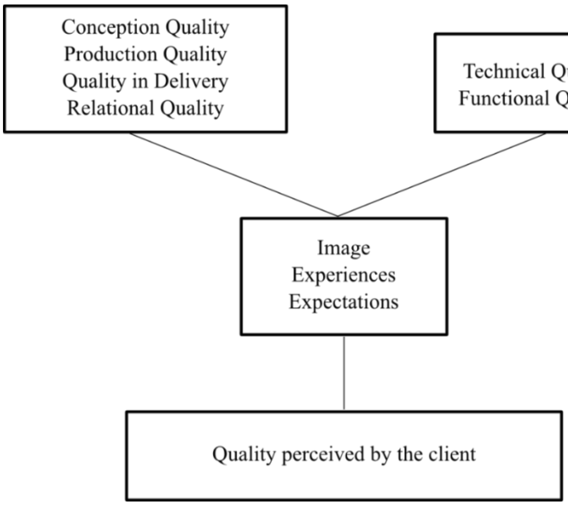
Source: Gummesson (1987)

Figure 14. 4Q model of offering quality of Gummesson (1987)

Perceived service quality depends on four factors; from one hand it depends on quality in conception and quality in production and delivery, and on the other hand, on relational quality and technical quality.

Quality in conception refers to a form in which separate elements of a product (good or service) are developed and conceptualized into a functional pack. Quality in production and delivery deals with a posterior phase and refers to a way in which this pack is produced and delivered comparing to its original concept. Relational quality refers to quality perception experienced by customer during the process of delivery. Relational quality is therefore enhanced by elements focusing on the customer, attention and competence. Technical quality refers to a product on its own and includes benefits and advantages for the customer, in both, short and long term.

With an emphasis on achievements of the total perceived quality of Grönroos model and the 4Q model of offering quality of Gummesson, the model of quality of Grönroos-Gummesson was designed. For Grönroos and Gummesson (1990), perceived quality is influenced from one hand, by quality in conception, quality in production, quality in delivery and relational quality, and, on the other hand, by technical quality and functional quality. All these elements have an impact on expectations, experiences and an image of a company (look Figure 15).



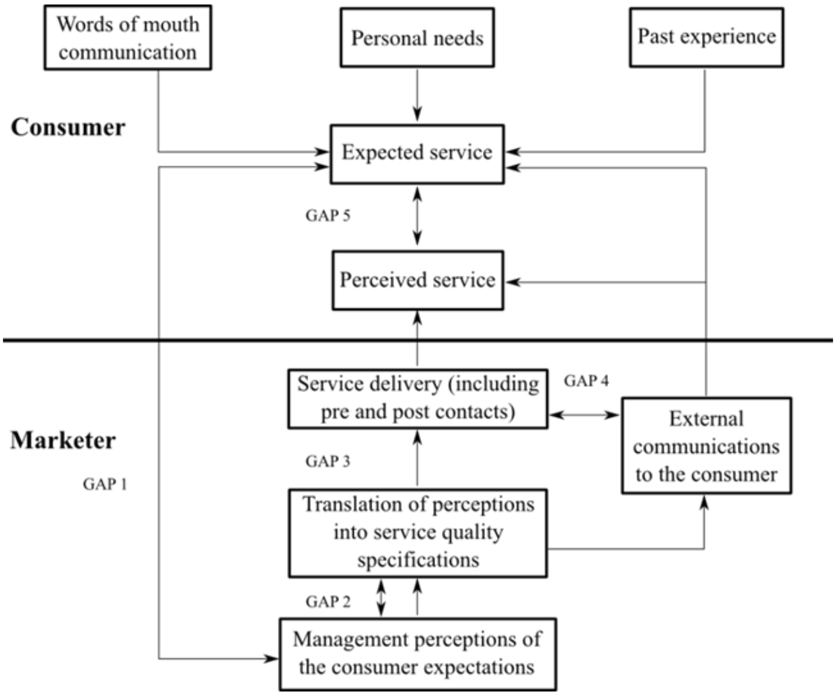
Source: Grönroos (1990)

Figure 15. Grönroos-Gummesson model of quality (1990)

A conception of a product is a starting point of a product delivery process and influences technical quality and functional quality. A production phase of a product influences functional quality and establishes technical quality. In case of a service, a client is present in the production process and actively participates in the production of a service. This way, a perception that a customer has about the production process influences functional quality. A delivery process influences functional quality and, in case of services, occurs simultaneously with the production. Relational quality is directly related with functional quality and relies on relationships between the product provider and the client.

The model considers an importance of expectations of a customer toward a product, and experiences with a use of a product, which have an impact on perceived quality. The third element, an image, is also approached as it influences quality perceived by a customer, as well.

As it can be seen, a significant position in quality models is occupied by factors of expectations and experiences. Basing on the model of satisfaction of Oliver (1980), which assumes that satisfaction of a customer is a function of difference between performance and expectation, Parasuraman, Zeithaml and Berry (1985) developed the model GAP of quality. This model proposes measuring a difference between expectation and performance along the quality dimensions and is presented in Figure 16.



Source: Parasuraman, Zeithaml, & Berry (1985)

Figure 16. GAP analysis quality model of Parasuraman, Zeithaml and Berry (1985)

According to this model, service quality is a function of perception and expectation, and can be modeled as:

$$SQ = \sum_{j=1}^{k} (Pij - Eij)$$

where:

SQ = overall service quality; *k* = number of attributes;

Pij = performance perception of stimulus *i* with respect to attribute *j*;

Eij = service quality expectation for attribute *j* that is the relevant norm for stimulus *i*.

A difference between the perception of performance and the expectation is considered a measure of customer satisfaction and a measure of service quality toward a specific dimension. These quality dimensions are generic features of the service divided into items, which result in a total sum as a whole service from the point of view of a customer.

Similarly to previous models, this one includes expectations, which are internal patterns used by customers in order to evaluate quality of a given experience. Expectations, as the model states, are influenced by factors such as word-of-mouth communication, previous experiences and personal needs of a customer (Parasuraman, Zeithaml, & Berry, 1985).

The first gap explains discrepancy between consumer's expectations and management's perceptions of those expectations. It is crucial that managers realize what customers expect from the organization and its activity in order to provide what is hoped to provide and minimize this gap.

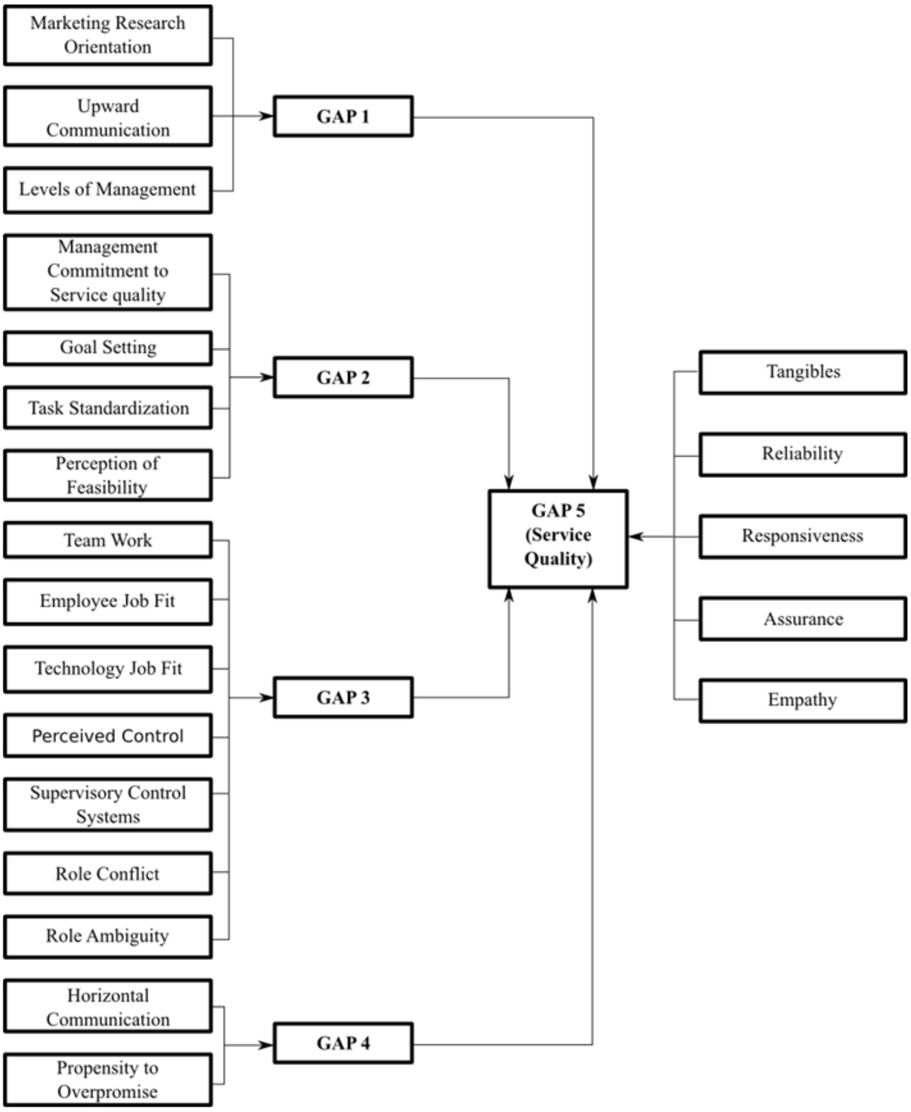
The second gap shows a difference between management's perceptions of a consumer's expectations and service quality specifications. Knowing what a customer expects turns to be insufficient as it is vital to put in practice (production) identified expectations.

The third gap relates to a difference between service quality specifications and the service that has actually been delivered, that is, the performance gap. Several elements may come in cause in discussion of this dimension, all related with the proper organization.

The fourth gap shows a discrepancy between service delivery and communication to consumers about service delivery. Quality and quantity of information exchange with customers is necessary to be discussed when considering a difference between what is told to be delivered and what has been promised to be delivered.

The fifth gap explains a difference between consumer's expectations and the perceived service. While the first four gaps are related with an organization, this one is associated with a client. This gap depends on a size and a direction of four gaps associated with service quality of the marketer's side and contains the essence of the whole model. If a client is not provided a service according to previous expectations, the resulting disappointment may provoke a weak perception of service quality.

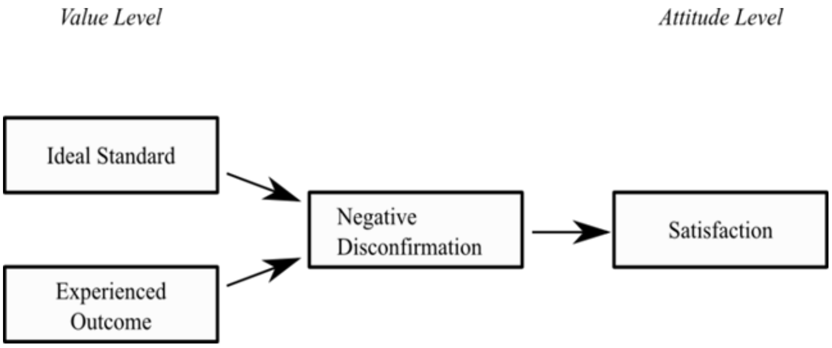
In 1988, the four gaps were further delineated, what led to creation of the extended quality model, which is depicted in Figure 17. In this model, the attention was given to communication and control process as the performance base for the organization.



Source: Zeithaml, Berry, & Parasuraman (1988)

Figure 17. Extended model of service quality of Zeithaml, Berry and Parasuraman (1988)

In 1992, Mattsson developed an ideal value model of service quality. The model, presented in Figure 18, calls for a value approach to service quality and deems it an outcome of satisfaction process. At the value level, two factors are considered: ideal standard and experienced outcome. The model suggests the use of an ideal standard toward the experience and a comparison between them. It demonstrates that a negative disconfirmation determines satisfaction on the attitude level; hence, this negative disconfirmation is the key determinant of consumer satisfaction (Mattsson, 1992).



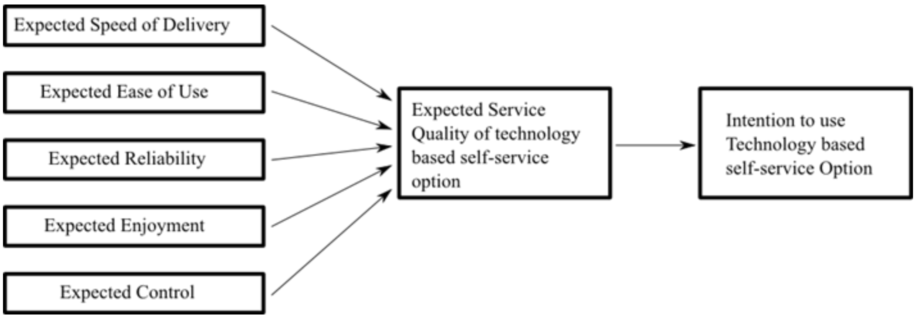
Source: Mattsson (1992)

Figure 18. Value and attitude in negative disconfirmation – Mattsson's (1992) model of service quality

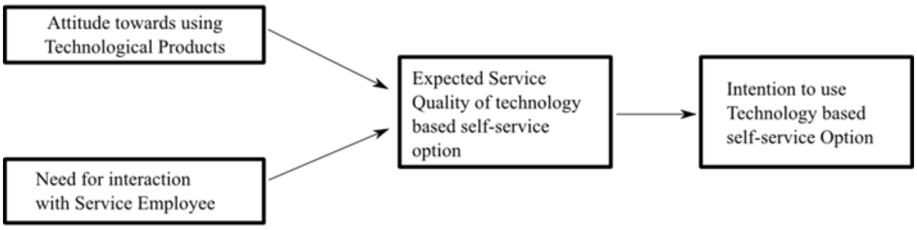
Dabholkar (1996) proposed two alternative models of service quality for technology-based options in self-services, in which expected service quality might influence intentions to use technology-based service option. Self-services are becoming nowadays especially popular given savings in service delivery costs. Figure 19 provides a graphical representation of Dabholkar's models.

The attribute model is based on what consumers expect from a self-services option. It differentiates expected speed of delivery, expected ease of use, expected reliability, expected enjoyment and expected control as determinants of expected service quality, which, in turn, conditions an intention to use a technology-based self-service option.

The overall affect model is based on a consumer's feeling toward the use of technology. It employs an attitude toward using technological products and a need for interaction with a service employee to determine expected service quality of a technology-based service option, which may lead (or not) to an intention to use this technology-based option.



(a) Attribute based model

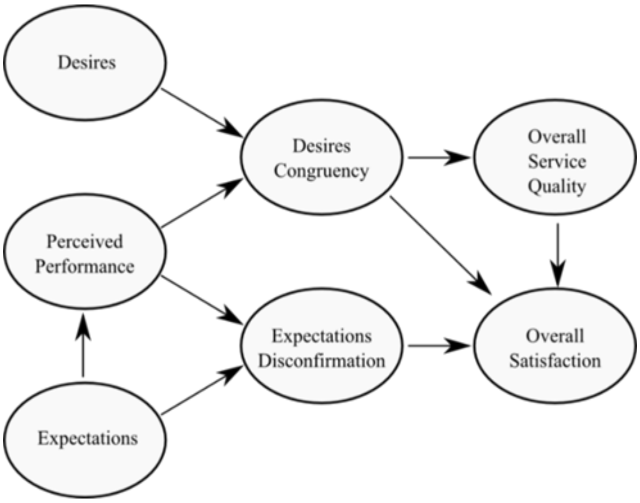


(b) Overall affect model

Source: Dabholkar (1996)

Figure 19. Attribute based and overall affect models of Dabholkar (1996)

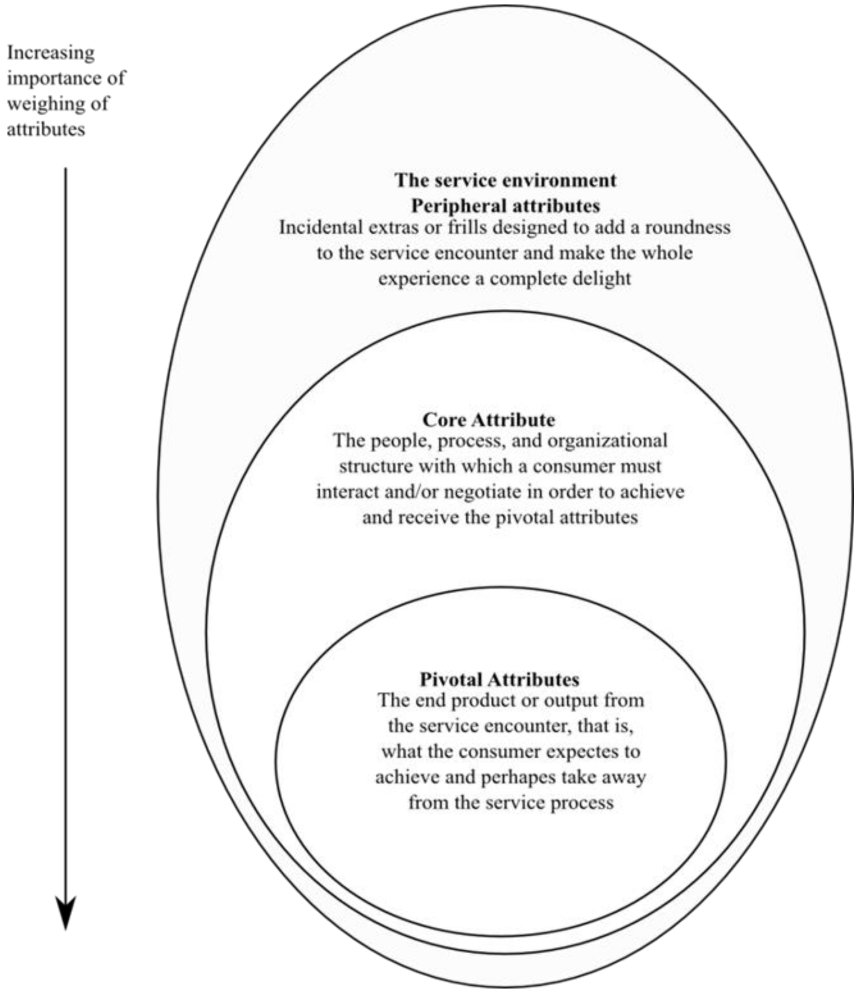
The model of perceived service quality and satisfaction proposed by Spreng and Mackoy (1996) aims to deepen the understanding of factors that influence service quality and consumer satisfaction. The model envisages effect of expectations, perceived performance, desires, desired congruency and expectations disconfirmation of overall service quality and overall satisfaction. It is presented in Figure 20.



Source: Spreng & Mackoy (1996)

Figure 20. Satisfaction service quality model of Spreng and Mackoy (1996)

The authors of the PCP attribute model, Philip and Hazlett (1997), propose a form of a hierarchical structure according to an increasing importance of attributes weighting. They distinguish three classes of attributes: peripheral attributes, core attributes and pivotal attributes. Every service in consideration consists of these three overlapping areas. Philip and Hazlett's model is depicted in Figure 21.



Source: Philip & Hazlett (1997)

Figure 21. PCP attribute model of Philip and Hazlett (1997)

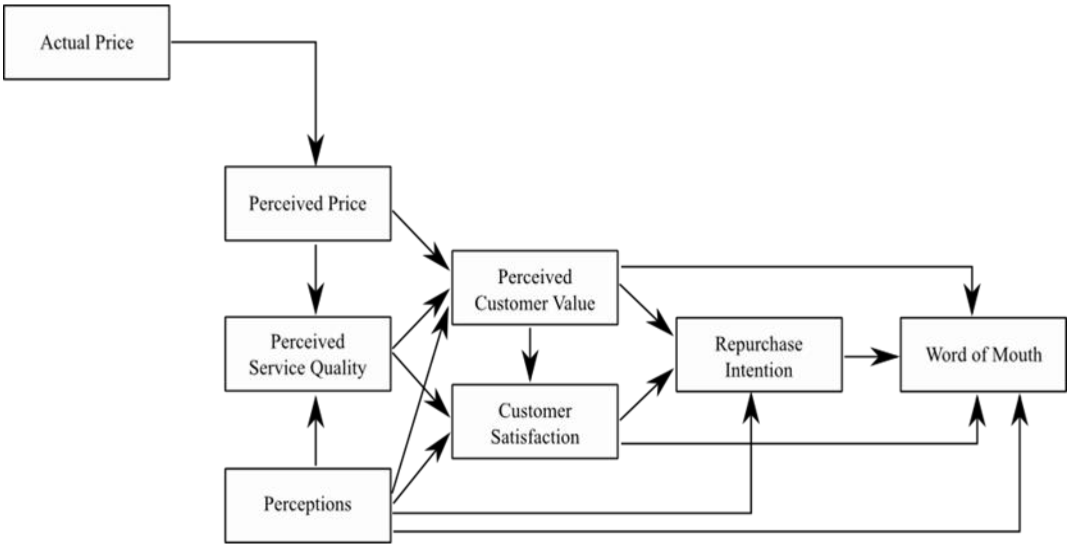
Pivotal (output) attributes are located at the core of the model and determine why a consumer decided to approach a given organization seeking a contact through its products, and have the highest weight in influencing the ultimate satisfaction level. The attributes are defined as what a consumer expects to receive and achieve though a contact with a company product.

Core attributes are centered on pivotal attributes and can be understood as people, processes and the organizational structure with which a consumer needs to interact in order to achieve or receive pivotal attributes.

The third type of attributes focuses on peripheral attributes which can be defined as extras, able to make delightful a total experience of a consumer. These extras are frills designed to add roundness to the service encounter.

A starting point to every product assessment are pivotal attributes and their achievement, however, with a more frequent use, core and peripheral attributes can come to gain a higher level of relevance.

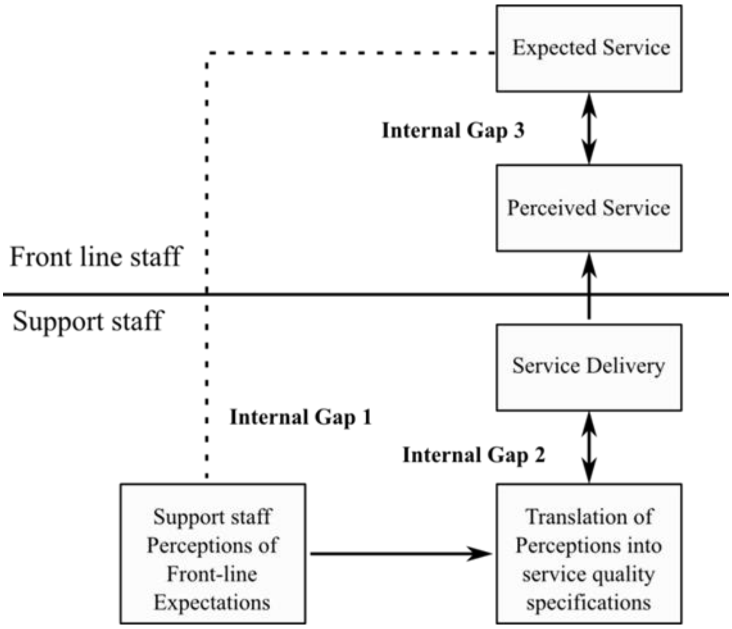
Oh (1999) developed the integrative service quality, customer value and customer satisfaction model. This model focuses mainly on post purchase decision process. The key constituents of the model are perceptions, perceived customer value, customer satisfaction and repurchase intention. It assumes that perceived price and perceived service quality exert direct influence on perceived customer value. Furthermore, perceived service quality and perceptions influence directly customer satisfaction. Finally, word-of-mouth communication is conceptualized as a direct, combined function of value, perceptions, customer satisfaction and repurchase intentions. Figure 22 presents Oh's (1999) model.



Source: Oh (1999)

Figure 22. Model of service quality, customer value and customer satisfaction of Oh (1999)

Frost and Kumar (2000) created the internal service quality model that was based on the concept of the GAP model (Parasuraman, Zeithaml, & Berry, 1985) and applied it initially in a large service organization. The model evaluates dimensions and their relations that influence service quality among internal customers (front-line staff) and internal suppliers (support staff) within an organization. The graphical representation of the model is provided in Figure 23.



Source: Adapted from Frost & Kumar (2000)

Figure 23. The internal service quality model of Frost and Kumar (2000)

The first internal gap in the model depicts a difference between the support staff's (internal supplier) perceptions and front-line staff's expectations (internal customers). The second internal gap demonstrates a difference between service quality specifications and the service actually delivered, what brings an internal service performance gap. The third internal gap focuses on front-line staff and portrays a difference between front-line staff's expectations and support staff's perceptions of service quality (Frost & Kumar, 2000).

3.2.3. Instruments measuring service quality

Together with a question of service quality, the attention should be driven into measurement techniques and underlying them measurement instruments applied in empirical research. This section presents two most important and globally recognized service quality measurement instruments: SERVQUAL and SERVPERF.

3.2.3.1. SERVQUAL

The GAP model of service quality is considered a good tool for measuring a discrepancy between a service which is actually delivered to a consumer and perceptions of this service from the point of view of this consumer. The SERVQUAL is a measure of service quality developed by Parasuraman et al. (1988) which intends to comprehend different dimensions of perceived service quality and thus can be generalized to any type of service.

For the authors of the instrument, initial research relied on determinants of service quality, which they investigated within ten dimensions: reliability; responsiveness; competence; access; courtesy; communication; credibility; security; understanding the customer; and tangibles (Parasuraman, Zeithaml, & Berry, 1985). Afterwards, items questioning for and explaining each of the dimensions were developed, consisting, in the first attempt, of 97 statements.

The SERVQUAL was based on ten underlying dimensions and these could be defined as (Zeithaml, Parasuraman, & Berry, 1990):

a) tangibles – appearance of physical facilities, personnel and communication materials;
b) reliability – ability to perform the promised service dependably and accurately;
c) responsiveness – willingness to help customers and provide prompt service;
d) competence – possession of the required skills and knowledge to perform the service;
e) courtesy – politeness, respect, consideration and friendliness of contact personnel;
f) credibility – trustworthiness, believability, honesty of the service provider;
g) security – freedom from danger, risk,or doubt;
h) access – approachability and ease of contact;
i) communication – keeping customers informed in language so that they could understand, and listening to them; and
j) understanding the customer – making the effort to know customers and their needs.

According to Parasuraman, Zeithaml and Berry (1985), these ten characteristics of service quality contribute to both, the expectations of the service to be provided, as well as to evaluation of the service when that is received.

At that point of research, ten original dimensions of service quality collapsed into five dimensions and remained in the structure: the tangibility aspects of the service; the reliability of the service provider; the assurance provided by the service provider; the responsiveness of the service provider; and the service provider’s empathy with customers. The SERVQUAL was revised in 1991 by replacing the expression ‘should’ by ‘would’ and changing the negatively worded items from the original version to a positive format. The change for ‘would’ in the expectations part was made because the authors argued that the word ‘should’ might lead to unrealistically elevated expectations scores. Further changes to the SERVQUAL instrument were also made by distinguishing between desired and adequate service, and including into the measure these both levels of expectations (Zeithaml, Berry, & Parasuraman, 1993; Berry & Parasuraman, 1997).

The SERVQUAL has been proven to be a well-developed, multi-item instrument of acceptable reliability and validity (Parasuraman, Berry, & Zeithaml, 1988). Nyeck et al. (2002) have stated the SERVQUAL measure remains “the most complete attempt to conceptualize and measure service quality” (p. 101). However, while some scholars have appointed the SERVQUAL as reliable and valid, others have argued it is ambiguous in its measurement of service quality (Bowers, Swan, & Koehler, 1994). Especially, Bowers, Swan and Koehler (1994) have disputed that the SERVQUAL is not a sufficient instrument to measure service quality in health care since it was developed originally for other industries. However, the instrument has been, in fact, used over decades for a multiplicity of services, from banking, financial services, and education to health services as well, among others (Nyeck et al., 2002).

3.2.3.2. SERVPERF

The SERVPERF arose as a subsequent instrument to measure service quality as a result of work of Cronin and Taylor (1992). The authors focused their research interest on conceptualization and measurement of service quality, and its relationship with consumer satisfaction and purchase intentions.

At first, the objective of Cronin and Taylor was to seek an alternative model to the one proposed by Parasuraman, Berry and Zeithaml (1988). It was considered that there was few, either theoretical or empirical body of evidence justifying application of the gap theory for the difference between expectations and performance as basis for a service quality measure construction. The conclusion of the authors appointed perceptions as a better predictor of service quality.

Cronin and Taylor (1992) have argued that the SERVQUAL enhances confusion between satisfaction and attitude and that service quality can be approached as similar to an attitude. According to the authors, service quality is a form of consumer attitude and what determines service quality is performance rather that a difference between performance and expectations.

Service quality in this understanding is calculated according to the formula:

$$SQ = \sum_{j=1}^{k} Pij$$

where:

SQ = overall service quality;

k = the number of attributes;

Pij = performance perception of stimulus i with respect to attribute j.

The SERVPERF has received significant conceptual and empirical support in services research (Lee, Lee, & Yoo, 2000). In a more recent study, Brady, Cronin and Brand (2002) have replicated and extended Cronin and Taylor's (1992) work confirming the superiority of the SERVPERF as a more appropriate method for measuring service quality. The authors have specifically stated that the SERVPERF outperforms the SERVQUAL in terms of capturing the variance in consumers' overall perceptions of service quality and validating the conceptualization of service quality as an antecedent of consumer satisfaction (Zhou, 2004).

Page and Spreng (2002) have conceptualized a direct link between an individual good/service attributes and satisfaction. They have tested alternative models, including a difference score effect model and a direct effect model and, in both service and good settings, the authors have demonstrated that performance attributes are much stronger predictors of satisfaction compared to expectations, and further confirmed the performance-only model to be superior (at the attribute level) (Zhou, 2004).

The SERVPERF appears to be an interesting alternative to the SERVQUAL with an ease of use, as the number of items was reduced to a half. The original items employed by Cronin and Taylor (1992) from Parasuraman, Berry and Zeithaml (1988) were deemed sufficiently well developed in order to be maintained in the empirical part of the research. The instrument has been considered to be more efficient (Cronin, Steven, & Taylor, 1994) and analysis of structural models developed on basis of the SERVPERF has pointed into a theoretical superiority of the scale.

3.2.4. Concept of satisfaction

While there is not a clear consensus regarding the definition of satisfaction, most would involve "an evaluative, affective, or emotional response" (Oliver, 1989, p. 1). Satisfaction is defined as a response from a consumer. In other words, it is a judgment about whether a particular good or service conveys to a satisfactory level of realization related to consumption including upper and lower levels of achievement (Oliver, 1980). This definition calls for a specific attention for two reasons. Firstly, it focuses on a consumer and not, as expected, on a client. A consumer is a person using the product, while a client is only who effectively pays for it. A client might not necessarily become a consumer. Secondly, it admits that satisfaction has a lower and an upper boundary, what brings a researcher to the conclusion that satisfaction is a concept with its limits. Oliver (1993b) states that “these terms illustrate the point that satisfaction implies a filling or fulfillment” (p. 72). Klaus (1985) defines satisfaction as “the customer’s subjective evaluation of a consumption experience, based on some relationship between the customer’s perceptions and objective attributes of the product” (p. 21). For Howard and Sheth (1969) client satisfaction is the cognitive state to be appropriately rewarded for a ‘sacrifice’ committed in the purchase process.

Satisfaction is perceived to be related to psychological outcomes. Mannell and Kleiber (1997) note that “psychological outcomes and benefits” (p. 185) have been used by researchers to describe the social psychological process that satisfaction represents. Customer satisfaction is the leading criterion for determining quality that is actually delivered to customers together with an accompanying service. Satisfaction is however not a universal phenomenon and not everyone gets the same satisfaction level out of the same experience.

While there has been a substantial increase of interest in satisfaction and, consequently, a growing body of literature encompassing this interest, comparatively less attention has been paid to customer satisfaction/dissatisfaction with services (Lietchty & Churchill, 1979). Czepiel et al. (1985) suggest that satisfaction with a service is a function of satisfaction with two independent elements. These are: the functional element and the performance-delivery element, i.e. a service. What allows for a judgment on a level of satisfaction with both, a good and a service experience is denominated the disconfirmation paradigm.

The disconfirmation paradigm holds that predictions customers make in advance of consumption act as a standard against which they measure the organization’s performance. It postulates that satisfaction should be approached as a gap between expectations of a client toward a service to be experimented and an effective execution of this service (Oliver, 1980). The disconfirmation paradigm is a process based on three key elements: (a) some basis of evaluation (may be approached as expectations toward service performance); (b) comparison of expected performance with perceived performance; (c) post-purchase verdict was perceptibly better or worse, leading to a feeling of satisfaction of dissatisfaction (Hill, 1986). An expectation is a belief that a product either possesses a certain characteristic or may lead to a certain outcome with its use (Olson & Dover, 1976). Expectations are compared to perceived performance to arrive at an appraisal. In this way, a certain level of satisfaction/dissatisfaction deriving from every unique experience is perceived. More specifically, an individual’s expectation can be (a) positively disconfirmed when performance exceeds expectations; (b) negatively disconfirmed when performance does not reach a level of expectations; and (c) confirmed when performance is approximately equal to expectations. Satisfaction therefore can be defined as evaluation resulting from the fact that experience has been at least as good as it was expected to be.

A body of research has been dedicated to investigating the concept of satisfaction, its antecedences and consequences. A review of literature has revealed over 40 different instruments used to measure consumer product or service satisfaction, from retail to airline settings (Haddrell, 1994 cited in Danaher & Haddrell, 1996).

Scholars point out that antecedences of satisfaction are expectations and performance (Anderson & Sullivan, 1993) or service quality (Cronin & Taylor, 1992). Cuthbert (1996) in his study argues that the most important contributor to satisfaction constitutes actually the service encounter. The most commonly mentioned consequences of satisfaction are loyalty, reduction in the price elasticity, increase in a number of clients, better reputation, and lowering the transaction costs (Anderson, Fornell, & Lehmann, 1994).

3.2.5. Relation between service quality and satisfaction

Research on service quality, satisfaction and service value has dominated services literature in last decades. Both conceptual and operational root has given special attention to identifying a relationship among and between these constructs (Cronin, Brady, & Hult, 2000) and a nature and direction of a relationship between service quality and customer satisfaction has been subject of a particular debate (Cronin & Taylor, 1992).

There is quite a fuzzy relationship between concepts of service quality and satisfaction nowadays. Both of them pretend in fact to evaluate a process of a service delivery from the point of view of a consumer. Service quality and customer satisfaction have both been defined as matching the expectation of a service with what has actually been experienced by a customer. However, differences between these terms should be acknowledged.

The conceptualization and operationalization of service quality has a more recent heritage than satisfaction. It was initiated by Parasuraman, Zeithaml and Berry (1985), but it also stemmed from the expectancy-disconfirmation paradigm proposed by Oliver (1980). Parasuraman, Berry and Zeithaml (1988) argued that service quality is “related but not equivalent to satisfaction” because “perceived service quality is a global judgment, or attitude, relating to the superiority of the service, whereas satisfaction is related to a specific transaction” (pp. 15-16). Swan and Combs (1976) postulated that consumers make judgments on a set of product attributes, some of which are relatively important in determining satisfaction.

Oliver (1993a) identified few major elements that differentiate between service quality and satisfaction. It was suggested that dimensions that comprise opinions on quality are quite specific to delivered service. Satisfaction can be determined by a broader set of elements, also from those that come from outside the immediate service delivery. Quality is deemed to be determined more by external cues while satisfaction is determined by conceptual cues. Judgments of service quality do not depend on experiences with the service environment or service providers and those of satisfaction do. Finally, service quality judgments are made based on ideals and excellence in relation to service delivery, while satisfaction judgments are based on predictions/norms for service delivery (Ting, 2004).

Oliver (1980) suggests that in the absence of prior experience with a specific service provider, expectations define an initial level of perceived service quality and the first contact with the service allows for a revision of that initial level of service quality. Further experiences lead to subsequent disconfirmation and modification of the current opinion, changing eventually a level of perceived service quality. Finally, the redefined level of perceived service quality has an impact of a consumer purchase intentions toward the concrete service provider. In this way, Oliver's (1980) research states that service quality and consumer satisfaction are similar but distinct constructs. They are related in that satisfaction arbitrates effects of prior to the experience perceptions on service quality to result in a reviser service quality, derived from the experience.

Previous experience is, in the first place, essential to evaluate satisfaction. While it is necessary to have a direct contact with a product and experiment it in order to make judgments about a level of satisfaction, in case of service quality this requisite is not met. Hence, it is possible to judge service quality without knowing a product from the first hand. Second, satisfaction is influenced by a series of past experiences while service quality usually comes from a specific experience. Third, satisfaction is dependent on a value. On the other hand, service quality can be understood as a ratio between perceived quality and price. It can also be defined as benefits obtained taking into account an expended value (Anderson, Fornell, & Lehmann, 1994).

Zeithaml (1998) argues that when the term 'service quality' is used to refer to a global, long-term attitude toward a service provider, customer satisfaction is generally recognized as an antecedent of quality. In situations where the term is used to refer to something more concrete, such as quality of delivered service, then there seem to exist a stronger tendency for seeing quality as an antecedent of satisfaction. Bolton and Drew (1991) consider satisfaction as an antecedent to service quality, while Patterson and Johnson (1993) state that satisfaction is related to "a specific transaction or consumption experience", and service quality "represents a more global judgment across multiple service encounters" (p. 92). Cronin and Taylor (1992) support the viewpoint that satisfaction ensues service quality offering evidence that service quality contributes to overall satisfaction. They tested that relationship across four industries and reported that service quality had a significant impact on user satisfaction in all four industry samples, while the causal path from satisfaction to quality was not significant. They concluded affirming "service quality is an antecedent to satisfaction" (p. 65). Rust and Oliver (1994) support this position in the suggestion that quality is "one of the service dimensions factored into the consumer's satisfaction judgment" (p. 6). Bloemer and Ruyter (1995) deem that "from a theoretical perspective, the most important finding of our empirical study is that overall satisfaction should be treated as a super-ordinate construct to service quality. From this perspective, quality can be viewed as one of the factors that determine customer satisfaction" (p. 51).

3.2.6. Service quality in health care

Service quality and customer satisfaction have become critically important considerations in delivering health services. As with any other area of research, a clear distinction between concepts of service quality and satisfaction in health services remains challenging. There is a significant difficulty in a definite conceptualization of both definitions (Gill & White, 2009).

Lohr (1990) defines quality of care as a a degree to which health services for individuals and populations increase a likelihood of desired health outcomes and are consistent with current professional knowledge. A number of other proposals of defining quality of care are listed in Table 29.

Table 29. Definitions of quality of care collected by Legido-Quigley et al. (2008)

Author/Organization	Definition
Donabedian (1980)	Quality of care is the kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts.
Department of health (UK) (1997)	Quality of care is: - doing the right things (what) - to the right people (to whom) - at the right time (when) - and doing things right first time.

Council of Europe (1998)	Quality of care is the degree to which the treatment dispensed increases the patient's chances of achieving the desired results and diminishes the chances of undesirable results, having regard to the current state of knowledge.
WHO (2000)	Quality of care is the level of attainment of health systems' intrinsic goals for health improvement and responsiveness to legitimate expectations of the population.

Source: Adapted from Legido-Quigley et al. (2008)

Also, several authors and organizations have defined quality of care by describing the concept according to a set of dimensions. The most frequently used dimensions comprise effectiveness, efficiency, access, safety, equity, appropriateness, timeliness, acceptability, patient responsiveness or patient-centeredness, satisfaction, health improvement and continuity of care. A compilation of commonly used dimensions of quality of care is provided in Table 30. These are, however, neither comprehensive nor mutually exclusive.

Table 30. Dimensions of quality of care as determined by selected authors

	Donabedian (1988)	**Maxwell (1992)**	**Department of Health (UK) (1997)**	**Council of Europe (1998)**	**IoM* (2001)**	**JCAHO** (2006)**
Effectiveness	X	X	X	X	X	X
Efficiency	X	X	X	X	X	X
Access	X	X	X	X		X
Safety	X			X	X	X
Equity	X	X	(X)		X	
Appropriateness	X	X		X		X
Timeliness			X		X	X
Acceptability		X		X		
Responsiveness		Respect Choice Information			Respect Patient-centeredness	
Satisfaction			(X)	X		
Health improvement	X		X			
Continuity					X	
Other		Technical competence Relevance		Efficacy		Availability Prevention/ early detection

*IoM: Institute of Medicine ** JCAHO: Joint Commission on Accreditation of Healthcare Organizations

Source: Donabedian (1988); Maxwell (1992); Department of Health (1997); Council of Europe (1998); IOM (2001); JCAHO (2006) cited in Legido-Quigley et al. (2008)

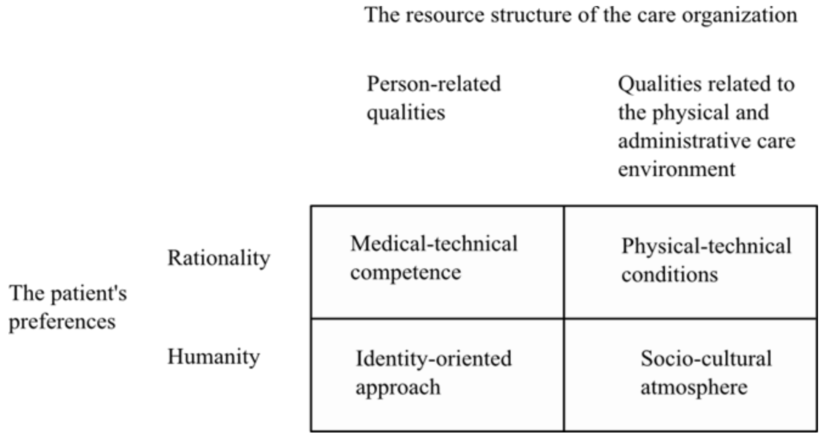
In the health care setting, care entities are deemed to provide the same or similar types of services, however, quality of provided services may vary among them up to diverse levels. Conversely, nowadays patients are not only more aware of alternatives of an existing offer, but rising standards of service have increased their expectations. Patients are becoming more critical on service quality they experience. Patient satisfaction rankings are used to judge quality of care provided by a health care organization, an individual physician's quality of care and to determine physician reimbursement in different settings (Weingarten et al., 1995). Service quality and patient satisfaction can be therefore used as a strategic differentiation tool aimed at gaining a strategic advantage on the care market which other organization will find hard to compete with (Lim & Tang, 2000).

Perhaps the most remarkable research in the area of service quality in health services in the last decades has been that of Donabedian (1988). The author developed a conceptual framework of service quality in health services based on a triad between structure, process and outcome. Structure comprehends all characteristics and features of environment where care is delivered, encompassing material resources, human resources and organizational structure. Process can be understood as actions activated to provide and receive care services. Finally, outcome can be defined as a result, an effect of care services that are carried out, both from the viewpoint of an individual and the whole society. These three elements of the triad are directly and closely interrelated and should be always considered together.

Donabedian (1988) claims that definition of service quality is an indispensable step before making any assessment. This depends on what the focal point of the assessment is, whether it is the performance of practitioners or the contribution of patients and the health care system as well; on how broadly policy makers in a given setting define health and responsibility for health of a citizen; on type of preferences, individual or social, which determine the optimum; and on type of care, the maximally effective or optimally effective, which is sought. Donabedian's approach to describing and evaluating quality of care services has been widely accepted and is probably one of the very few points of consensus in the field of quality of care.

Donabedian (1990) extended the initial framework a few years later and added seven pillars: efficacy – capacity of health care to improve health; effectiveness – the improvements in health that are possible to be achieved; efficiency – the ability to achieve the best possible health condition at the lowest cost; optimization – the most favorable balance between the costs and the benefits; acceptability – consistency with the preferences of a patient in relation to accessibility, doctor-patient relationship, facilities, effects of care and costs of health services; legitimacy – agreement between care and socially defined preferences; and equity – fairness in the distribution of care. In this model, the attention is driven not only to preferences of patients, but also to socially acceptable preferences for ensuring care services for the population.

Wilde et al. (1993) attempted forming a theoretical understanding of quality of care from a patient perspective using a grounded theory approach. The model includes two strands through which the evaluation of quality is made: the resource structure of a care organization and patient's preferences. The resource structure of a care organization consists of person-related and physical- and administrative environmental qualities. The patient's preferences part has a rational and a human aspect. The model is presented in Figure 24.



		The resource structure of the care organization	
		Person-related qualities	Qualities related to the physical and administrative care environment
The patient's preferences	Rationality	Medical-technical competence	Physical-technical conditions
	Humanity	Identity-oriented approach	Socio-cultural atmosphere

Source: Wilde et al. (1993)

Figure 24. Model of quality in health care of Wilde et al. (1993)

Within this framework, patients' perceptions of quality of care may be considered from four dimensions: a medical-technical competence of caregivers; physical-technical conditions of a care organization; a degree of identity-orientation in the attitudes and actions of caregivers; and socio-cultural atmosphere of a care organization (Wilde et al., 1993).

One of leaders in conceptualizing patient satisfaction with health care services has been Linder-Pelz (1982). She has considered patient satisfaction level as a positive evaluation of several different dimensions to be distinguished within health care. Furthermore, the author has suggested measuring satisfaction by means of a procedure that would position a subject in the affective and evaluative dimensions. This assessment would be related to the individual's conviction toward a particular health care attribute and evaluation of this concrete attribute (Gagnon et al., 2006). Pascoe (1983) has perceived patient satisfaction as "a health care recipient's reaction to salient aspects of the context, process, and result of their experience" (p. 189). This view characterizes patient satisfaction as an evaluation of a directly received service.

The evaluation is seen as a comparison between noticeable characteristics of the individual's health care experience to a subjective standard.

3.3. Summary and conclusions

In recent decades there has been a great deal of interest in conceptualization and measurement of consumer satisfaction and perceived service quality, by both, managers and academic researchers. The construct of service quality as conceptualized in service marketing literature centers on perceived quality, defined as a consumer's judgment about an entity's overall excellence or superiority. A special attention has been given to quality and customer satisfaction measurement. A number of measurement instruments have been developed on basis of theoretical constructs and applied empirical studies. Among instruments, those the most commonly used worldwide have been the SERVQUAL and the SERVPERF, with a long-lasting discussion on the superiority on one over another. Concepts of service quality and customer satisfaction have been successfully applied to several industries, including health care. As demonstrated by a wide body of literature, the health services area represents the same challenges to conceptualizing and measuring service quality and patient satisfaction as any other.

This chapter has presented a discussion on the constructs of service quality and satisfaction. It started with the conceptualization of services in the economy and identifying unique characteristics of services. Services are a class of products with features distinctive from goods and can be understood as a series of activities to a lower or higher extent intangible. Subsequently, concepts of satisfaction and service quality together with a number of service quality models and measurement instruments were depicted and presented. While the SERVQUAL and the SERVPERF induce quantitative techniques to measure service quality, attention should also be given to scholars who deem a use of qualitative methods when approaching service quality and customer satisfaction. Finally, the approach to health care services from the point of view of service quality was made.

CHAPTER FOUR:

QUALITY OF LIFE AFTER CEREBROVASCULAR ACCIDENT

A perceived opinion on proper health status is a recommended indicator of health condition of a population (WHO, 1996a). In Portugal, consecutive National Health Surveys have revealed a limited decrease of persons who consider their health condition as bad or very bad and an increase of persons considering their health status as good, in both genders. Interestingly, women judge their health condition as bad and very bad more frequently than men (Ministério de Saúde, 2004). The percentage of persons appreciating good and very good health decreases with age what corresponds to rather bad and very bad perception of health among the elderly (Ministério de Saúde, 2004). Health constitutes also one of factors on basis of which the majority of elder people evaluate their quality of life, next to social contacts, dependency, material conditions and social comparisons (Netuveli & Blane, 2008).

There is a general agreement that effects of treatment should be measured in terms of quantity of survivals but also their quality (Fallowfield, 1990). While the prime concern of an acute state is focused on survival, the next question that arises regards quality of further life. Especially for stroke patients, the question of ‘further life’ gains significance as cerebrovascular accident is a factor leading to morbidity, disability and dependency, what imposes high costs to a patient, a family (both financial and psychological) and health and social care systems (WHO, 2010a).

This chapter provides an overview of the most relevant issues related to quality of life, in the first phase in general terms, and then focusing specifically on the perspective of cerebrovascular accident. Sections 4.1 and 4.2 present historical background and the concept of quality of life, respectively. Section 4.3 discusses the notion of quality of life assembling it with the notion of health-related quality of life. The following Section, 4.4, demonstrates general aspects of quality of life, while Section 4.5 discusses factors that may influence quality of life after stroke with their possible impact on a patient’s life. The further part of the chapter is devoted to the measurement of quality of life. Section 4.6 deliberates a broad-spectrum of questions of quality of life measurement including the employment of general and disease-specific instruments. Section 4.7 focuses on measuring quality of life in patients after stroke, providing the most frequently used measures, as a result of the literature review, and discussing challenges in measuring quality of life in stroke survivors.

4.1. Historical background

The concept of quality of life is entrenched in Greek philosophy. Philosophers of that time mention happiness as the finest objective of a well-lived life thus associating its quality with happiness (Lubben & Gironda, 2004). Over time, the interest in quality of life percolated into economics and politics. The term was used shortly after the II World War to support the idea that quality of life was a concept related to a person's overall well-being rather than simply limited to financial security and defeat of deficit of material resources. Further concerns involved the risk of a negative ecological impact on societies due to uncontrolled economic growth (Ordway, 1953). These economic considerations accompanied a growing political interest in quality of life in the 1960s. The American President L.B. Johnson used the term 'quality of life' in his speech at Madison Square Garden. His Special Message to the Congress on Conservation and Restoration of Natural Beauty, set off a new initiative, by many considered ahead of his times, aspiring at preserving natural areas and guaranteeing air and water quality for the population. As a deep enthusiast of the assumption that a good life derives not from financial security, but from a complex set of aspects related to the status of the surrounding environment, and thus going far beyond the prosperity, Johnson led to passing an exceptional number of laws aimed at protecting the country natural resources, enhancing its people's life quality.

Scientific interest in quality of life intensified in the 1970s. It involved social scientists, economists and politicians, followed by clinicians and policy makers. It was universally acknowledged that quality of life was a multidimensional concept and it could be considered from a variety of disciplines viewpoint. Research on a specific relation between health status and quality of life has been growing, with the first wave in the 1970s, and later, especially from the 1990s. Over time, more and more components have been included as those possibly impacting a person's life quality, such as culture and spirituality, giving place to a growth of disciplines considering quality of life as a source for research and to interesting interpretations of evidence.

Since then, this increasing body of research has become evidently influential in health care services organization and provision, social policy, economic development and education. As a consequence, different definitions of quality of life have arisen from a variety of disciplines.

4.2. Quality of life notion

In its original meaning, quality of life was clearly related to subjectively perceived emotions, such as satisfaction and happiness (Campbell, Converse, & Rodgers, 1976). Early works on quality of life referred to material aspects of living of a society, which automatically determined the living conditions of an individual. In this understanding, quality of life was largely shaped by standard of living, and interest in life of a society surpassed interest in an individual’s choices (Landreth & Colander, 2005). Material and economic perspectives on quality of life were predominant still in the 1940s and the 1950s, starting to shift toward more individual characteristics since the 1960s and involving other than solely social indicators. Over time, the concept seems to have expanded by incuding aspects of physical, psychological, functional and social health (de Haan et al., 1993), providing conceptual overlap with activities of daily living or motor function. Despite conceptual implications, quality of life remains a notion rooted in individual perceptions and values, and capable of contributing to identification of necessary support and services.

In this manner, quality of life has been defined in many different ways, especially among different disciplines. Following the ancient belief, Shin and Johnson (1978) deem happiness to be the fundamental purpose of life, what makes people’s action and choices driven by the search for happiness, and relate happiness with quality of life. It can also be defined as perceived global satisfaction and satisfaction within a number of key domains with a special emphasis on well-being (Hörnquist, 1990). Michalos (2007), among other scholars, uses the term ‘quality of life’ as equivalent to happiness and well-being. Following the results of their empirical study, McKevitt et al. (2003) find happiness to be the main component of quality of life, although not its synonym.

Calman (1984) holds that quality of life can be understood as a gap between an individual’s hopes/expectations and their present experience. Campbell, Converse and Rodgers (1976) define quality of life as a concept characterized by a balance between ‘good’ and ‘bad’ with a reference to an individual’s position and an individual’s perspective towards life. Quality of life has also been described as a degree of needs satisfaction within the areas of physical, psychological, social, activity, material and structural needs (Hörnquist, 1982). Some scholars appoint into satisfaction of needs (Hörnquist, 1982), psycho-social and physical well-being, and health-related subjective experiences (Guyatt & Jaeschke, 1990). One way of resolving the problem of definition is to leave this task to an individual person by simply asking the question: ‘How would you rate your present quality of life?’ (Ahlsiö et al., 1984; Gough et al., 1983).

However, nowadays, the understanding on a multidimensional character of quality of life predominates (Aaronson, 1988). A consensus about the definition of quality of life has yet to be reached, but scholars agree that it is a multidimensional concept, comprising physical, mental and social domains (Buck et al., 2000).

Certain implications arise from the specificity of the definition of quality of life. Calman (1984) emphasizes that quality of life can only be assessed and described as a specific feeling by an individual. Therefore, while taking into account many aspects of life, it must be related to that individual’s goals and objectives, its improvement is related to the ability to identify and achieve these goals, illness and treatment may modify the goals and the goals must be realistic. Moreover, action is necessary to narrow the potential gap, the gap between the expectation and the reality may be the driving force for some individuals and as each of the established goals is achieved new ones are identified opening the gap again. In this manner, quality of life should be considered a process not a state, a continuous search for a gap fulfillment (Calman, 1984).

4.3. Quality of life versus health-related quality of life

Health is an important component of quality of life. Many terms are used interchangeably to discuss status and measures related to the impact of health condition on functional status and well-being. As such, quality of life is frequently used as a synonym of well-being and health-related quality of life (HRQoL). Moreover, many investigators seem to proxy quality of life to other terms intended to describe a patient’s health, such as health status or functional status.

At the broadest level, quality of life may refer to health status only, as well as it may combine environmental and economic factors, such as income or education, which undoubtedly can impact overall well-being. As much as lack of consensus on what ‘quality of life’ represents remains, a boundary between the concepts of quality of life and health-related quality of life is also unclear. Commonly, the terms can be found to be used synonymously.

Overall quality of life may encompass health-related and non-health-related elements. Since overall quality of life includes non-health-related factors, for instance, social relationships, spirituality and other life-related circumstances, but also those that are strongly related with health, namely emotional, mental, physical or functional, in the theoretical discussion on quality of life, overall quality of life should be distinguished from health-related quality of life. In this logic, patients asked to evaluate their quality of life might be invited to evaluate relative contributions of health-related versus non-medical phenomena (Gill & Feinstein, 1994).

The concept of health-related quality of life is a multidimensional approach to quantify patients' burden of disease (Haacke et al., 2006). While it is common to see the use of a term 'well-being' as a synonym of quality of life, it is its narrower viewpoint and constitutes an important albeit not the only aspect of quality of life (Bech et al., 2003). It is recognized that quality of life nowadays calls to include spiritual and religious aspects, of which evidence shows to be universal across cultures, as suggested dimensions of quality of life (WHOQOL Group, 1995).

Health-related quality of life refers to functioning and well-being in physical, mental and social dimensions of life. More specifically, it refers to physical, psychological and social domains of health seen as distinct areas that are influenced by person's experiences, beliefs, expectations, and perceptions (Testa & Simonson, 1996). Health-related quality of life aims therefore to tackle those aspects of quality of life affected by a disease. It reflects the way patients perceive and react to their health status (Gill & Feinstein, 1994). A specific definition of health-related quality of life has also been proposed as of "the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment, or policy" (Patrick & Erickson, 1993, p. 22). The first part of the statement, 'value assigned to the duration of life' reflects how narrow a scope of health-related quality of life is as a valued end-point in health care (Read, 1993).

At present, no common theory of health-related quality of life exists. Measures of physical and cognitive functioning, perceived distress, and performance in activities of daily living are employed to reflect subjective quality of life. Consequently, some critics suggest substituting the term 'health-related quality of life' by 'subjective health status' in order to obtain an indicator of a patient's subjective perspective that would have a clearly defined unambiguous connotation. On the other hand, one study found that health status and health-related quality of life were considered by patients as distinct constructs (Smith, Avis, & Assmann 1999). Smith, Avis and Assmann (1999) argue that while health status was primarily associated to physical functioning, health-related quality of life was more related to mental health. These results highlight a need for further efforts toward theoretical improvement of the concept of health-related quality of life and a development of adequate measurement methods.

Quality of life that regards a health-related factor can be suitably measured only by determining opinions and insights of patients because rather than a basic rating of health status, it is a uniquely personal perception, denoting the way that individual patients feel about their health condition and non-medical aspects of life.

A broad consensus has emerged on dimensions that should be incorporated in the health-related quality of life assessment. It includes physical, functional, psychological and social health. Physical health refers predominantly to disease-related symptoms. Functional health comprises self-care, mobility and physical activity level, as well as capacity to carry out various roles in relation to family and work. Cognitive functioning, emotional status and general perceptions of health, well-being, life satisfaction, and happiness are the central components of the psychological life domain. Finally, social dimension of health includes the assessment of social contacts and interactions (de Haan et al., 1993). These four quality of life domains are also reflected, in part, in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) of the WHO.

The purpose of medical interventions today is to favor the duration of life and to assure its quality (Fassino et al., 2002). HRQoL is a useful concept for determining the efficacy of therapeutic interventions, for gaining a better understanding on reactions to health conditions, more specifically, a given illness, and for enhancing supportive care.

4.4. General aspects of quality of life

Quality of life requires numerous conceptual steps to adapt its theoretical consideration to the clinical area. Koller, Klinkhammer-Schalke and Lorenz (2005) propose four of such premises which encompass: definition of the concept of disease-related quality of life; definition of thresholds, allowing to make a distinction between an acceptable level of quality of life and an unacceptable burden that requires immediate action; availability of comprehensible and action-oriented quality of life diagnostics; and implementation of the quality of life concept and diagnostics into routine patient care, and availability of effective therapeutic options.

The World Health Organization emphasizes that health of populations is determined not by health sector activities alone but by social, economic and environmental factors, and hence by policies and actions beyond the mandate of the health sector. Quality of life relates closely to the definition of health issued by the WHO comprehended as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1946, p. 100). Numerous factors are associated to health and impact health condition in different manners. Gender and socio-economic status are seen as basic, often interacting conditions in health and disease processes. Also, psycho-social factors influence a state of health and link up with gender and socio-economic status as determinants of health. More difficult life conditions and missing resources, poverty and social exclusion are all associated to less healthy lifestyles with difficulties in access to health care services and treatments. On the other hand, these issues related with health lead to worsening socio-economic conditions (Ministério de Saúde, 2004) with a long-term snowball effect and no real perspectives for a solution.

Determinants of health as identified by Health Canada (Public Health Agency of Canada, 2002) are: income and social status; social support networks; education; employment and working conditions; social environment; physical environment; personal health practices and coping skills; culture; healthy child development; health services; gender; and biology and genetic endowment.

During last decades there has been an increasing consensus about the importance of patients' subjective accounts of health in monitoring medical outcomes. In fact, proper essence of quality of life and health-related quality of life is derived from subjectivity. While some components may lead to an objective measurement of the condition and symptoms, only together with a subjective feeling about an impact of such factors the assessment of quality of life can be complete. Objective factors assess a person's general condition, capacities and abilities, and can provide indicators such as weight or blood pressure, or assess a capacity to perform certain tasks. Subjective elements focus rather on feelings related with a specific capacity or condition, general experiences and satisfaction.

Measuring quality of life is useful in gaining a better understanding of patients' reaction to illness and for development of a curative processes, as well as in monitoring the efficacy of medical care. An interpretation of quality of life findings may be complicated due to a wide variety of methods used in evaluation (de Haan et al., 1993). Still, it is vital to consider quality of life measures from institutional and patient perspective. They can offer a great potential in informing economic analyses and resource allocation decisions, and influencing health care policy (Guyatt, Feeny, & Patric, 1993). On a patient's side, quality of life instruments help quantify the result of interactions between received care (Siekierski & Rutkowska, 2008), coping capabilities and received social support.

ICIDH was published in 1980 by the WHO as a tool for classifying consequences of disease, injury and other disorders and effects of these consequences on a patient's life. It is a helpful tool for research on implications of disorders with a long-term or permanent sequel, including stroke. It illustrates how a disease can engage impairment, defined as a loss or abnormality of psychological, physiological or anatomical structure or function. Impairment may lead to disability, defined as a restriction or inability to perform an activity in a way considered normal for a person. Handicap in turn may arise as a result of impairment or disability. Handicap is defined as a disadvantage that restricts or prevents the performance of a role deemed normal (Buck et al., 2000). In light of these considerations, quality of life seems to be located beyond the impairment-disability-handicap continuum.

4.5. Factors influencing quality of life after cerebrovascular accident

The World Health Organization definition of stroke is: “rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” (WHO, 1988). Cerebrovascular accident refers to an injury to the brain that occurs when a flow of blood to brain tissue is interrupted by a clogged or ruptured artery, causing brain tissue to die because of lack of nutrients and oxygen. Arterial blood transports oxygen and nutrients to all cells of the body. When arteries are unable to perform this function due to rupture, constriction or obstruction, the cells nourished by these arteries die.

Medicine considers two forms of stroke: ischemic, which is caused by a blocked blood vessel that supplies blood to the brain, and hemorrhagic, which reflects in bleeding into or around the brain. Hemorrhagic stroke has typically a high initial mortality rate (Hamedani et al., 2001). Ischemic stroke refers to a limited access of the blood supply to the brain and a consequent loss of oxygen and nutrients for brain cells, and accounts for approximately 80% of all stroke cases (Truelsen, Begg, & Mathers, 2000). Ischemic stroke can be further broken down into two subtypes: thrombotic, also called cerebral thrombosis, and embolic, also termed cerebral embolism. The cerebral thrombosis is the most prevalent of ischemic strokes. It can be seen in nearly all aging populations worldwide.

Many risk factors for cerebrovascular accident have been described. They may refer to inherent biological traits, physiological characteristics that predict future occurrence, behaviors, social characteristics and environmental factors that may be physical, geographic or psychosocial. Age and hypertension are the leading factors to thrombotic stroke. Heart disease, obesity, diabetes, smoking, oral contraceptives in women, polycythemia and sleep apnea are also risk factors for thrombotic stroke, as is a diet rich in cholesterol-producing, or fat food. Risk factors for hemorrhagic stroke include high blood pressure that can, over a period of time, cause the ballooning out of arteries known as aneurysm, and also causes the hereditary malformation that produces defective and weakened veins and arteries. Substance abuse is another major cause of hemorrhagic stroke. Stimulants such as amphetamine drugs, cocaine and chronic alcoholism can cause a weakening of blood vessels that can result in hemorrhagic stroke (de Reuck, 2009; Koosam, 2013; Olubunmi, 2007).

Stroke survivors frequently represent lower quality of life than persons who did not suffer cerebrovascular accident. Various empirical studies on quality of life in cerebrovascular accident indicate that physical disabilities have a negative impact on quality of life, but this may not necessarily be a case. Stroke patients with little or no physical dysfunction can also experience compromised life quality (Labi, Phillips, & Gresham, 1980; Viitanen et al., 1988). As relevant as physical disability appears to be a psychological status of a person. Thus, reduced quality of life after stroke appears to be related not only to physical but also to psychological and social domains.

Even with a certain progress in post-stroke recovery, stroke patients have shown over time a deteriorating effect of depression on their quality of life (Angeleri et al., 1993). With frequent one-side motor limitations, patients find it difficult to cope with daily activities and challenges. Especially those who used to conduct active lives before cerebrovascular accident and have been strongly limited in their freedom of movement may present long-term depressive symptoms (Lutz & Young, 2010). A dependency in ADL has been shown to be associated with physical functioning and general health domains of quality of life. Sources of depressive disorders have also been linked to a lack of social support influenced by changes in traditionally strong family ties. Failure to maintain or reestablish social bounds is considered to be an important determinant of poor quality of life. Stroke survivors who can count on social support of kins and non-kins have been shown to represent better outcomes (Wyller et al., 1998). Furthermore, communicative disorders have been found to be significantly associated with poorer quality of life (Kwa, Limburg, & de Haan, 1996).

4.6. Measurement of quality of life

In the traditional approach, health of populations has been measured by mortality or morbidity statistics, consultation rates, or use of services, among others. These measures, however, are acknowledged to have many limitations and last decades have been marked by a growing interest in socio-medical indicators, which have been aiming to assess health in terms of quality of life (Seigmann & Elinson, 1977). While the term ‘quality of life’ is increasingly used in clinical medicine and medical research, it remains rarely defined, what has led to a confusion when measurement of the construct has been attempted. Quality of life is deemed to be a difficult construct to define and, consequently, to measure because cultural, ethical, religious and other personal values influence perceptions of quality of life.

The concept of quality of life encompasses a wider than standard of living set of components: physical and mental health, leisure time, social belonging and, therefore, performing quality of life measures allows a better comprehension of how actual health condition interferes with a person's daily life.

Measuring quality of life, as it is understood and valued from an individual perspective, is usually carried out by identifying what specific aspects have come to be esteemed by an individual and by matching these to an individual's perceptions of personal satisfaction. Quality of life is commonly measured with a complex collection of items, scales, domains and instruments (Gill & Feinstein, 1994). An important fact to emphasize is that all these measures of quality of life are proxies as quality is difficult to quantify. A multiplicity of available quality of life, both generic and disease-specific, tools requires a foregoing analysis of their components and reported robustness in conducted empirical studies, which will lead to a sensible choice having in consideration the individuality of the study sample.

A number of criteria should be considered when a quality of life measure is to be chosen pointing several challenges to quality of life assessment. These criteria comprise reliability, validity, responsiveness to change over time, precision, appropriateness and acceptability (Fitzpatrick et al., 1998). Reliability is the extent to which measurements for the same individual on separate occasions or by different researchers produce similar results. Validity is the extent to which an instrument measures what it is meant to measure. One of the most meaningful indications of validity is the extent to which a relevant patient group was involved in generating the content of a measure. Responsiveness of a measure is its ability to detect even small differences within an individual over time. Precision is a feature concerned with a number and accuracy of distinctions made by a measure, that is, precision of response categories or of numerical values (Fitzpatrick et al., 1998). Precision can also be evaluated by the extent of which ceiling or floor effects influence measurement (Buck et al., 2000). A measure is appropriate if it matches its specific purpose and questions of the trial in terms of the nature of the patient group. Acceptability of a measure is determined by verification of the extent to which a patient finds the measure suitable and tolerable, usually by pretesting it in terms of general structure, taxonomy and response options (Fitzpatrick et al., 1998). In light of these considerations, as indispensable characteristics of a quality of life measure, Fitzpatrick et al. (1992) find multidimensional construct, reliability, validity, sensitivity to change, appropriateness to question or use, and practical utility.

Measures of quality of life can have an objective or a subjective character (Netuveli & Blane, 2008). An objective measure is created on basis of observations external to the patient, such as standard of living or health status. An example of definition of quality of life in its objective dimension points out, for instance, an individual’s command over resources in a form of money, possessions, knowledge, mental and physical energy, social relations, security and so on, through which this individual can control and consciously direct their living conditions (Lawton et al., 1999). A subjective measure is composed on basis of an individual’s responses such as life satisfaction or happiness. A good example of definition of quality of life in its subjective dimension is “an individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment” (WHOQOL Group, 1995, p. 1405) and one of the most common in its use definition of quality of life met in the literature.

4.6.1. Generic measures

Quality of life measures can be classified into (a) generic scales or health profiles; (b) disease-specific scales; and (c) scale batteries (Patrick & Deyo, 1989). Generic measures are developed for general and not specific target population and may be suitable for use with a variety of patient populations. Such measures allow for different types of comparisons across patients groups. They provide a possibility of detecting relative effects of disease and treatment on different life domains. Generic quality of life instruments can be applied across a wide range of populations and interventions, whereas specific instruments are designed to assess quality of life only of particular subpopulations. Disease-specific measures are destined to tailor a specific condition and have been so far developed for several health conditions. While they cannot offer cross-disease comparisons, they are more sensitive to issues particularly relevant among a specific population of patients from the point of view of quality of life. The third option is a battery of scales for measuring a particular dimension or an aspect of health. These can measure activities of daily living, social functioning, and cognitive functioning, among others. By using focused and specific, frequently unidimensional measures, a researcher is allowed to conduct an in-depth assessment of a given life domain. One important disadvantage of such approach is their impossibility for comparisons across studies. For a patient, they may offer unacceptably high burden associated with their completing (de Haan et al., 1993).

Generic measures are designed to compare treatment alternatives for the same health condition or to compare a number of different health conditions, often chronic. Thank to their attributes, they are especially useful for comparing projects and programs, and deciding on health policies (Blaug, 1994).

4.6.2. Disease-specific measures

While generic measures offer an option to be applied to different diseases, conditions, states and populations, a growing interest of scholars has moved into instruments designed specifically to evaluate quality of life in a given health condition. Disease-specific measures assess specific states and concerns of diagnostic groups. They can present more sensitivity to detection and quantification of relatively small changes that are relevant to a certain universe of patients and to clinicians (Patrick & Deyo, 1989). Specific measures, as applied to a specific condition only, allow to study an impact of this condition on a person’s life, also longitudinally (Blaug, 1994).

For cost-effectiveness studies and comparisons of outcomes across different populations and interventions, a choice would rather fall into generic measures. For a comparison between generic and disease-specific instrument from the viewpoint of their advantages and disadvantages, consult Table 31.

Table 31. Strengths and weaknesses of available measures of quality of life in clinical trials according to Guyatt, Feeny and Patric (1993)

Measure	Strengths	Weaknesses
Generic instrument	Is a single instrument Detects differential effects on different aspects of health status Allows for a comparison between interventions or conditions	May not focus adequately on area of interest May not be responsive
Specific instrument	Is clinically sensible May be more responsive than generic instrument	Does not allow comparison between conditions May be limited in terms of population and interventions
Utility measurement	Provides a single number representing net impact on quality of life Allows for the cost-utility analysis Incorporates death	May involve difficulty in determining utility values Does not allow examination of effects on different aspects of quality of life May not be responsive

Source: Adapted from Guyatt, Feeny, & Patric (1993)

4.7. Measurement of quality of life in patients after cerebrovascular accident

In early 1990s, van Gijn (1992) asserted that measurement of outcomes after stroke used to be subject of little formal examination. That situation has changed considerably over time. At present, measurement of quality of life has been considered one of the most important ways to measure outcomes after stroke.

Stroke is an injury that may result in serious physical and cognitive impairment over a long period of time, placing negative effects into patient’s quality of life (Yamakawa et al., 2005). Medical considerations related to cerebrovascular disorder worsen patient’s quality of life and appoint further problems to be solved.

In case of patients with cerebrovascular disorder, the procedure of collecting data requires balancing between response rates and costs, especially those perceived by patients. Possible patient burden should be evaluated and taken into account when designing data collection methodology of any study involving stroke survivors.

4.7.1. Generic measures

Two widely used generic evaluation tools of quality of life are the 36-item Short Form Health Survey and the World Health Organization Quality of Life Assessment, containing 100 items (WHOQOL-100), with its abbreviated version, the WHOQOL-BREF.

The Medical Outcomes Study 36-Item Short-Form Health Survey (the SF-36[7]) is a generic quality of life questionnaire designed in the USA and has been shown to be both, valid and acceptable in a normal healthy population, and reliable across diverse patient groups. The SF-36 was first published in 1986 (Ware & Sherbourne, 1992). It was developed by a group of the RAND Corporation researchers for the Medical Outcomes Study, in an investigation of the functioning and well-being focused on adult patients with chronic medical conditions (Stewart et al., 1989).

The SF-36 is a short, 36-item questionnaire which measures eight dimensions of health status, covering three aspects of health of major concern to individuals: functional status, well-being and the overall evaluation of health. In total, 35 of the items contribute to these states and a further unsealed single item questions about a change in health status over the previous year (O’Mahony et al., 1998). Thus, the SF-36 items represent multiple operational definitions of health, including function and dysfunction, distress and well-being, objective reports and subjective ratings. Most of the SF-36 items have their roots in instruments that have been in use since the 1970s and 1980s.

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[7] MOS SF-36 is another abbreviation form commonly in use

The SF-36 assesses eight areas of general health: limitations in physical activities caused by the disease; limitations in social functioning as a result of physical and/or emotional problems; limitations in the usual role functioning as a result of emotional problems; limitations in the usual role functioning as a result of physical health problems; bodily pain; general mental health; vitality (energy and fatigue); and general health perceptions. A single item provides an indication of perceived change in health. For the eight dimensions, scores are coded, summed and transformed onto a scale from 0 (the worst possible health status) to 100 (the best possible health status). The SF-36 is constructed to satisfy minimum psychometric standards necessary for group comparisons and proven useful in comparing general and specific populations, estimating relative burden of different diseases. On the other hand, some floor and ceiling effects have been reported for several SF-36 subscales. The instrument can be administered in about 10 minutes with a high degree of acceptability and data quality. It is suitable for self-administration or administration by a trained interviewer, both in person or by telephone, to persons aged 14 or older (Ware, 2000). It is recommended for use in health policy evaluations, general population surveys, clinical research, and clinical practice.

In the middle of the 1990s, an abbreviated version of the SF-36, the SF-12, was developed. The instrument provides a solution to a problem faced by many researchers who must confine a survey length. The instrument was designed to reduce respondent burden while achieving minimum standards of precision for purposes of group comparisons involving multiple health dimensions. While it imposes the minimum saddle on respondents, it generates the physical and mental component summary scores. It has been demonstrated that these components summary scores of the SF-36 are highly replicable by the SF-12 (Pickard et al., 1999). The SF-12 requires 5-10 minutes to be completed.

The World Health Organization Quality of Life Assessment (WHOQOL-100) is a generic measure designed for use in patients with a wide spectrum of psychological and physical disorders. Its 100 items are organized in 25 facets, subsumed within six domains: physical health, psychological well-being, spiritual, environment, independence and social relationships (WHOQOL Group, 1998). The instrument includes also one facet covering general health and overall quality of life. Therefore, the measure is multidimensional; it has been validated in several culture-specific and language-specific versions. The concept of quality of life behind this measure is clearly distinguished from the concept of health status which is narrower and focuses on physical impairments and functional disabilities. The higher the score attributed by a respondent, the better perceived quality of life.

The short form of the World Health Organization Quality of Life Assessment has been developed for pragmatic reasons and is called the WHOQOL-BREF. The WHOQOL-BREF contains 26 items of four domains: physical health, psychological well-being, social relationships and environment. These domains cover six of the original core instrument. The domain 'physical health' includes 7 items, the domain 'psychological well-being' includes 6 items, 'social relationships' includes 3 items, and 'environment' has 8 items. Each item is rated on a 5-point Likert scale and the domain scores are transformed to finally situate between 0 and 100. There are two items reflecting global indicators of quality of life and satisfaction with health, and these are not included in the calculation of the domain scores.

De Haan et al. (1993) identified nine generic quality of life measures that could be used in stroke research. These include the COOP Charts; the McMaster Health Index Questionnaire; the Nottingham Health Profile; the Sickness Impact Profile; the Medical Outcomes Study Short-Form Health Survey; the Karnofsky Performance Status Scale; the Quality of Life Index; the Euroqol; and the Quality of Well-being Scale.

The Darmouth COOP Functional Health Assessment Charts (the COOP Charts, also known as the COOP/WONCA Charts) comprise nine simple charts that are visually appealing because of the use of pictures providing added value for stroke patients due to its simplicity. They are quick and easy to use and may be a useful tool in stroke care, where time, communication and concentration level constraints might limit the use of disease-specific scales. The instrument was initially developed to routinely measure patients' perceived health and physical, emotional and social functioning in general practice. Each item-chart of the scale measures one life domain. Each chart is a direct indicator of function in the domain and summing up for a total score is not encouraged. The adult-version of the COOP (an adolescent version has been developed, as well) encompasses the following domains: physical function, emotional function, daily activities, social activities, social support, change in health, overall health, pain, quality of life. While it is suitable for clinical practice, this fact may impose some limitations as of its analytic value (de Haan et al., 1993).

The McMaster Health Index Questionnaire (MHIQ) is a 59-item generic measure encompassing three dimensions of health. The physical function is assessed by 24 items covering mobility, physical activity, self-care, communication and global physical function. The 25 social function items cover issues related to relatives' support, friends' support, work and material welfare, global social functioning and general well-being. The emotional function is evaluated by 25 items covering attitudes toward personal relationships, critical life situations, self-esteem and overall emotional function. The measure takes around 20 minutes to administer (Browne et al., 2004). Methodologically, the use of different response categories as well as skip movements in case of non-applicable items may bring certain concern and confusion. Voices have been also raised as the authors assumed some of the items to make part of two domains of the instrument at the same time (Browne et al., 2004).

The Nottingham Health Profile (NHP) is a generic instrument that was primarily developed to measure perception of health status in population surveys. It was first described in 1981 (Lyden & Hantson, 1998). The main aim of the measure is that it should reflect an individual rather than a professional definition of health. The NHP consists of two parts. Part one addresses principally serious health problems as potentially disabling disorders covering energy, pain, emotional reactions, sleep, social isolation and physical abilities, and part two refers to effects of health on seven life areas: work, home maintenance, social life, home life, sex life, interests and hobbies, and holidays. The NHP questionnaire consists of 38 items, requiring a ‘Yes’/’No’ response to questions grouped into six subscales. Scores for each group may range from 0 to 100, with 0 being an indication of perfect health state (Saladin, 2000). There are six domains the instrument, comprised of emotional, social, physical, pain, energy and sleep. It is a self-administered measure and its completion takes approximately 10 to 15 minutes (Lyden & Hantson, 1998).

The Sickness Impact Profile (SIP) was developed in the United States and first published in 1976. It has been refined in the course of a series of field trials over several years. It is intended to be broadly applicable across diverse demographic and cultural groups. It is a measure of 136 items, encompassing in total 12 domains: ambulation; mobility; body care and movement; social interaction; emotional behavior; communication; alertness behavior, sleep and rest; eating; home management; recreation and pastimes; and employment. The physical dimension contains items measuring a broad range of ADL, mobility and complex physical activities. In contrary to other quality of life scales, this instrument focuses on restrictions or recent alterations of behavior rather than subjective feelings. Sickness is measured in its relation to comportment. Total scores are further converted into a percentage of the maximum possible impairment, from 0% (what represents no impairment) to 100% (representing the maximum impairment). Its average completion time requires 20-30 minutes. It can be administered by an interviewer or be self-administered (Lyden & Hantson, 1998). Because of its length, the SIP is primarily suitable for cross-sectional studies (de Haan et al., 1993). This measure has been base for developing its stroke-adapted version, called the SA-SIP 30.

The Karnofsky Performance Status Scale (KPSS) is a generic measure, originally designed as an outcome measure in cancer research and currently also applied to other patient populations, including stroke survivors. This scoring system is named after Dr. David Karnofsky, who described the scale with Dr. Joseph H. Burchenal in 1949. The instrument is a rating scale, evaluated by an interviewer. An important characteristic of this scale is that it considers death as a relevant end point. The KPSS allows patients to be classified as to their functional impairment. The score runs from 100 to 0, where 100 is ‘perfect’ health and 0 is death. Accordingly, the instrument considers the score of 90% as capable to normal activity, with a few symptoms or signs of disease, 80% as performing normal activity with some difficulty, representing some symptoms or signs of disease, 70% as caring for self, not capable to normal activity or active work, 60% as requiring some help, while can take care of most personal requirements, and 50% when a patient requires frequent help and medical care. Furthermore, 40% corresponds to disabled, requiring special care and help, 30% is severely disabled, hospital admission may be indicated but no risk of death exists, 20% is specified as very ill, urgently requiring admission, requires supportive measures or treatment and 10% represents a rapidly progressive fatal disease processes. The KPSS can be employed especially successfully in longitudinal stroke studies (de Haan et al., 1993).

The Quality of Life Index (QLI) in its primary objective was designed to measure quality of life in persons with chronic health conditions. It evaluates the major life domains, including living situation, family relations, social relations, daily activities, finances, safety and legal problems, work and school, and health (as well as religion in some versions) (Lehman, 1995). An initial version contained 38 items, divided into four subsections. Later, a stroke-specific version of the QLI was developed, with three more subsections: communication, self-care and mobility. Satisfaction and importance of statements are evaluated on a scale from 1 to 6. The total score may range from 0 to 30, with higher scores indicating better quality of life.

Another generic measure of quality of life in terms of health status is the EuroQoL (EQ-5D). The EuroQoL is a brief, standardized, generic measure of quality of life that provides a profile of a patient function and a global health state rating. It consists of two pages, the descriptive system and the EuroQoL visual analogue scale (EQ VAS). The EuroQoL descriptive system comprises 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has, in the current version, five levels: no problems; slight problems; moderate problems; severe problems; and extreme problems. In a previous version, three levels used to be applied: no problems, some problems and extreme problems. The change was justified with an objective to improve the instrument sensitivity and reduce ceiling effects. A respondent is asked to indicate their health status by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. The EQ VAS records a respondent’s self-rated health on a vertical, visual analogue scale where the endpoints are labeled 'the best imaginable health state' and 'the worst imaginable health state'. This information can be used as a quantitative measure of health outcome as judged by individual respondents. The EQ-5D was primarily designed for self-completion by respondents and is well suited for use in postal surveys, face-to-face interviews and in clinics.

The Quality of Well-being Scale (QWBS) offers utilities of health states and symptoms measured on three functional scales and a symptom/problem complex. Functional scales focus on disabilities and social functioning. A problem/symptom complex offers a focus on relevant stroke outcomes, reflecting physical and, until some limit, emotional aspects of quality of life. Similarly to the Karnofsky Performance Status Scale, this instrument considers death as an end-point. Although it has been so far widely used in different populations, it requires quite extensive training for its application (de Haan et al., 1993).

Some empirical studies have also employed the HUI measure in its several versions. The HUI is a generic multi-attribute health status classification system, first described in 1970 as a precursor to the version in use today. The basic version encompasses the domains of: sensation, mobility/dexterity, emotion, cognition, self-care, pain, vision, hearing and speech. The instrument appears promising in terms of reliability, validity, responsiveness, acceptability, and usefulness in patient management. The HUI refers to both the HUI Mark 2 (HUI2) and the HUI Mark 3 (HUI3) instruments. These are generic health profiles and preference-based systems for the purposes of measuring health status, reporting health-related quality of life, and producing utility scores. The HUI2 and the HUI3 contain a generic comprehensive health status classification classification and a generic quality of life utility scoring system. The HUI 2 and the HUI 3 count together for several unique health states that they are capable to describe (Horsman et al., 2003). The HUI 2/HUI 3 combined versions measure is a relatively short instrument, with only nine items covering nine domains. These domains are: emotion, cognition, self-care, pain, vision, hearing, speech, ambulation and dexterity. Each item evaluates in this way one domain offering quite limited approach to life quality assessment. The HUI requires in average 20 minutes for its completion.

4.7.2. Stroke-specific measures of quality of life

The need for stroke-specific quality of life instruments is widely acknowledged and several stroke-specific, some directed uniquely to ischemic and other to hemorrhagic stroke types, instruments have been published. Buck et al. (2000) have made a review of instruments applied to assess quality of life after stroke and pointed the following stroke-specific outcome measures as used in stroke quality of life research: the FAI; the Niemi Quality of Life Scale; the Ferrans and Powers Quality of Life Index – Stroke Version; the Viitanen Life Satisfaction Interview (for long-term survivors); the Stroke Rehabilitation Outcome Study; the Ahlsiö Quality of Life Interview; and the SA-SIP 30.

The Frenchay Activities Index (FAI) has been developed specifically for use in stroke patients. The Frenchay Activities Index is a short measure with only 15 items, encompassing three domains: domestic chores, outdoor activities and leisure and work. The FAI consists of a single summary score (with a range of 15 to 60 points), as well as three subscale scores: domestic, leisure/work, and outdoors. It requires 3-5 minutes for its completion. Buck et al. (2000) argue that the FAI is the only stroke-specific measure that can be used to successfully assess quality of life with proxy respondents when necessary.

The Niemi Quality of Life Scale is a quality of life instrument that includes 58 items. These items cover four following domains: working conditions, activities at home, family relationships and leisure activities. The measure is interviewer-administered. While it has demonstrated to be valid and reliable, no responsiveness reports have been published (Niemi et al., 1988). No reports are available for the average completion time, either.

The Ferrans and Powers Quality of Life Index – Stroke Version is a stroke-specific quality of life measure with 38 items. The four evaluated domains include: health and functioning, socio-economic, psychological/spiritual and family (Ferrans & Powers, 1985). No records mention time necessary for its completion.

The Viitanen Life Satisfaction Interview is a measure designed for long-term survivors and contains in total only seven items, covering seven different domains: life in general, self-care ADL, leisure, togetherness-friends, togetherness-family, marriage and sexuality. The authors of the measure have not specified time necessary for its completing.

The Stroke Rehabilitation Outcome Study is a very short disease-specific instrument, with six items. Three domains are of interest of the measure: level of satisfaction with life in general, number of person-to-person contacts and active participation in the community. Completion time has not been reported (Granger, Hamilton, & Gresham, 1988).

The Ahlsiö Quality of Life Interview is a stroke-specific measure without a specified number of items and without a determined number of domains (Ahlsiö et al., 1984). Therefore, it is impossible to point out areas covered by the instrument. Yet, it assesses global quality of life. Time necessary for completion has not been reported.

The Stroke Adapted Sickness Impact Profile (SA-SIP 30) is an adaptation of the 136-question-SIP. It is a 30-item measure encompassing eight domains: body care and movement, social interaction, mobility, communication, emotional behavior, household management, alertness behavior and ambulation. Although stroke-specific, it further needs to evaluate dependability, sensitivity and soundness. While acknowledging time necessary for completion of the instrument as one of the disadvantages of the 136-question-SIP, the authors of the measure do not refer further on results of estimated time required for completion of the SA-SIP 30 (Christensen & Larson, 1993).

Likewise, other stroke-specific quality of life measures have been developed.

The Quality of Life Index (QLI) - Stroke Version is a 64-item questionnaire composed of two parts. Part I measures satisfaction with four domains of life: health and functioning, socio-economic, psychological/spiritual and family, and part II measures importance of the same domains. Subjects respond to items on a 6-point scale, which in Part I ranges from ‘Very satisfied’ to ‘Very dissatisfied’, and in Part II ranges from ‘Very important’ to ‘Very unimportant’.

The Stroke Impact Scale (SIS) is a disease-specific outcome measure. It contains 64 items which were thought to be the most appropriate to assess post-stroke quality of life. The items encompass eight domains: strength, hand function, activities of daily living/instrumental activities of daily living, mobility, communication, emotion, memory and thinking, and participation. Four of these domains can be combined to produce a composite physical domain score. This general physical score covers: hand function, mobility, strength and daily life activities. Altogether, they score into one domain. The other domains are scored individually (Saladin, 2000). An individual domain score ranges from 0 to 100.

The Stroke-Specific Quality of Life Scale (SS-QoL) is a single stroke outcome measure that aims to efficiently assess various domains important in determining stroke-specific quality of life across a spectrum of stroke symptoms and severity. It assesses quality of life in twelve domains and provides an overall estimate of health-related quality of life. The SS-QoL comprises 49 items, looking at domains of energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, vision, upper extremity function and work-productivity. Scores range from 1 to 5, with higher scores indicating better health-related life quality. Domain scores are calculated using unweighted average values of items in that domain. The overall SS-QoL score is unweighted average of the domain scores and ranges from 1 to 5 (Green & King, 2010). The authors of the instrument argue that the SS-QoL may be more sensitive to meaningful changes in health-related quality of life than the generic SF-36 (Williams et al., 1999).

4.7.3. Challenges to quality of life measurement in stroke patients

With a decline of mortality rates related to cerebrovascular accident, patients are increasingly likely to live with acquainted impairments and disabilities, some residual yet other substantial putting in consequence a continuous limitation on their daily activities. In this perspective, quality of life becomes one of central topics that need to be considered where the impact is often life-long and multidimensional.

Pros and contras of various instruments need to be considered when employing the one of choice assessing quality of life. Generic instruments are developed to be used by a wide range of patient populations. Their unquestionable advantage is a possibility to compare relevant effects of interventions on quality of life. Therefore, it is recommendable to use generic instruments always when a comparison between health condition or a range of illnesses is to be carried out (Saladin, 2000). Williams (1998) emphasizes that generic measures, when applied to stroke patients, represent a set of problematic issues, namely: (a) content validity of domains, that is, appropriate areas of potential dysfunction may not be assessed; (b) content validity of items, that is, meaningful questions to quantify function in a specific area may not be asked, and (c) sensitivity to change or responsiveness, that is, generic measures may not detect clinically important changes in health-related quality of life.

With a choice of employing a disease-specific measure, a researcher faces several completion technique options, such as self-completion, personal interview, telephone interview or electronic means. As in case of generic scales, disease-specific measures can be applied when a researcher considers different completion techniques, such as self-completion, personal interview, telephone interview or even by electronic means. Since some of stroke-specific instruments are relatively recent, they still require data from clinical trials for their refinement.

Measurement of quality of life in stroke patients, who frequently present communication disorders is challenging, also from the methodological viewpoint. One way to approach this difficulty is asking the patient’s significant other(s) to rate quality of life on behalf of the patient. Proxy measurement involves asking the respondent to answer a set of questions the way the person finds the most probable the patient would. A manner of verification the correctness rate of such responses is determination of score agreement between communicable patients and their caregivers. Nonetheless, even in case of a full concordance, findings should not be generalizable to the population of patients with communications disorders. Inability of a highly relevant part of patients to provide valid responses into the study may yield results that cannot be generalized to the total patient population of interest.

4.8. Summary and conclusions

Quality of life after cerebrovascular accident and methods of measuring this aspect of disease has been viewed with a growing interest over years. In light of a number of possible consequent impairments after stroke, measurement of quality of life of its survivors needs to comprise not only physical, but also psychological, functional and social aspects. Conversely, increased integration at administrative level and changes in service configuration for stroke patients can be achieved, but do not necessarily translate into enhanced quality of care (Bickman, 1996).

In the absence of consensus about the meaning and constituents of quality of life, a confusion detected in quality of life literature could be alleviated for every study in its applied definition of quality of life. On the other hand, multiplicity of measures, generic and disease-specific, not necessarily proven to be valid and reliable, calls for specification and standardization of the concept of quality of life. Spilker, Simpson and Tilson (1992) report that over 160 different measures were used in published literature only in the year 1991. This number has risen significantly up to date.

This chapter has brought closer relevant literature review regarding quality of life. It has presented the idea and definition of quality of life with its historical background, and has shown a relation between the concept of quality of life with other terms, frequently used as its synonyms, such as well-being, life satisfaction or health status. Conceptually, quality of life differs from health-related quality of life and this peculiarity and distinction have been emphasized and demonstrated. Nevertheless, literature review points out a common equivalent use of these terms by academics.

A typology of measures exists in a common use to quantitatively approach quality of life. Quality of life instruments can be either generic, applicable to any health condition and patient population, or disease-specific, constructed bearing in mind a particular group of patients and their specific health-related issues. The chapter presented the most frequently used in cerebrovascular disease studies generic and specific quality of life measures and described their main characteristics.

PART TWO

CHAPTER FIVE:

METHODOLOGY

Chapters 1 to 4 of this thesis presented relevant concepts on which this study was based. This chapter presents and discusses in detail the way the research was carried out. It starts with an introductory section on methodological issues (Section 5.1), followed by the rationale of the study (Section 5.2. Next, a research framework and design (Section 5.3) is provided. It includes contextualization of the study in Subsection 5.3.1 and the strategy adopted for the literature search in specific parts of the study in Subsection 5.3.2. Methods, with procedures and measures underlying the study are described in Section 5.4 with the division into Patients' study (Subsection 5.4.1) and Entities' study (Subsection 5.4.2) since two separated, complemented universes were studied under this research. Information on data collection is provided in Section 5.5. Finally, Section 5.76 outlines data processing and analysis.

5.1. Methodological issues

In its development, scientific research has experienced a discussion on relevance and superiority of either quantitative or qualitative methods. Scientific method is a group of procedures and techniques applied in order to know, understand and investigate phenomena. It consists of studying a phenomenon in possibly the most rational manner searching for evidence and proves of ideas, affirmations and conclusions, or for techniques and processes to solve problems while specifying new elements of knowledge (Freixo, 2010). Quantitative research: rationalistic, positivist and based on a 'scientific paradigm' has been opposed to qualitative research: interpretive and anti-positivist (Guba & Lincoln, 1982). In research inolving health issues, quantitative approach allows for understanding a linkage between people's beliefs and their health, nevertheless, it does not give a response to a source and reason of such beliefs (Aled & Bugge, 2006). Tones and Green (2004) consider that quantitative research alone is not able to give much contribution to science. A choice of a research method to be applied has been driven by philosophical foundations that support research concerns and research orientations (Freixo, 2010).

A primary concern of quantitative methods is measurement. The interest in a phenomenon must result in providing its quantifiable dimension. A quantitative research method is therefore a systematic process of observable and quantifiable data collection. It reflexes a complex process leading to a possibly least biased result. It encompasses quantifying objective facts and their scope, giving a chance for generalizing the results for similar realities, and predicting and controlling events. This approach brings thus a number of advantages: accountability allows for precision, a higher objectivity, comparison and reproduction, and, finally, inference (Freixo, 2010).

A qualitative method consists of observation, description, interpretation and appreciation of a phenomenon and its environment exactly the way they are, without an attempt to control any of its aspects. A large focus in this approach is given to a description or interpretation rather than an evaluation of the fact (Freixo, 2010). The term 'qualitative' was attributed by Kirk and Miller (1986) and later broadly adopted by the scientific community. Erickson (1986), however, proposes a term 'interpretative research', and acknowledges the object of analysis as predominant to research design and techniques. Some scholars prefer the expression 'comprehensive paradigm' (Lessard-Hérbert, Goyette, & Boutin, 2008).

Gauthier (1987) points out the proximity between the researcher and the study participants in qualitative research, both in the field and language: "the tradition of qualitative research (…) consists essentially in studying and interacting with people in their field, through their language, without employing a detachment that would lead to use symbolic forms strange to this environment" (p. 32). Wilson (1977) considers qualitative method as ethnographic since events are studied in their natural forms, in the field, and facts can only be understood and appreciated by researchers when they understand perception and interpretation of facts by participants. Qualitative research is hence characterized by five features: it employs a natural situation as the information source and the researcher as the information collection tool; it has description as a primary concern, while data analysis exists only as a secondary option; it focuses on the process as a whole; the information is analyzed inductively; and it is concerned in explaining the meaning of things (Bogdan & Biklen, 1992). Scholars in favor of qualitative methods sustain that this approach is characterized by flexibility with certain phases of the research process reached simultaneously (Freixo, 2010). In fact, qualitative research rarely permits to follow a sequential, fixed model.

Popay (2003) presents the contribution of qualitative research within two, divergent, models:

1) The enhancement model, which assumes that qualitative research supplements evidence acquired from the use of rigorous quantitative techniques providing possible results which shall be further tested with the use of quantitative methods;
2) The epistemological model, which adopts an equality relation between qualitative and quantitative approaches, making their potential contribution to explaining the investigated phenomena complementary, although recognizing differences between them which may lead to eventual tensions.

Table 32 summarizes essential differences between quantitative and qualitative methods. Within quantitative and qualitative research, diverse techniques are available to answer research question(s). It is the responsibility of the researcher to choose the most appropriate ones.

Table 32. Comparison of quantitative and qualitative research methods

Quantitative	**Qualitative**
Objective	Valorization of subjectivity
One reality	Multiple reality
Reduction, control, prediction	Discovery, description, comprehension
Measurable	Interpretative
Mechanist	Organist
All is a sum of parts	All is more than a simple sum of parts
Statistical analysis report	Narrative report
Separation of the researcher relatively to the process	The research makes part of the process
Subjects	Participants
Free of context	Context-dependent

Source: Freixo (2010)

5.2. Rationale of the study

Demographic, socio-economic and epidemiologic challenges have been putting pressure on policy makers (Pierson, 2006) requiring change in the paradigm of health and social care provision. Traditionally oriented toward acute care health care systems have been facing a growing prevalence of long-term conditions as complementary to severe cases of progressively older populations. It has been deemed far too much what the health care system can manage on its own. An escalation of demand for complex and multidisciplinary care services in aging societies has raised an urgent need to provide methodologies and tools to improve the coordination and continuity of care (Andreasson & Winge, 2010). Currently, research allowing for understanding the use of services, patient flow among interventions and interactions between health and social care providers, especially concerning patterns of collaboration and communication between them is not only required, but vital.

Recent WHO reports point into 15 million cerebrovascular accident cases annually, from which over 30% die and the remaining part suffer stroke consequences with temporary or permanent incapacities affecting their quality of life. Stroke burden is estimated to rise from nearly 38 million disability-adjusted life years (DALYs) globally in 1990 to 61 million DALYs in 2020 (Mackay & Mensah, 2004).

In Portugal, similarly to other developed countries, the mortality statistics are highly influenced by non-communicable diseases, especially those of the circulatory system. Cerebrovascular accident is the principal cause of death and disability, with the highest incidence, prevalence and mortality among Western Europe countries (Truelsen et al., 2006). Correia et al. (2004) calculated a crude annual incidence of stroke in Portugal of 3.05 (2.65 to 3.44, 95% CI) and 2.69 (2.44 to 2.95, 95% CI) per 1000 inhabitants for rural and urban population, respectively. This compares with corresponding European values of 2.02 (1.69 to 2.34, 95% CI) and 1.73 (1.53 to 1.92, 95% CI). It is estimated that 2-3 persons die in Portugal due to stroke every hour, and one fifth of survivors become totally dependent (Martins, 2006).

With no indication for further hospitalization in an acute care unit, patients still require care while the community has habitually not developed any sustainable answer yet. Close relatives appear many times the only source of support in daily life activities. Cerebrovascular disorders are therefore an important issue in public health policy (Truelsen et al., 2006) and have been calling the attention of policy makers worldwide.

Collaborative action is believed to be a reasonable response and a driving force for providing comprehensive health and social care in eyes of challenges facing the society (Kickbusch & Quick, 1998). Its rationale passes through a synergy, extent to which the involvement improves partners' ability to take action and achieve objectives (Lasker, Weiss, & Miler, 2001) while addressing complex needs. Collaborative engagements, established in a more formal or informal way, have been gaining recognition and practical significance over time and in a global context. The practice has brought researchers with questions on theoretical concepts supporting collaborative success. Recently, such linkages between health and social care, sometimes with evidence from the experience from other sectors, have been described in literature.

Collaboration among organizations within and between sectors has been a subject of interest of health and social care industries (Greenwald, 2008). Partnering across sectors has been increasingly recognized by international community as a fundamental element of health and social care strategy. The model of intersectoral partnership is based on understanding that sectoral disparities can be a source of innovative solutions (Charles & McNulty, 1998). It encompasses particular concepts of collaboration and raises a question of trust, commitment and responsibility while establishing, maintaining and evaluating the linkage.

An interest for partnerships and cross-sector partnerships arose with the understanding that a few theoretical concepts existed, as to date, to explain their phenomenon. While partnerships among sectors had been gradually used in practice and some evidence on their performance existed in literature, very little had been written formally. Practical evidence suggested their above average potential in addressing complex problems, yet, requiring for that purpose involvement of different bodies, often from different jurisdictions. The work encompassed, as a starting point, the conceptualization of partnerships and intersectoral partnerships, and their importance in health and social care. This would lead to defining the current status, structure and specificity of collaborative engagements between sectors for patients who overcame cerebrovascular accident. Systematic review of legislation would provide a deep insight on the extent to which intersectoral action in Portugal, especially in health and social care, is supported by existing laws and regulations. Both, institutional and patients' perspectives ought to be taken into analysis in order to obtain a comprehensive view of the phenomenon of intersectoral partnering. Since it is universally acknowledged that patients' reports on their health and satisfaction with quality of care are as relevant as clinical health measures (Aragon & Gesell, 2003), among which quality of life is extensively applied and broadly regarded (Varricchio & Ferrans, 2010), the further challenge was to assess stroke patients' quality of life, and perceptions on satisfaction and service quality of institutions constituting the network of care. Finally, basing on the map of care service providers to be identified in the Aveiro district, the objective of the work was to determine the collaboration intensity between them and propose a framework of patient-centered collaboration intensity model that would bear in mind some features of a cross-sector patient flow. To our knowledge, no such work has been ever developed.

5.3. Research framework and design

For achieving the general and specific objectives of the study, quantitative and qualitative components were employed. In light of Popay's (2003) considerations, it was based on the epistemological model, with no strong predominance of quantitative approach and in harmony between both types of research. The general recommendation states for complex problems, especially when those have not been deeply investigated before, the qualitative component should prevail so that more realities could be exposed and analyzed (Guba & Lincoln, 1994). The research on intersectoral linkages in health and social care is scarce. Hence, in order to explore the current practice of intersectoriality for stroke patients in Portugal, qualitative tools were selected. They comprised interviews with patients who overcame cerebrovascular accident and contacts with entities found to constitute the network of care for stroke survivors in order to determine the level of collaboration intensity between them. These contacts resulted in a number of additional interviews carried out with key informants representing those institutions. Both interview guides were designed on basis of literature review supporting them.

Specific objectives of the study aimed at establishing concepts, demonstrating perspectives, evaluating scope and importance of given phenomena, and testing relationships and their eventual strenght between constructs of perceived service quality, patient satisfaction and quality of life, taking into consideration collaborations existing in Portugal between stroke care and support providers while analyzing implications of such results. The concept of intersectoral partnerships was chosen to be theoretically supported by the concept of networks. The interest fell into determining the existing network of care for stroke patients, relationships and their intensity between its members. For the above purposes, exclusively qualitative methods would not be sufficient, especially in terms of their problematic validity and reliability. While qualitative methods function well in gaining an in-depth view into the investigated phenomenon, quantitative methods are recommended when searching for generalizable findings. Quantitative methods in form of questionnaires, measuring quality of life, service quality and satisfaction, and contacts with entities involved in care and support were employed to be studied through network analysis, as they allow for a more robust evidence to be drawn. Nonetheless, recognizing network analysis to be used as an exclusively quantitatively method would be a substantial redundancy. Intensity of collaborative relationships between entities would be determined using a model found the most appropriate to the context from the literature review. However, as Ragin and Becker (1992) state, network analysis is a case study, hence, situated in a distinctive space and time dimension. Despite the development of statistical tools for social networks, one cannot forget the network in question represents specific circumstances; still, the more nodes, the more level of conceivable generalizability may be deliberated.

The study applied therefore mixed methodology. A mix-methods research approach has become more common in recent years to the point that some scholars differentiate it from pure qualitative and pure quantitative approaches as a distinct research (Creswell, 2008). Yamazaki et al. (2009) alert, however, that this tendency has not had such impact on health sciences.

A mixed methodology comprises a number of mix-methods and their adoption depends, among others, on the following factors (Bryman, 2006):

- The number of data sources;
- The number of research methods;
- The prioritization of quantitative or qualitative information over the other;
- The simultaneous or sequential data collection;
- The function of integration (for instance, exploration, explanation, triangulation);
- The occurrence of methods at different phases of the research process.

5.3.1. Contextualization of the study

Portugal is a country located in the south-west of Europe comprising the continental part and two archipelagos, Azores and Madeira, the autonomous regions. The continental part of the country is agglomerated into 18 districts. Districts are divided into 308 municipalities (*municípios or concelhos*), further subdivided into 4260 parishes (*freguesias*) until the change in 2013, which diminished this number into 3091[8]. Municipalities and parishes together with the national governmental structure are the only officially legally standing local administrative units for the governance purpose. The Portuguese population reached 10.6 million people (INE, 2011) and has been steadily increasing.

The district of Aveiro is located in the central region of the country, between the districts of Porto, Coimbra and Viseu. It covers an area of 2808 km2 and has population of over 750 000 people. The district is constituted of 19 municipalities. The capital of the district is the city of Aveiro.

The responsibility for health care provision is of the Ministry of Health, and for social care is of responsibility of the Ministry of Labor and Social Solidarity that is also liable for social benefits such as pensions, unemployment and incapacity benefits. Structures of care provision exist under both systems, which, ideally, should be complementary and contributing for the best outcome of the citizen in need. In this spirit, the National Network of Integrated Continuous

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[8] The changes were applied on a basis on Law no. 75/2013 from 12 September

Care was brought to life. Its mission is to provide support in continuity of care by means of diverse and accordingly chosen levels of integrated care unceasingly contributing to its development. For that purpose, different entities of the network were created with different targets and goals, making frequent use of already existing structures. In this moment, the network is constituted from three levels of integrated care: convalescence (short-term) units, medium-term and rehabilitation units and long-term and maintenance units; offering also palliative care units supporting situations of dependency and incapacity, with a strong focus on home care.

The network of care for patients who underwent cerebrovascular accident may consist of a range of entities, some of them operating within the National Network of Integrated Continuous Care, hospitals, a typology of rehabilitation units, Private Institutions of Social Solidarity, *Misericórdias* (mercies), health centers, city councils, parish councils, the Social Security, fire departments offering transportation services, religious entities (providing spiritual and often material and financial support support), physiotherapy clinics and other private service providers whose services may be beneficial to a patient (a gym, a swimming pool).

Health centers, primary care establishments, are public sector entities delivering care through public funds. They constitute an entry point to the health system, with GPs and primary care nurses (and in some cases specialists) and have gone in recent years through a deep reform. Primary care centers provide a wide range of services, including, in addition to general medical care, prenatal care, family planning, home visits, preventive services such as screening for breast or cervical cancer or some preventable diseases (Barros, Machado, & Simões, 2011). Besides health centers, primary care can be also provided by private sector providers, and professionals contracted by or collaborating with the NHS (Simões, 2012).

Hospital services are provided mostly according to the integrated model, directly run by the NHS.

The network of integrated care is coordinated at the central, regional and local levels, allowing to adopt measures sometimes palpable only in the field. More specifically, the network promotes coordination between different institutions of care, with early referrals and what requires monitoring the patient’s situation and eventual adaptation of the condition to current needs to enhance improvement. Collaboration between the health and the social sectors together with the society, more or less related to a given case is crucial for a long-term success of the network.

Private Institutions of Social Solidarity are non-profit organizations that sprang from a private initiative, based at goodwill and availability of the community, and with a purpose of providing organized care. IPSS are financed through agreements with the State that supports their activity recognizing its value for public interest even in the Portuguese Constitution (1976, revision of 2005, art. 63). According to the data extracted from the Social Security, in 2012 there were 5051 IPSS and other 247 institutions assimilated to them. The forms under which those registered by the Social Security operated are provided in Table 33.

Table 33. Private Institutions of Social Solidarity registered in the Portuguese Social Security and their forms

Private Institutions of Social Solidarity registered in the Social Security	
Associations	3202
Social and Parochial Centers	1052
Foundations	207
Institutes of Religious Organizations	226
Misericórdias	346
Not specified	18
Total	**5051**

Source: Segurança Social (2012)

According to the Ministry of Solidarity, Labor and Social Security, in 2012 in the district of Aveiro there were 974 centers of occupational activities, 4209 day centers, 4442 nursing homes, 5681 entities providing domiciliary support service, and, moreover, 293 residential homes for the youth and 9285 day care centers for babies, summing up to 24884 institutions with a status of IPSS active in the region (Instituto de Solidariedade, 2014). The offer is extensive as it is directed to diverse target population groups.

Misericórdias have a long tradition in the Portuguese history. They are organized in order to meet social needs while performing the Catholic worship, in harmony with their spirit and quintessence, and based on the Catholic principles and morals. Over centuries these charitable organizations played an important role in providing social (and until very late, health) assistance to the community; nowadays, they continue to do so, yet, not exclusively. In fact, services provided by *Misericórdias* are very similar to those offered by IPSS. Following the latest data for the country, from those affiliated to the National Union of *Misericórdias*, there are 398 *Misericórdias* and other 80 remain inactive. In the district of Aveiro there are currently 21

Misericórdias. The estimates are more uncertain concerning other charitable entities as no formal registers exist.

City councils and parish councils may play an important role in the network of care as they have legal, organizational and financial and means to establish a scheme of technical support for patients after stroke.

Firemen in Portugal are a branch of civil protection and, depending on a unit, a combination of firemen by profession, volunteers and mixed. Interestingly, and what differs Portugal from other countries, a part of the operational service of a fire department contributes in a high level to the functioning of the care system, on basis of the cooperation agreement between the Portuguese League of the Firemen and the Ministry of Health. The specific norms are regulated further by the law, as the transportation rules and the co-payments depend on the patient’s health condition and the type of transporting entity (the general agreement with the Ministry of Health specifies also details of cooperation with other potential transportation entities).

The Social Security is the central service of the administration of the State. It creates, coordinates and supports the social regimes. The Social Security is a very relevant source of information in what financial support for stroke patients and caregivers concerns. The district of Aveiro holds 24 local units of the Social Security, some of them temporary (situation for the day 5 February 2014).

Physiotherapy clinics are private entities developing their activities often through a model of service contracting with the State. Typically, the State regulates, delivers and finances services, however, this standard model has been fading away with insufficient means to both, investing in equipment and providing services (Barros & Gomes, 2002). At the same time, and in order to be effective, the contracting parties need to create control of the patient flow with supporting information system, and to guarantee qualified human resources to gain competitive advantage (Barros & Gomes, 2002). The payment system is predominantly retrospective.

Religious entities are recognized as for their power to bring support and spiritual carefulness. There is also evidence they can provide material and financial support for persons in need. (The study had no restrictions regarding patients’ religious beliefs).

5.3.2. Literature search strategy

The present work is embedded in four main thematic areas, which have been discussed in previous chapters. The bibliographic review on cross-sectoral action aimed to allow for the understanding the theoretical and practical approach to intersectoriality.

The literature review regarding the concept, rationale, evolution and application of intersectoral linkages used initially keywords ‘intersectoral’, ‘multi-sector’, ‘among sectors’ and ‘cross-sector’, and all their possible combinations with ‘partnership’, ‘partnering’, ‘action’, ‘collaboration’, ‘initiative’, ‘approach’ and ‘linkage’. As it was appraised, the use of terminology related to intersectoriality was not consensual among authors and some referred to activity among sectors as ‘multi-agent’, ‘multi-stakeholder’ and/or ‘multi-agency’. In fact, these terms can be both applied to one and multi-sector organizational contacts, but the expressions were added to the search criteria. The decision to add ‘public-private partnerships’ into the terminology of partnering arose from quite recent and negative reputation of such initiatives in Portugal, especially in areas of health and social care, and the predominant idea outspread throughout the society by media creating a harmful image of collaborative initiatives. The interest focused on defining the intersectoral action as a theoretical concept, its relevance for the economy and factors determining its success.

Screening for available evidence related to the theory and practice of intersectoral partnering included journals, books, conference papers and proceedings, grey literature (white papers, reports, case studies descriptions and guidelines). This was done in two steps. First, literature was collected and screened on basis of titles, abstracts (if available) or summaries. Whenever identified any of the aspects of intersectoral action, full text of the document was retrieved. Additionally, references of documents found relevant to this study were screened and eventually reviewed. The attempt to retrieve all accessible information on comprehending the partnership phenomenon resulted in defining the terminology related to partnering, in which (depending on authors) some levels belong to the partnership intensity continuum, and some terms exist individually. The evidence of intersectoral initiatives in international and Portuguese formal documentation for health and social care were extracted. Finally, indicators of partnership performance were collected.

The methodology adopted in preparing the present work was based, firstly, on a comprehensive literature review focused on the following sources: electronic databases (Medline and Scopus), reports of the WHO, the European Commission, the OECD and other international organizations, documents and reports of the Ministry of Health, the Ministry of Solidarity, Labor and Social Security, the National Network of Integrated Continuous Care and other relevant involved bodies which activity is associated to health and social care services provision, books, national reports, research reports of academic institutions and other entities, databases and other sources of grey literature.

Exhaustive and critical literature review shall allow for determining the knowledge and evidence existing to date regarding the investigated phenomenon (Freixo, 2010). A systematic review of the Portuguese legislation was performed among terminology of collaboration revised in the theoretical part of this study (‘coalition’, ‘alliance’, ‘cooperation’, ‘coordination’, ‘collaboration’, ‘partnership’), the expression ‘intersectoral’, and all their possible combinations. In addition, the terms ‘integration’, ‘articulation’, ‘intersectoral articulation’and ‘intersectoral strategic program’ were incorporated to the search. The search included the 1st and 2nd Series of legislative acts of *Diário da República*. The 1st Series search comprehended documents from 1 January 1960 to 23 May 2014. The 2nd Series search comprised documents from 1 January 2000 to 23 May 2014. In the 1st Series of *Diário da República* one can find the most relevant legislation, such as constitutional laws, decree laws, regional legislative laws, decrees of the President of the Republic, decisions and declarations of the Constitutional Court of Portugal, resolutions of the Cabinet of the Ministers and ordinances with generic dispositions, resolutions of Legislative Assemblies of the Autonomous Regions and regional decrees, among others. The 2nd Series of *Diário da República* embraces normative dispatches of the government members, dispatches and notices of local governments, among others.

The search for the same expressions was made among publications and documents available from national bodies. The search comprised reports and documentation published by the Ministry of Health, the National Network of Integrated Continuous Care and the Ministry of Solidarity, Labor and Social Security, in the first step, and, if such were found, other ministries and relevant bodies which activity was related to the provision of health and social care services.

As an addition to the systematic review of legislation, additional manual search was carried out simultaneously with the documentation search. One reason for that was having identified documents as potential regulatory acts that could contain relevant information regarding intersectorial action having an impact on health and social care in the country. Another motive for that decision was the fact of having had previous knowledge of some legislation with explicit or more implicit content on intersectoriality.

One of the potential theoretical explanations for intersectoral activity could be the network concept and networks functioning in the organizational context. For the purpose of the bibliographic examination, electronic databases (Medline and Scopus) and the internet were searched. The interest fell into the network concept and its historical evolution, network typologies, actors, and network characteristics. Social network analysis as a procedure concentrates on patterns of relationships and represents structure and positions using graphical models.

Screening for bibliographic references on quality of life involved keywords ‘quality of life’, ‘health-related quality of life’, ‘measure’, ‘measurements’, ‘instrument’ and their adequate combinations. In the second step, the search examined a presence of ‘generic measures’ and ‘disease-specific measures’, with a special interest on existing stroke-specific measures for quality of life. The intent was to identify relevant information in electronic databases (journals), but the internet was also searched as it was found that some instruments had been developed, modified and/or validated as a component of Master or Doctoral theses.

The fourth thematic area in which this thesis was embedded is the concept of service quality and user satisfaction. Electronic databases, books and grey literature were searched for ‘service quality’, ‘user satisfaction’, ‘patient satisfaction’, ‘model(s)’, ‘measuring’, ‘measurement’ and ‘instrument(s)’ keywords, and their adequate combinations, for concept and evidence supporting the type of relationship between service quality and satisfaction.

5.4. Methods

The present study is assumed to have an exploratory character as, to our knowledge, no works on intersectoral partnerships from the viewpoint of the network theory and the relation between cross-sector initiatives, quality of life, service quality and satisfaction have been conducted and published to date. Data collection was handled in two distints phases. Participants of the study consisted of patients (phase one) from the district of Aveiro who suffered cerebrovascular accident, and care and assistance providers (phase two) from the region that were firstly identified and contacted in order conduct further analysis of their collaborative relationships and carry out a more specific interview with key informants of each type of the institution with an objective to gather their viewpoint on collaborative linkages and the care system as a whole and confront it with the one from patients’ side.

5.4.1. Patients’ study

As the data for phase one of the present study were collected in parallel and thank to the permission of the HOMECARE (Clinical Continuity by Integrated Care) EU funded project -

grant agreement no. 2222954, funded by EU-FP7 ICT, it followed strictly its previously stipulated procedures.

Patients suspected to have had suffered cerebrovascular accident arrived to the emergency room of the Hospital Infante D. Pedro in Aveiro (HIP). The hospital is currently part of Hospital Center Baixo Vouga (*Centro Hospitalar Baixo Vouga*). Participants for phase one were recruited in HIP from patients admitted to its Stroke Unit.

Patients admitted to the Stroke Unit of HIP with the diagnosis of stroke were evaluated through the eligibility criteria. Exclusion criteria were:

- Age less than 25 or more than 85
- Pregnancy
- FIM[9] score higher than 100
- Residency outside of the district of Aveiro
- Serious speech and language disturbances
- Psychological illness or dementia disturbances influencing the participation in the study
- Previously diagnosed damages to the central nervous system or motor apparatus illness that influences the participation in the study
- Other severe co-morbidity that influences the participation in the study
- Transfer to another ward for more than 5 days

Only patients fulfilling all inclusion criteria were considered to the study.

All patients were informed about the ongoing study and its objectives and were asked the permission to be part of it. Patients who agreed to participate in the study signed informed consent (in case of patients who did not know how to write or were unable to write in a consequence of stroke, a fingerprint was considered a sufficient proof) and were included for further procedures of data acquisition.

The study was approved by the Ethical Committee of the Hospital Infante D. Pedro.

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[9] FIM – Functional Independence Measure is a basic indicator of a patient’s disability typically used during an episode of hospitalization. The instrument is grouped into two subscales (the motor and cognition) and its total score may value between 18 and 126. The higher the score, the more independent the patient in performing the task associated with a certain item.

Patients, beside the general staff of the Stroke Unit, met the specific group of the professionals involved in the project. In the hospital environment these were the Chief Neurologist and the Chief Nurse of the Stroke Unit. Additionally, due to the a highly fragmented character of the Portuguese health and social care systems and the absence of the information system linking all intervening entities, the study employed a case manager who would be present in the hospital in order to establish a closer contact with the patient and eventual relatives, if such were present in the Unit. A case manager was a qualified gerontologist, who would follow each patient during six months after discharge. There were two case managers in the study.

In the hospital, however, in several cases, the next destination of the patient remained unknown as the post-discharge model in Portugal is very complex and diversified. Patients may be discharged directly to their (or a relative's) residence, they also can be directed to one of the existing RNCCI rehabilitation units (convalescence, medium-term and long-term) or stay in a nursing home. All these within an inpatient practice. On the other hand, patients may be discharged and use outpatient rehabilitation at different types of clinics and first and second line hospitals. According to the Portuguese legislation, these can function as public organizations, private non-profit organizations, for-profit organizations or public-private partnerships.

5.4.1.1. Expectations sheet

Expectations sheet was composed of two parts. The first part included a list of possible entities that a patient after cerebrovascular accident might be expected to enter in contact with. The list of entities comprised those providing any type of care, support or assistance to a stroke survivor, such as health and social care, financial support, spiritual support, technical aid, transportation services, etc. This part contained three possible responses: 'Yes', 'Maybe' and 'No'. The second part of the questionnaire was built from more specific questions relative to views and knowledge a patient had at the time about the formal system of care and informal support that could count on, and finally, perception of the own health condition. That part of the questionnaire was rated as the first one except of the last item inquiring current health status, which was measured in a 5-point Likert scale, where 1 meant 'Very bad' and 5 -'Very good'. In both parts, the option 'Does not know/Does not respond' was available.

The first part was created with an objective to list entities that might come to provide care and support to stoke survivors. From these a respondent could easily choose those expected to interact with within the next half a year. An open-ended questionnaire applied in that specific universe might not bring satisfactory responses while too demanding for a patient. The second part resulted from conversations with professionals taking part in the HOMECARE study and considered few most relevant aspects a stroke patient might think about.

5.4.1.2. Experiences sheet

Experiences sheet was applied six months after discharge from the Stroke Unit and listed entities possible to have been contacted within that time with an eventual question of the number of times (if yes) of these contacts. If a contact took place, the entity was identified on the sheet in order to enable further data manipulation. In situations where a participant did not remember or could not distinguish the entity, a special effort was made by discussing some additional issues that might have helped overcome the problem.

5.4.1.3. Stroke Specific Quality of Life Scale

In the traditional approach, commonly used indicators of population health encompass mortality, morbidity, consultation rates and use of health services, among others (Seigmann & Elinson, 1977). However, over time, more importance has been given to the perceived opinion of own health condition (WHO, 1996a). In fact, there is currently a common agreement that the effects of treatments should take into account not only the quantity of survivals, but also their quality (Fallowfield, 1990).

Quality of life is a concept that permits to better understand a human reaction to certain health condition, and to determine efficacy of a therapeutic intervention and propose eventual supportive care. Opinions vary when considering areas influencing quality of life, which is characterized by a high subjectivity when reported by a patient. It may include questions of happiness and satisfaction, aspects of physical, functional, psychological and social health (Campbell, Converse, & Rodgers., 1976; de Haan et al., 1993).

The choice of an instrument to be used in the study depends therefore on the objectives to be achieved. It is recommendable to employ generic measures when the interest sits in a comparison between health conditions. Yet, those can fail to detect specific aspects of disease when applied. Williams (1998) argues that employing generic measures in case of stroke patients brings a number of problematic issues, namely content validity of the domains, content validity of the items and sensitivity for a change, that is, responsiveness.

The principal axis of this study involved the role and importance of intersectoral initiatives for assuring quality in patient-driven health and social care, patient satisfaction and quality of life. In this understanding, the interest resided in a broader range of factors that influence one's quality of life and quality of life was here one of components under investigation, although not only one. While a stroke-specific measure would allow to make a concrete judgment on the impact on health-related quality of life for cerebrovascular accident survivors, a generic measure brings the advantage to encompass a wider spectrum of factors. It is not, however, developed to tackle specific conditions for stroke patients and there was concern on not having capacity of focusing on disease-specific elements that only stroke survivors might experience. Also, present study did not have in its interest making a comparison between different ranges of illnesses but focused on one condition. A deeper analysis led to choosing disease-specific scale. An appealing, disease-specific measure identified during the critical review process was the Stroke-Specific Quality of Life Scale.

The SS-QoL aims to assess the spectrum of possible post-stroke symptoms, covering 12 domains with 49 items. Higher scores indicate better function (Williams et al., 1999). The SS-QoL was shown to demonstrate excellent internal reliability (the Cronbach's α values for each domain ≥ 0.73). Construct validity was assessed by comparing a given domain scores with similar domains of existing and established measures. Most domains were moderately correlated with established outcome measures (r^2 ranged from 0.3 to 0.5). Also, most domains were responsive to change (Williams et al., 1999). The measure has been tested in patients with mild to moderate stroke. It has not been tested in patients severely affected by cerebrovascular accident.

The original SS-QoL items were translated from English to Portuguese by two researchers. Next, the scale was reviewed by two gerontologists, both of them native Portuguese speakers. When translating the integral assessment instrument to another language, one must guarantee that the translated version measures the same construct as the original scale. The technique applied was 'back translation' which consists in translating the previously translated instrument back to its original language (Presser et al., 2004). Results of this procedure were suitable and therefore a further use of the instrument was legitimate.

A number of interesting critics arose when translating the scale. Some items are constructed in form of a question and a respondent must give an opinion on each item using the corresponding response set as indicated on the scale (Williams et al., 1999). This can be confusing as it takes additional time to detect which response set is the correct for the item in cause. Other questions do not have a direct way and use an affirmative form. The response key set can be found in Table 34.

Table 34. The SS-QoL response key set

1.	Total help	A lot of help	Some help	A little help	No help needed
	1	2	3	4	5
2.	Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
	1	2	3	4	5
3.	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
	1	2	3	4	5

Source: Adapted from Williams et al. (1999)

Furthermore, at that stage a number of questionable items were identified regarding employed wording and a possible answer it might lead to. In the Language, Mobility, Self-care, Upper Extremity Function, Vision, and Work/Productivity dimensions, the authors propose a set of questions asking ‘*Did you have trouble’…?*” and ‘*Did you need help…?*’ Depending on the interpretation of a question formulated in such manner, the response could be driven by cultural factors or not. The fact is that in the Portuguese language, especially bearing in mind the population of the study, an answer could be ‘Yes’ or ‘No’, rather than ‘Total help’, ‘No help needed’, and ‘Couldn’t do it at all’ or ‘No trouble at all’. Another, even more serious issue concerning the interpretation, which called the attention was a set of three items:

- *‘Did you lose your balance when bending over to or reaching for something?’* (Mobility dimension)
- *‘Did you have to repeat yourself so others could understand you?’* (Language dimension)
- *‘Did you have to stop and rest more than you would like when walking or using the wheelchair?’* (Mobility dimension)

None of the proposed response possibilities from the response set suited these questions. In fact, the most indicated answer would be ‘Yes’ or ‘No’, unless the form was changed (from *‘Did you lose your balance when bending over to or reaching for something?’* to *‘I lost my balance when bending over to or reaching for something’* (what imposes an ‘Agree’/‘Disagree’ answer)).

One more challenge in using the SS-QoL instrument for evaluating quality of life in the studied population was the fact the measure had not been yet validated for the Portuguese language from Portugal. The original measure was created in English and was, in fact, validated for the Portuguese from Brazil (dos Santos, 2007), together with cultural and language adaptation.

Cultural and linguistic relevance is an important element when developing or adapting a measure. In the specific case of quality of life, perceptions between cultures and countries vary on what constitutes quality of life. Cultures differ in perceptions on lifestyles and behaviors, also those related to health, attitudes, and typology and frequency of social interactions. Schmidt and Bullinger (2003) suggest that both, a perception of quality of life and health need to be understood when dealing with quality of life in cross-national studies. Differences in perceptions on health and quality of life have been increasing due to populations' migration. The process of globalization has changed a structure and features of nations. In this way, national versions of quality of life measures are meant to fully reflect a culture and a language (Skevington, Bradshaw, & Saxena, 1999).

Psychometric properties of an instrument applied for the research are vital for guaranteeing that conclusions are valid and feasible. While in management and economics use of different types of questionnaires is a common practice and voices on their properties are less frequently raised, research in health care finds a sufficient level of reliability, validity and responsiveness indispensable for a further use of an instrument.

Validation of an instrument is a process that evaluates evidence permitting to believe that the instrument measures what it is supposed to measure (Hobart, Lamping, & Thompson, 1996). Validity encompasses three components: criterion validity, content validity and construct validity.

Criterion validity concerns a good capacity to have empirical association with another, well-established instrument, commonly used to measure a characteristic of interest. Whenever possible, a 'gold standard' for a given case is identified and compared with.

Content validity verifies whether a composition of a measure demonstrates an ability to be sensitive to within-patient change (Williams et al., 1999) and reflects well the domain of interest. It is particularly important in clinical trials.

Construct validity encompasses an evaluation of a degree of confidence deposited in the instrument believing it measures what it was designed for. The interest goes to its capacity to distinguish groups of respondents and lead to consistent results (Hobart, Lamping, & Thompson, 1996).

In light of previous considerations regarding problematic issues of the SS-QoL, it was decided to present the SS-QoL measure as two sets of items, in which the first regarded difficulties that some patients felt after cerebrovascular accident and the second asked for a level of concordance/discordance with the affirmations made. Each item was followed with a response set, measured in a Likert scale, as in the original instrument, from 1 to 5 in the increasing order. Consequently, in the first part, response 1 was classified as ‘Couldn’t do it at all’ and 5 as ‘No trouble at all’. In the second part of the measure, response 1 meant ‘Strongly agree’ and 5 meant ‘Strongly disagree’. During a pre-test, this approach was found to be correct and allowed the smoothness of the data collection process.

5.4.1.4. Careperf measure of service quality

The objective to measure perceived service quality and satisfaction with institutions constituting the network of care encompassed the study on service quality models and instruments in use.

Traditionally, attempts to measure a construct of service quality focused on the goods sector. Only in the 1980s, Parasuraman, Zeithaml and Berry (1985) stated that the understanding service quality could and should be extended to the services sector. Cronin and Taylor (1992) proposed that service quality was a form of consumer attitude and deemed performance the crucial element for determining quality rather than a combination of performance and expectations. They argued that the concept of service quality as understood by the SERVQUAL was confusing with the concept of satisfaction. The SERVPERF was a variation of the SERVQUAL scale with 22 items focused on service performance. In several posterior works, the superiority of the SERVPERF has been proven, in both, simultaneous application of the SERVQUAL and the SERVPERF, and a better fit, thus explaining a greater variance when comparing to service quality measured by a single item (Brady, Cronin, & Brand, 2002; Cronin & Taylor, 1992). The SERVPERF items, adapted to the present study are provided in Appendice 4.

Questions 1 to 4 of the SERVPERF (Tangibles) refer to physical facilities (including building, renovation, equipment, etc.). Questions 5 to 9 describe the capacity to fulfill promised services accurately and dependably (Reliability). Questions 10 to 13 measure Responsiveness, that is, the service provider’s willingness to help the customers and provide the timely service. The dimension of Assurance (questions 14 to 17) refers to employees’ ability to encourage trust and confidence, and involves courtesy, competence, security and credibility (Ojo, 2010). The last part of items (questions 18 to 22) is used to measure Empathy, that is, individualized attention given to the facility users.

The Careperf contains items extracted from the original SERVPERF and modified to suit into the specificity of health and social care services. Additionally, few more items were proposed in order to encompass issues specific to the health and social care environment and investigate how they impact the perception of service quality. The scale was a subject of statistical suitability in further steps. The initial proposed items were:

- *'XYZ knows a patient record (e.g. previous exams and results, medication)'*
- *'Professionals of XYZ do not provide information on services and treatments available at other institutions'*
- *'Professionals of XYZ inform about entities that might help in patient's specific case (e.g. appointments, transportation by firemen, social support, exams, spiritual support)'*
- *'Professionals of XYZ put patients in contact with entities that may be useful in their case (e.g. appointments, transportation by firemen, social support, exams, spiritual support)'*
- *'When necessary, XYZ contacts the entity who treated a patient before (e.g. family doctor, fire department)'*

These items were thought to determine communication and information flow. There was an interest whether institutions in the network of care were informed and up to date with the patient medical information, and whether they provided patients with the information about other possible and available treatments and entities which could be helpful for them, and the availability of such information.

- '*Employees of XYZ do not respect the privacy of patients'*
- *'XYZ has conditions guaranteeing that patient's data are not accessed by unauthorized persons'*
- *'Professionals of XYZ treat patient information confidentially'*
- *'XYZ has conditions that guarantee privacy'*

These items were developed to assess conditions relevant to guarantee privacy, both in terms of the physical condititions and facilities, and patient medical information.

- *'Professionals of XYZ use comprehensible language'*
- *'Professionals of XYZ encourage patients to speak of their situation with family and friends'*
- *'Professionals of XYZ explain what to do in order to avoid similar situations in the future' [i.e. cerebrovascular accident]'*

The last group of items was developed to evaluate moral and human attitudes among professionals in the network of care for stroke patients.

The original items were translated from English to Portuguese by two researchers. Next, the scale was reviewed by two gerontologists, both of them native Portuguese speakers. When translating the integral assessment instrument to another language, one must guarantee that the translated version measures the same construct as the original scale. The technique applied was 'back translation' which consists in translating the previously translated instrument back to its original language (Presser et al., 2004). Given that the population of the study suffered cerebrovascular accident, what habitually leads to some level of cognitive impairment and respondents were expected to be averagely elder, a pre-test was conducted in the initial phase of the study. It allowed to tackle down some problematic issues, especially in wording, and to verify whether the construct to be measured was the same as expected. Several modifications to the initial version were made in terms of difficulty of applied expressions. It became necessary to provide common versions of words (cerebrovascular accident - stroke) and give examples in case of some items. These modifications were found to provide a more comprehensible structure than the initial one. Moreover, the word 'employee' from the original SERVPERF was decided to be translated into 'professional' or 'employee' (=worker) as it was found to better illustrate the professional position within the institution (medical staff vs. administrative staff).

The instrument applied the same as the original SERVPERF 7-point Likert scale where 1 meant 'Strongly disagree' and 7 meant 'Strongly agree'. It is argued that a scale that offers respondents a greater range of answers enhances its reliability (Oppenheim, 1992).

The final version of the Careperf measure contained some converted items, where 1 was the highest score and 7 was the lowest score from the viewpoint of service quality, deeming necessary previous transformations before any statistical analyses.

The measure was applied regarding patient experience with Hospital Infante D. Pedro to which the patient was admitted with cerebrovascular accident diagnosis, other hospitals (if hospitalized in a consequence of stroke), any inpatient rehabilitation unit(s) the patient was admitted after stroke, physiotherapy clinic(s) used, and a health center. The above entities had been considered previously to the study as the ones expected to be more contacted and, as such, were assessed using a quantitative measure.

5.4.1.5. Lubben Social Network Scale-18

The relevance of social relationships during the course of life is indisputable, and while their origins and purposes differ over the lifespan, strong associations have consistently been found supporting the assumption that stronger social bonds enhance mental and physical health outcomes (Umberson & Montez, 2010). On the other hand, low levels of social support networks have been proven to correlate with depression, hospitalization and mortality (Lubben & Gironda, 2004).

This rising awareness of scholars resulted initially in a number of works with no theoretical background and severe inconsistencies in defining of what social networks were and what they included. Lubben and Gironda (2003) report a number of synonyms they found in literature to define that construct, such as social bonds, social integration, meaningful social contacts, social ties, guidance, emotional support, human companionships, reciprocity, and confidants.

The first Lubben Scale (LSNS) was developed in 1988 and revised in 2002 giving origin to the LSNS-R together with an abbreviated version of the LSNS-6. The purpose of the last version was to compress as much information as possible and still meet clinicians' needs. Then, the expanded LSNS-18 version allowed for directing specifically oriented purposes.

The Lubben Social Network Scale-18 (LSNS-18) (Boston College) is an 18-item, self-reported scale to assess current social relationships and therefore, an eventual isolation in adults. The key set applied by the instrument is provided in Table 35. Each subscale is composed of six items, with the same questions, referring to family, neighbors and friends sequentially. Responses are measured in a 6-point Likert scale, from 0 to 5. In three subscales, the maximum possible score is 30, and the higher the score, the higher considered social support a person received from the group under consideration. The total maximum score of the scale is 90. The scale consists of an equally weighted sum of items and can be considered either within a group or as a total score.

Table 35. Answer key for the LSNS-18

none	one	two	three or four	five thru eight	nine or more
0	1	2	3	4	5
less than monthly	monthly	few times a month	weekly	few times a week	daily
0	1	2	3	4	5
never	seldom	sometimes	often	very often	always
0	1	2	3	4	5

Source: Boston College (2014)

The original scale uses in itself simple and comprehensible language; however the translation from English to Portuguese was confirmed by a native Portuguese researcher. Again, the technique applied here was ‘back translation’ (Presser et al., 2004).

5.4.1.6. Interview with stroke patients

Interviews are a well-established method for data collection in qualitative research, having reached a status of a standard in health care research (Silverman, 2000). They can be defined as a form of conversation between the interviewer and the interviewee on a specified topic, generating an interaction and leading to a deeper understanding on the interviewee’s perceptions. Interviews are a powerful tool for gathering information, especially when difficult and sensitive topics are concerned (Frey & Fontana, 2000). This fact puts on the interviewer an additional responsibility to create a connection and empathy in order to encourage the participant to interact as from their viewpoint the interview is a unique experience. Thus, an interview is capable to assess thoughts, perceptions and feelings, and provide an insight to how a certain person understands the world (Patton, 2002).

At the same time, by employing a person to drive a conversation, interviews cannot be considered an impartial data collection method. The final effect depends on the participation of, at least, two persons, and their involvement, given that they exert mutual influence on each other (Rubin & Rubin, 2005).

For researchers, different options of conducting interviews exist. Patton (2002) points out structured, unstructured and semi-structured forms of interviews.

Structured interviews are questionnaires with an underlying, highly specified structure that shall simplify the process of coding and analyzing data (DiCicco-Bloom & Crabtree, 2006). Rubin and Rubin (2005) argue that structured interviewed are the most appropriate to be administered when short and simple answers are expected and acceptable responses to questions. However, when searching for deeper understanding of a phenomenon and comprehending people’s experiences and opinions, a broader response is desirable, therefore, structured interviews should not be applied.

Unstructured interviews are characterized by a high level of flexibility in the process of gathering data. A limited number of broad topics are prepared to guide the conversation and obtain an in-depth perspective of the interviewee, what results in rich and extensive information. In some cases, no questions are prepared in advance (Rubin & Rubin, 2005). Conversely, a high degree of variability between interviews (and interviewers, when applicable) may be noted what hinders the process of data analysis and comparison.

Semi-structured interviews are a data collection tool with the principles sitting in between the two previous formats. They require a definition of the topic to be discussed with the interviewee, although still allow for creating additional questions when necessary and changing the order of questions (Rubin & Rubin, 2005). This method of inquiry combines open questions with a chance for a further exploration of specific questions. A semi-structured interview begins with a group of open-ended questions which allow participants to deliver deep and detail responses, encouraging patience and clarification. It is conducted with a fairly open framework which brings focused, conversational communication between two parties. Whilst a structured interview has a limited number of well-formalized questions, a semi-structured interview allows for raising new questions as a result of what has been discussed. The interviewer in a semi-structured interview generally has a framework of themes to be explored. Data are analyzed qualitatively.

While interview and questionnaire data are commonly reported conjointly, the protocol of data collection and analysis in a questionnaire and in an interview differs. Harris and Brown (2010) deem them possibly complementary methods of data collection. In case of questionnaires, their performance as a research tool can be susceptible to design, sampling and non-response errors, respondent and/or administrator unreliability or a mistake. More challenges are brought in the analysis phase, with errors in coding and analyzing results. An interview provides information based on personal contact hence it is contextually driven. Qualitative interview data can provide the researcher with an in-depth insight on the participants' opinions, thoughts and attitudes. The interviewer may deepen a general comprehension of an issue by questioning and allowing an interviewee to confer, elaborate on ideas and clarify doubts. On the other hand, the interviewer's manner of administering questions may lead to a manipulation of responses as well as leading the interviewee to answer what is socially accepted and desirable. This, however, can also apply to a questionnaire administration and research disagrees at this point about which research modes are most influenced in this manner (Richman et al., 1999). In contrary to a questionnaire, interview results are hardly replicable and difficult to generalize as based on relatively small sample sizes and due to the fact that respondents may be, in fact, answering different questions.

For the purpose of the present study, a semi-structured format was thought to be the most suitable and decided to be applied as it shares advantages of structured and unstructured interviews. In this manner, the care pathway of each participant of the study was drawn and subjective experiences and opinions were gathered, giving space for discussing complementary issues regarding situations that occurred within six months after discharge from the stroke unit.

The next decision regarding interviewing participants related to means by which each interview was to be conducted. Conducting interviews at the University of Aveiro was impossible due to a number of reasons. The sample to be investigated included stroke patients and it was expected, even six months after the event, to suffer consequences of cerebrovascular accident. Speech or motor functions were expected to be the most affected, in line with previous evidence. For a participant, this would require a physical effort and time spent on journey, which in case of that population constitutes a serious burden. It was also thought participants would feel more comfortable in their usual environment. Moreover, some of patients at the time of interview were staying at nursing homes, under institutional responsibility. Legal constrains related to taking a patient from a nursing home led into decision to undertake interviews at the current place of stay of the patient. Finally, employing other methods such as telephone or internet would be problematic.

The interview guide was designed with an objective to explore patient's perspective about the contact with institutions, transitions between them, and functioning of the system as a whole with an extended insight into subjective feelings related to these experiences. Open-ended questions intended to obtain the greatest thematic depth that would allow to explore its meaning ensuring data saturation (Masniak, 2003).

There were two, general, objectives of the interview:

- Investigating the respondent's perceptions about contacts with institutions of health and social care, support, aid, transportation and others, and transitions between them;
- Investigating perceptions of service quality in entities that were not evaluated using the Careperf measure (the institutions expected, *a priori*, to represent the number of interactions too low to be treated by quantitative statistical methods).

The guide was constructed in a way to follow the way a patient passed throughout the health and social care systems from the moment of discharge and tackle other entities that contributed to the final experience. Contacted institutions were listed in each case. Participants were asked about their experiences and subjective opinions on specific issues arising from those contacts. Flexibility and lack of restrictions were guaranteed by the interviewer.

Questions were made about all entities involved in provision of care and support except the ones that were already evaluated by the participant using the Careperf measure. Questions prepared for the interview reflected the dimensions and the most relevant issues from the Careperf instrument in a qualitative manner.

The interview began with a set of questions on a possible contact in one or more rehabilitation unit (inpatient stay) and the experience related with it. If the respondent was not hospitalized in a rehabilitation unit within the six-month period of the study, that part was omitted. Next, the guide inquired for a subjective assessment of the conditions the patient felt to have in the current place of stay, from the viewpoint of specific needs related to cerebrovascular accident.

The second part of the interview tackled specific entities the participant had contact with in the course of the six months from stroke. It started with the moment of emergency, and the further steps that were made to provide the patient with medical assistance. From entities found to be contacted by a given participant, the next group of questions regarded the first and eventual further contacts with the entity, formal diagnosis of the patient's condition or needs, the type of received support and its evaluation, physical infrastructure and its evaluation, promptness, privacy and payment for the service.

One issue of special interest to the present work was information on other services and treatments received from the entity in cause, and availability of such information for wider community.

The last group of questions tackled informal social support received from family, neighbors and friends, and perception if its importance with an eventual impact on a patient's life.

Additionally to the open questions set, a few supplementary queries in a quantitative format were appended, regarding entities with which a patient interacted formally and informal social support from family, neighbors and friends. Interest of one set of items focused on satisfaction with a given entity and the perception of the price paid (if paid) for its services.

- *'Relatively to services provided by XYZ, you consider yourself…'*
- *'Relatively to the price you paid, you consider services of XYZ…'*

Another group of items assessed a personal perception of social support from kins and non-kins:

- *'How do you evaluate support you have had from your family?'*
- *'How do you evaluate support you have had from your neighbors?'*
- *'How do you evaluate support you have had from your friends?'*

One quantitative question was a general item assessing the opinion about the community support:

- *'How do you evaluate support that the community provides currently to cases such as yours?'*

The last quantitative question assessed general perception of health status:

- *'How do you evaluate your health condition in this moment?'*

These quantitative questions were evaluated with a 5-point Likert scale, in which 1 corresponded to 'Very bad' and 5 corresponded to 'Very good'. The option 'Does not know/Does not answer' was also available.

The interview procedure involved two team members; one researcher was responsible for conducting the interview and the second made additional annotations that found valuable for the study and dealt with interferences that might arise. The interview guide was constructed in a way to best catch perceptions, thoughts and feelings of the participant. Each participant was asked the permission for discussing with the interviewer experiences after stroke and, in case of a positive answer, a permission to record the interview. Patients were again ensured about the anonymousness and confidentiality of the data. The data were collected using a digital voice recorder, SONY ICD-P620. All possible adjustments were made to the recorder to guarantee the best sound quality. Each interview was recorded under another file name. The files were transferred to the computer and transcribed using specialized software. For clearer understanding of the content, software controlled the speed of voice and headphones were used.

5.4.2. Entities' study

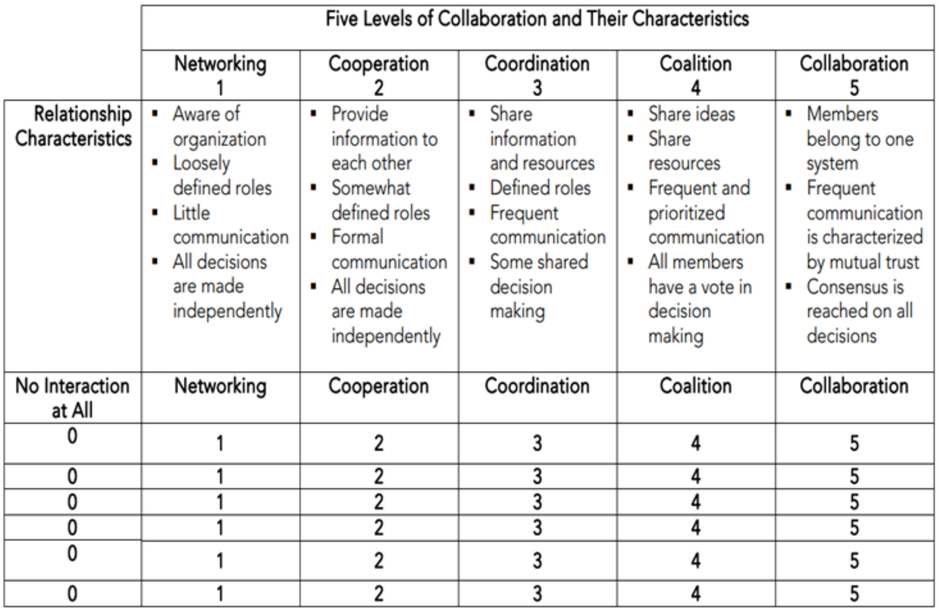
The second phase of the study encompassed identifying and enquiring stroke care and support providers in the Aveiro district. The number of entities mentioned by patients in the Experiences sheet and during interviews constituted a good starting point for the search. Further, a comprehensive search for care providers by type was conducted in order to ensure the highest quality of data. This was done from miscellaneous sources depending on the entity, that is, formal sources (the Ministry of Health, the RNCCI, *União de Misericórdias*) and web pages.

Identified care and assistance entities were later listed and contacted in order to confirm their current situation (active/inactive) and services they provided (whether adequate for stoke patients). Snowballing method was used in order to gather information on entities less accessible through general databases (physiotherapy clinics). With the final list of institutions, those were analyzed in terms of strength of collaborative relationships they maintained between each other. Each entity that agreed to collaborate in the study was requested to assess its relationships in terms of collaboration with others from the network.

Since institutions could be aggregated regarding the typology they represented it was considered feasible to conduct a further interview with a representative of each type of entity providing care and assistance to subjects of the study. The objective of such choice was to understand the position that type of entity played in the network of care and to provide a picture of awareness toward collaboration, its reality and daily practice. Finally, it was hoped that this approach would contribute with further insights into differences between the patient and the care and support provider perspective.

5.4.2.1. Collaboration intensity within the care network for stroke patients

The model of Frey et al. (2006) was used as a tool of determining the intensity of collaboration between entities. This model is based on Hogue's (1993) classification which assumes five stages of relationship strength between organizations, with networking, cooperation, coordination, coalition and collaboration. Among several models under consideration, that was found the most suitable to measure the level of collaboration intensity. Other existing models were thought either too constricted (e.g. three levels) or too extensive (e.g. a seven-stage model) in terms of collaborative stages, the latter one predicting difficulties of its application by interviewees already at the stage of the study design. A five-stage model seemed to be sufficiently broad to encompass the complexity of partnering in the considered context. Frey et al. (2006) recognized additionally that, besides networking (level 1), cooperation (level 2), coordination (level 3), coalition (level 4) and collaboration (level 5), no interaction might exist between entities under consideration, and that possibility was reflected by adding the level 0 to indicate 'no collaboration'. Frey et al. (2006) adjusted the categorization described in detail by Hogue (1993) and provided a shortened and a more simple definition and description for respondents (compare with Figure 25) making the first attempt to validate the model and discussing issues of its reliability.



	Five Levels of Collaboration and Their Characteristics				
	Networking 1	Cooperation 2	Coordination 3	Coalition 4	Collaboration 5
Relationship Characteristics	▪ Aware of organization ▪ Loosely defined roles ▪ Little communication ▪ All decisions are made independently	▪ Provide information to each other ▪ Somewhat defined roles ▪ Formal communication ▪ All decisions are made independently	▪ Share information and resources ▪ Defined roles ▪ Frequent communication ▪ Some shared decision making	▪ Share ideas ▪ Share resources ▪ Frequent and prioritized communication ▪ All members have a vote in decision making	▪ Members belong to one system ▪ Frequent communication is characterized by mutual trust ▪ Consensus is reached on all decisions
No Interaction at All	Networking	Cooperation	Coordination	Coalition	Collaboration
0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5

Source: Frey et al. (2006)

Figure 25. Five levels of collaboration and their features according to Frey et al. (2006)

A pre-test of the model proposed by Frey et al. (2006) was made in order to guarantee its further applicability into the Portuguese context. During a pre-test, few issues related to the interpretation of the original classification were raised. More specifically, doubts concerned the levels of coalition and collaboration. One problem was with the meaning of the expression ‘coalition’, somewhat confusing despite having provided a short explanation of the level. Another problem was related to collaboration, of which definition indicates that members on that level belong to one system. A term suggested as more suitable to that description was ‘integration’. That, however, would change the measure elaborated by Frey et al. (2006) right at the study design phase. One solution to that challenge was using the specification provided by the authors with a support of a numbered format as indicators of the intensity of collaboration. The decision fell therefore into using the model in its original form and giving special emphasis on explaining well the levels originally proposed. A numbered format instead of using a full taxonomy would be employed only in exceptional cases if a respondent expressed serious difficulties in understanding the definitions.

5.4.2.2. Interviews with key informants of care and assistance providers for stroke patients

As complementary to interviews with patients, the opinion of key informants from entities identified as care and support providers for stroke survivors was considered. The premise behind that idea was to confront the care provider’s perspective with the patient’s one. Again, the qualitative approach was deemed more advantageous for this part of the study as the one allowing to expand the understanding of the topic under investigation. The qualitative approach would address wider issues bringing a contribution to understanding awareness interviewees would had on collaboration that might eventually enhance organizational setting of collaborations and its everyday practice and stroke patients' life and its quality.

Two methods were considered initially to gather information from key informants: focus groups and individual interviews. At the first sight, a focus group method seemed more attractive, especially due to a possibility to face informants from different organizational settings in one place at the same time, and to tackle and discuss in group their perspectives. Such attributes were believed appealing for the purpose of the present study. Possible obstacles for an eventual organization of the focus group were mostly related to logistical factors. However, an initial attempt to contact a few key informants revealed a limited willingness and readiness for a group discussion. Thus, person to person semi-structured interviews were chosen as a preferable method for data gathering.

The interview guide was prepared in advance. It was based on the initial draft on issues emerging from the literature review. The framework used as a baseline for the interview guide was the one of Valentijn et al. (2013), which steered the issues to be raised during the interview according to the proposed levels and which then were adapted to the context and specificity of the study. The framework is part of the conceptual model of the authors focusing on dimensions of integrated care. According to the authors, three levels constitute integration of care: the Macro (system) level, the Meso (organizational) level, and the Micro (clinical) level.

At the Macro level, integration relates to systemic determinants such as legislation, general regulations, budget policy and allocation, efficiency and/or quality incentive schemes, professional practice regulations, professional compensation schemes, among others (San Martin-Rodriguez et al., 2005). System integration obliges to combine structures, processes and methods in order to provide adequate response to population growing health and social care complex needs. At the Macro level, integration is concerned on issues of population quality of life, quality of care and patient satisfaction (Valentijn et al., 2013).

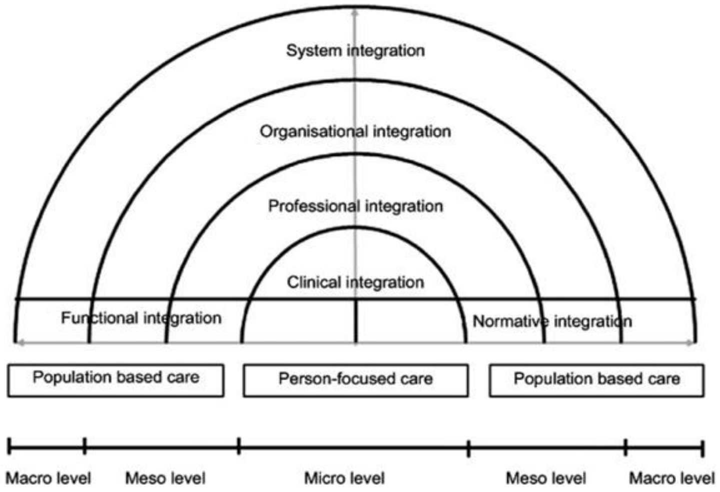
At the Meso level, integration may relate to two of its forms: organizational integration and professional integration. It applies to the way and the degree to which care services are provided to a patient in interconnected and interrelated routines between care entities. Organizational integration relates with relationships between entities to provide comprehensive services. Professional integration refers to collaboration between professionals within one care organization and between care organizations, and gains its importance in a society with complex health care conditions with multiple comorbidities and accompanied by social care needs (Valentijn et al., 2013). Generally, at the Meso level integration concerns a set of factors which will exert a positive or negative impact at a relationship between actors comprising issues such as human resources management, training and skills of care providers, professional roles and accountability limits, service approaches, and bureaucratic structures (Browne et al., 2004; San Martin-Rodriguez et al., 2005).

At the Micro level, according to Valentijn et al. (2013), clinical integration is defined as “the coordination of person-focused care in a single process across time, place and discipline”. A person-focused care is thus essential in this approach, however, as admitted, that is not necessarily a case as a tendency drifts rather into disease-focused integration (Stange & Ferrer, 2009 cited in Valentijn et al., 2013).

Functional integration is one dimension of integration which connects and supports a relation between clinical integration, organizational and professional integration with the highest, system level. Functional integration encompasses instruments and tools necessary for linking managerial, financial and information systems in the continuum of the delivery of care services. In this way, functional integration comprises aspects of strategic planning, financial management, human resources, and information management (Valentijn et al., 2013).

Normative integration is another dimension of integration linking the Micro integration, the Meso integration and the Macro integration levels. It is considered less tangible than functional integration. Valentijn et al. (2013) define it as “the development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organisations, professional groups and individuals”.

The framework described above and employed as a starting point for constructing the interview guide is presented in Figure 26.



Source: Valentijn et al. (2013)

Figure 26. Conceptual framework for integrated care based on integrated functions of primary care of Valentijn et al. (2013)

The guide was prepared according to the framework and context of the study and derives from literature review including additional topics, which ensued from the interviews with patients. In this way, a number of issues relevant to stroke patients could encounter their counterbalance from the institutional perspective.

The first version of the guide was pre-pretested with a key informant from HIP. The key informant was a social assistant from the hospital. As a representative of the central entity of the study, she had a particularly extended vision of the health and social care reality including the functioning of the RNCCI and patient flow throughout the system and their situation. She provided supplementary insights to the interview guide.

The final version of the guide was modified according to topics that arose from the discussion with the key informant. One quantitative item was included to the interview with an objective to evaluate a perception of the community support that stroke survivors could count on. The guide was based on the understanding that in the intersectoral reality integration might not necessarily be the most appropriate level of a collaborative relationship between partners as integration of activities is context-driven and limited by legal, organizational and circumstantial factors. Collaboration between care entities seemed a more logic and feasible approach toward an eventual organizational relationship.

Entities chosen to represent a type of institution were those identified as having more interactions with participants of the study. An important step in the establishing the first contact was to identify the right person to be interviewed within the entity. The person with the best profile for the study would be the one with knowledge of institution as a whole, although with sufficient familiarity of legislation in force constituting basis for practice.

The first contact with an entity was made by telephone and had as an objective present the study and the purpose of the interview. The responsible was explained the importance of choosing the right person for the interview in order to achieve its goals. In case of a positive feedback, day and time of the interview were scheduled. In some cases, email or telephone contact of the interviewee was provided for scheduling convenient time directly. In those cases, a previous contact with the supervisor and the acquired permission were accentuated.

For several reasons, interviews had to be conducted in the local. The need to dispense an employee for an interview in an external localization could negatively impact a willingness. Interviewees would also be automatically obliged to arrange transportation, what would imply costs and more time out of service.

At the beginning of the session, each interviewee was presented shortly the study and the importance of the interview. Participants were asked permission for discussing with the interviewer issues related with support and care provided to stroke patients and eventual communication and collaboration with other entities in that matter. Participants were ensured about anonymousness and confidentiality of the data. The data were collected using a digital voice recorder (model SONY ICD-P620). Necessary adjustments were made to the recorder to guarantee the best quality of the sound. Each interview was recorded under another file name. The files were transferred to the computer and transcribed using specialized software. For a clearer understanding of the content, software controlled the speed of voice and headphones were used.

5.5. Data collection

Data collection began in the Stroke Unit of HIP when a patient was conscious and aware, within 72 hours, that is, around the second or third day after admission. According to the procedures of the HOMECARE study, patients were randomized into the study and control groups. The study group was a subject of the intervention of the team of professionals providing especially outlined treatment according to patients’ condition and needs, and could count on information, doubts clarification and support in what the health and social systems offered and how they functioned. The team, above the case manager, included a physiotherapist, an occupational therapist and a psychologist. The team worked with the patient at home for a maximum one month, although the case manager would follow patients within the next six months.

Additionally, the project leader was responsible for managing the overall project, defining, planning and organizing consecutive phases, attributing responsibilities, tracking and controlling the progress. The author of the study was the project researcher and accompanied case managers and collected data according to the schedule defined to the present work.

As strategies and skills were directly implemented into real life, it was possible for the patient and family members to continuously trail the evolution. The intervention was defined taking in consideration the patient's needs and expectations. Rehabilitation was focused on activities valued by a certain patient and happened in the natural context in order to facilitate a transfer of effort and adaptation to daily life. The content of activities differed from meaningful exercises (for instance, one participant wanted to be able to paint her nails again) and personal care to walking, doing shopping and outdoor activities. Another support the study group might have counted for was finding help in the community, especially concerning technical aids as a wheelchair or an articulated bed, or a possible help with a house adaptation concerned. What was also relevant was that family and supporters were involved in the process, receiving information about stroke the patient had suffered, its consequences in several aspects of life and advice on how to deal with them, and best manners of collaborating in the rehabilitation process. The team offered information and training tailored to the patient and the specific situation.

For patients discharged to the RNCCI unit for further inpatient rehabilitation, a contact with the professional team was retaken when the planning for home discharge started.

Patients in the control group received the usual care from the system. For those patients and their relatives it was expected that fewer opportunities existed to seek direct support and clarify eventual doubts that might have arisen.

The present work did not use the logic of RCT as it was considered that separation of the groups would not contribute to the primary interest of this study, that is, collaborative relations between entities and its impact on variables in question. A number of reasons contributed to this decision: the study had non-experimental design; there was no total control over subjects; participants of both groups could use any health and social care services or other type of support they desired, knew about or could afford; information about services and support available in the community did not depend merely on participation in the study group; and several other elements could enhance patient's information about the system functioning and availability of services.

5.5.1. General orientations

Data collection for the empirical part of this study comprised a number of quantitative and qualitative measures, spread over time. Patients were questioned about their expectations at discharge which were further confronted with experiences six months after, they were asked about their quality of life (with the use of the SS-QoL), social support (with the use of the Lubben Social Network Scale-18) and service quality of health and social care institutions they had interacted with (with the use of the Careperf measure, according to pre-defined criteria). Participants were interviewed in order to provide an insight to the systems' functioning, care transitions from the user's perspective and the service quality as experienced by the patient.

Entities identified as those constituting the network of care for stroke survivors were identified and contacted to evaluate the level of intensity of collaborative relationships with all other members of the network. Finally, key informants from the entities representing institutions of the network of care were asked the permission for an interview, as well.

5.5.2. Data collection schedule

Given the quantity of measures to be used and their variety, it was of great importance to organize well the data collection process in advance. Data were gathered according to pre-established schedule. All measures employed throughout the study span and the total duration of data collection of each of them, from the first to the last participant, are presented in Figure 27. Figure 28 provides more detailed information of data collection process, with the exact data collection timetable.

	Task name	Duration
(1)	Expectations sheet	31.5 months
(2)	Careperf	31.5 months
(3)	SS-QoL 2months	33.6 months
(4)	SS-QoL 6months	31.6 months
(5)	Experiences sheet	28.3 months
(6)	LSNS-18	28.3 months
(7)	Interview patients	28.3 months
(8)	Collaboration intensity	4.4 months
(9)	Interview entities	2.2 months

Figure 27. Study components and their duration

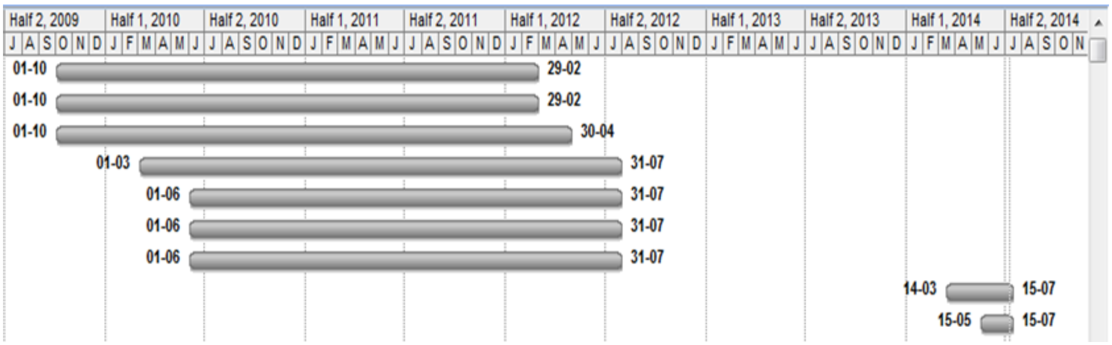


Figure 28. Data collection schedule

Data collection in the first phase started in April 2009 and terminated in April 2013 (last participant left the study) what corresponds to the trial period of the HOMECARE project. Individually, each respondent was accompanied during six months, and the starting point depended on time of cerebrovascular accident occurrence. Quantitative data were collected at baseline in the stroke ward and up to the end of the six-month follow-up at precisely defined moments. At that time, the participant was also asked to be interviewed providing qualitative data to the study. The present work went beyond time limits of the HOMECARE project.

In the second phase of data collection, information representing the institutional perspective was gathered. The objective of that phase was to counterbalance the standpoint of the care receiver by that of a care provider offering a comprehensive vision of the care system. For that purpose, institutions providing care and assistance to stroke patients were identified and contacted in order to determine collaborative linkages and strength between them. Furthermore, supplementary data were collected to enrich the study and provide an institutional insight. From institutions representing care providers, key informants of each type of supporting organization were identified and contacted to be interviewed. Semi-structured interviews were conducted in order to extend the understanding of the system and collaboration in the care sector from the care provider viewpoint.

The sequence of study measures application is presented in Figure 29.

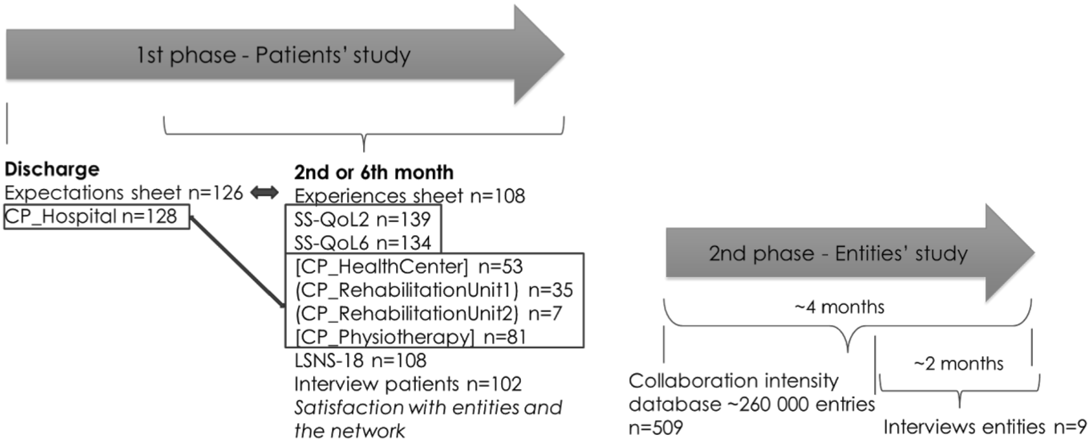


Figure 29. Distribution of applied measures in time

- Expectations sheet was applied at discharge from the Stroke Unit and had an objective evaluating most relevant aspects directly related to patient's post-stroke situation: entities thought to interact with in questions related to stroke and different types of expectations the patient's had.

- The Careperf measure was employed in the 2nd and/or 6th month (case-specific). The choice on its application depended on the individual decision as each patient's pathway and health condition were different. Only in case of HIP the Careperf was employed at discharge. The instrument assessed perceived service quality of the inpatient experience with HIP, (inpatient) rehabilitation unit(s), physiotherapy clinic(s) and a health center.

- The SS-QoL was applied two times throughout the study, two months after the patient's discharge from the Stroke Unit and then, again, in the 6th-month follow-up. A translation of the Stroke-Specific Quality of Life Scale was made from English to Portuguese with some necessary linguistic and cultural adjustments.

- Six months after discharge, patients were contacted by their case manager who had been following their situation in order to schedule convenient day and time to conduct an interview. One day before the scheduled interview the patient was contacted again to assure the interview taking place.

- Experiences sheet was applied six months after discharge from the Stroke Unit to determine institutions (and number of these interactions) that effectively provided any sort of care and support to the patient.

- The Lubben Social Network Scale-18, a measure assessing an individual's perceived social bonds was administered in the 6th month.

All efforts were ensured to provide suitable conditions of work and appropriate distribution of the study components in order to avoid eventual patient burden.

- Entities providing care and assistance to stroke patients in the Aveiro district were identified throughout the study. They were contacted in order to find how they perceived intensity with which they worked with each other in matters related with cerebrovascular accident. Bearing in mind the typology of entities to be contacted it was clear the amount of contacts to be established would be considerable. A number of three attempts of contact per entity were thus set up. In total, data acquisition took 4 months.

- Last stage of data collection consisted in interviews with representatives of care and assistance providers groups. They all took place at given entity. The interviews were conducted in part in parallel with adquiring data on collaboration intensity and took 2 months.

5.6. Data processing and analysis

A specificity of this study was that the data were collected during a considerable long period of time when considering the total time of data acquisition. One part was the data acquisition period at the Stroke Unit of HIP and a six-month follow-up of patients. While one patient was entering into the study becoming a subject of data collection procedures, other participants were already found at another point requiring the employment of other measures. All this was a long-term challenging process and required strong organizational skills. The second part of data collection comprised institutional contacts including identification of entities constituting the network of possible care and support providers for stroke survivors and determining the intensity of collaboration between members of that network. Interviews with representatives of identified institutions were to be conducted with an objective to gather a vision of a service provider on what existing collaboration for stroke patients at Macro, Meso and Micro Levels concerned.

As information from participants of the study was acquired continuously, it would be time consuming and not reasonable to verify all measures one by one, day by day. This was done with a frequency of every few weeks in order to tackle eventual errors in questionnaires.

Quantitative information obtained throughout this study was analyzed using the IBM SPSS Statistics version 21.0 software (SPSS Analytics, IBM, Armonk, NY, USA, 2013) and the IBM AMOS version 21.0 software (IBM, Armonk, NY, USA).

Analyses included, in general terms:

- descriptive statistics;
- parametric and non-parametric correlations;
- parametric and non-parametric tests of hypotheses;
- regressions;
- principal component analysis and factor analysis (with confirmatory factor analysis);
- structural equation modelling (SEM).

Descriptive statistics provide characteristic variables under consideration with use of appropriate measures (Altman & Bland, 1994, 1995). For quantitative measures, a presentation of variables depends on the size of a sample. For bigger samples and variables fulfilling normal distribution criteria, maximum, minimum and mean, and standard deviation as measures of concentration and dispersion are employed. For smaller samples and, consequently, deviating from a normal distribution, maximum, minimum, median or mode, and quintiles are recommended. In case of qualitative variables, suggested indicators include those related to frequencies - absolute or relative numbers, percent (Krzych, 2007). Following recommendations from literature, the study employed absolute and relative frequencies, percentage, maximum and minimum values, mean and standard deviations, and median and mean rank. Spearman correlation coefficient (*rho*) was also applied.

A difference in parametric and non-parametric hypothesis tests relies on constituting a class of statistical procedures of which one does and another does not rely on assumptions about a form of probability distribution data were retrieved from. The most common parametric assumption is that data are approximately normally distributed. That assumption may be, although not exclusively, related to sample size. That became in fact a barrier to perform some parametric tests in some situations and their non-parametric equivalents were used in the data analysis phase. For all analyses, as a reference for rejecting null hypothesis H_0 significance level $\alpha<0.05$ was defined. P-value reported in the tests was bilateral.

For nominal data, analysis for differences between proportions was carried out using Chi-2 independence test, after the verification of the assumption of not existing more than 20% of cells with expected frequencies lower than 5. In cases of not having fulfilled the assumption, the Monte Carlo simulation was employed.

T-test for two independent groups in relation to a continuous dependent variable for comparing differences in their means under the assumption that both samples are random, independent, and come from a normally distributed population with unknown but equal variances was employed.

T-test for two dependent groups was used to compare means between two related populations on the same, continuous, dependent variable under the assumption that both samples were random, independent and derived from a normally distributed population with unknown but equal variances.

ANOVA was used for testing differences between means in more than three independent groups relatively to a quantitative dependent variable, under the assumption of independence of observations, normality of distributions of considered populations and homogeneity of variances of data in the groups.

One-WAY Repeated Measures ANOVA was employed for comparing means of more than three matched groups under the assumption of sphericity. Greenhouse-Geisser correction was used to calculate p-value when variances sphericity was not assumed.

In order to test the adherence of normal distributions Kolmogorov-Smirnov (D) test was employed. In case of absence of normality ($p<0.05$) or in certain situations justified by a type of measure (ordinal), non-parametric tests were employed, more specifically:

Mann-Whitney (U) test, reported in a standardized Z measure was used for comparing two independent groups relatively to a quantitative dependent variable.

Kruskal-Wallis (H) test was used for comparing three or more independent groups relatively to a quantitative dependent variable. In case of having identified significant differences, pairwise comparisons were made.

A linear regression model, especially that including more than one explanatory variable leads to complex interpretation problems. A good model intends to explain the best a phenomenon in a simple manner and with a fewer number of predictors. Using a linear regression method obliges firstly to meet several assumptions. Normality of errors distribution is relevant as its violation compromises the estimation of coefficients and confidence intervals. This may be caused by an existence of extreme observations (outliers or leverages - influential points), which ought to be carefully inspected, not only for the needs of this specific assumption of the regression, but for the others as well. The inferences to violation of normality, show, however, substantial robustness with reasonably large sample size and scholars remind that the actual remedy for large data is the central limit theorem (Yan & Su, 2009). Linearity assumption verifies whether a relationship between regressors and the output variable is truly linear and it is a foundation of a linear regression method. Independence of errors assumes that errors of the dependent variable are uncorrelated with each other. Another assumption is homoscedasticity of residuals in a sense that different response variables have constant variance in the errors, independently on the input values of the predictor variables. Linear regression assumes also no multicollinearity within the predictors as it puts a risk on a meaning of the model input and the sense of the measured phenomenon. Multicollinearity is said to exist between explanatory variables in the regression if these variables by any means depend on each other or are related to each other. While running the model, first symptoms of multicollinearity are high correlation coefficients (between explanatory variables), and a high level of the Variance Inflation Factor-VIF. Multicollinearity is usually tested primarily by inspecting correlation coefficients between the explanatory variables to confirm none exceeding the level of 0.75 (Kutner, Nachtsheim, & Neter, 2004) and and an alarming level of bivariate correlation coefficient between explanatory variables diverges between authors rounding 0.70-0.75 and higher (Hair et al., 2010; Marôco, 2010). A common cut off for VIF is 10 (Hair et al., 2010) although attention should be given to the sample size. The ratio of predictors to the dependent variable should be ideally 15:1 or 10:1, depending on authors (Field, 2009).

Logistic regression is a designation attributed to a generalized linear model with a dichotomous response and dichotomous or continuous independent variables. The odds are defined as the probability of a 'success' outcome divided by the probability of a 'failure' outcome. Logit is the natural logarithm of the odds. The logistic regression model can be written as logit that is the log of the odds (Hair et al., 2010), as:

$$log_e\left(\frac{\pi}{1-\pi}\right) = logit(\pi) = \beta 0 + \beta 1X1 + \beta 2X2 + \cdots + \beta nXn$$

Odds ratio (OR) is a coefficient of association between exposure and outcome. Odds ratio represents the odds that an event (outcome) will occur given a certain exposure compared to the odds that an outcome will occur in the non-existence of an exposure (Szumilas, 2010).

Hosmer-Lemeshow test is commonly employed to verify the overall fit of a model to the observed data. The idea behind this test is to compare the observed and predicted number of events in each group of cases and to construct a goodness-of-fit statistic based in that outcome. The more the expected number approaches the observed, the smaller value the statistic will demonstrate, indicating a good fit. Hosmer-Lemeshow goodness-of-fit statistic used in logistic regression is proven to be more robust, especially when a study of a small sample is of concern (Hosmer & Lemeshow, 2000).

Factor analysis and principal component analysis (PCA) are two techniques often applied into identifying structures of measurement instruments. While differing in their underlying assumptions and applications, they are frequently, and incorrectly, assumed to be the same procedure. Both share a concern on decisions related to extraction of factors/components, number of factors/components to retain, rotation methods or sample size requirements. Moreover, in situations with more than 30 variables and communalities greater than 0.7 it is assumed that solutions of PCA do not differ much from those of factor analysis (Stevens, 2002).

Factor analysis is a statistical technique that seeks the least number of factors of a measure that account for a common variance shared by a set of variables of that measure. Field (2009) argues that factor analysis is most appropriate when “the primary objective is to identify the latent dimensions or constructs represented in the original variables” (p. 108). By reflecting the common variance of the variables, factors omit automatically variable-specific variance (Costello & Osborne, 2005).

Principal component analysis is a statistical technique that decomposes the data into a sum of uncorrelated components. Conceptually, the objective of PCA is to reduce the number of studied variables by analyzing the total observed variance (in contrary to factor analysis) into a new, smaller set of components equal to the number of original variables. Components reflect the common variance of the variables and their unique variance. PCA looks therefore for linear combinations of the originally inputted features. The first principal component (PC1) will always be the projection with the largest variance. A projection produces a linear combination of the variables with an arbitrary sign (since variance does not depend on sign). Each next PC is understood as a projection of the variables in the study, uncorrelated with the previous PCs and with maximal variance. That component is formed from the variance remaining after that associated with the previous components which have already been extracted.

Guidelines concerning a number of subjects to be involved in the study form two different approaches, one proposing a minimum sample size to be involved in the operationalization of the study, and another, suggesting a ratio of respondents to analyzed variables. Recommendations for the sample size vary, and while some scholars (Barrett & Kline, 1981) accept quite low numbers of subjects, according to others (Aleamoni, 1976) the optimal size should reach 400 observations. Comrey and Lee’s (1992) cited in Field (2009) advice is that a sample size of 100 is poor, 200 is fair, 300 is good and above 500 is very good. On the other hand, a sample size is a relative factor and its importance depends, unquestionably, on a number of variables in the study. For this reason, some authors (Gorusch, 1983; Hatcher, 1994) suggest the lowest subject to item ratio, such as 5:1 or 10:1. As a rule of thumb, a bare minimum of 10 observations per variable is necessary to avoid computational difficulties (Field, 2009).

A number of strategies are available to determine factors/components to be retained. The Kaiser (1960) criterion (latent root criterion) proposes excluding those with eigenvalues lower than 1. Another method is Cattell's (1960) scree plot. This graphical form is derived by plotting eigenvalues against the number of factors/components in their number of extraction and suggests ignoring those which eigenvalues level is off to the right of the plot seeking a clear break point of the curve. The percentage of variance criterion is an approach recommending achieving a specified percentage of total variance. A reason behind this logic is to guarantee that extracted factors explain at least a given percentage of variance. While no concrete indication exists, it is commonly accepted that 60% of the total explained variance (or less, in some situations) is a satisfactory level for social sciences (Hair et al., 2010).

An unrotated factor matrix is an initial solution containing factor loadings for each variable on each factor. Factor loading is a correlation of a variable and a factor, making a variable with a higher loading more representative for a certain factor. Since in most cases the initial solution does not bring adequate interpretation of the data, a rotational method is employed. Two types of rotations are possible, orthogonal and oblique, maintaining or not the 90-degree angle between axes and thus allowing correlated factors instead of independence between the rotated factors. Orthogonal rotation methods available in the IMB SPSS Statistics version 21.0 (SPSS Analytics, IBM, Armonk, NY, USA, 2013) include Varimax, Quartimax and Equimax, and oblique rotation methods include Direct Oblimin and Promax.

Communality is a total amount of variance a given variable has in common with the construct upon which it loads. Individual variables combined into a single measure are defined as summated scale comprised on all variables loading highly into a factor of which, in a posterior phase, an average score is used as a substitution variable. A requirement for a summated scale is that composing items are unidimensional. Items that loaded highly on one factor should compose a summated scale and in case a scale is built from multiple dimensions, each from them should find a manifestation in a separate factor. Unidimensionality may be assessed in an exploratory or confirmatory factor analysis (CFA) (Hair et al., 2010).

Reliability is a process of verification of a degree of consistency between several measurements of a variable. A common measure of reliability is internal consistency that applies to the consistency among the variables of the summated scale (Hair et al., 2010). The idea behind internal consistency is that items are supposed to be highly intercorrelated and measure the same construct. A number of diagnostic measures are in use for the assessment of internal consistency. The item-total coefficient consists of calculation of the Pearson's correlation coefficient between each item and the total score of the remaining items that belong to the same dimension. A low level of this coefficient for one item suggests that the item is not consistent with the domain of the other items. Literature provides suggestion of 0.30 as a minimum (Fruchterman & Reingold, 1991). Cronbach's alpha is widely interpreted as a measure of internal consistency of a psychometric test and verifies whether and to which extent the items of the instrument measure the same concept or construct, hence unidimensionality (Tavakol & Dennick, 2011). It assumes values from 0 to 1. Cronbach's alpha between 0.6 and 0.7 is considered acceptable, between 0.7 and 0.9 good to very good and over 0.9 is considered excellent (Kline, 1999).

The body of data analysis concerns data screening, assumption testing and sampling adequacy.

A correlation matrix with Pearson correlation coefficients between all pairs of items shall demonstrate variables that correlate fairly well but not entirely. Conversely, items with very poor correlation coefficients are recommended for elimination from further analysis. A reasonable indication are coefficients higher than 0.30 and higher than 0.90, respectively (Field, 2009). The significance of a correlation matrix can be evaluated through the Bartlett's Test of Sphericity (BTS). The test assesses whether a correlation matrix is an identity matrix that is, indicates the presence of non-zero correlations. As in all other tests, p-value of 0.05 was considered a limit.

Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy takes values between 0 and 1, and the closer it approaches 1, the better the score. Field (2009) reminds proper Kaiser's (1974) recommendation of a bare minimum of 0.5, and his evaluation of values between 0.5 and 0.7 as mediocre, values between 0.7 and 0.8 as good, and values between 0.8 and 0.9 as great, and above 0.9 as superb.

Structural equation modelling is a multivariate statistical technique for testing and estimating causal relations among multiple variables. By combining elements of factor analysis and a multiple regression, it allows for examining simultaneously interrelated relationships among measured variables and latent constructs. Exogenous constructs are a latent, multi-item equivalent of independent variables. Endogenous constructs are a latent, multi-item, equivalent of dependent variables (Hair et al., 2010). In a model of structural relationships, constructs are represented by several variables and related in a dependence and correlational form.

A structural equation model implies a structure of a covariance matrix of the measures. With the estimated model parameters, the model-based covariance matrix may be compared to the data-based or empirical covariance matrix. The quality of the model is measured from the level of consistency between these two matrices (Hair et al., 2010). A set of indices is available to evaluate the specified model. Model chi-square ($\chi 2$) is an absolute fit index, the only statistically-based fit measure for which p-value, as in other tests in the present work was considered equal and higher than 0.05 (Field, 2009). Goodness of Fit Index (GFI) was an early attempt to create a fit measure less sensitive to a sample size, however, the sensitivity issue remained (Hair et al., 2010). A possible range of GFI varies between 0 and 1 and a recommendation is equal and greater than 0.90 (Joreskog & Sorbom, 1984). Comparative Fit Index (CFI) is found between the most widely used fit measures. Values equal and above 0.90 are associated to a good fit (Hu & Bentler, 1989). Non-Normed Fit Index (NNFI) values recommended in literature are equal and greater than 0.90 (Bentler & Bonett, 1980), similarly to those of Incremental Fit Index (IFI) (Bollen, 1989). The Steiger-Lind root mean square error of approximation (RMSEA) is one of the most widely accepted measures that aims to take a correction on a sample size and a model complexity by including both in its computation. A lower RMSEA indicates a better model fit (Hair et al., 2010). A recommended value differs in literature and takes currently under consideration a sample size; it is however recommended that is should be lower or equal to 0.07 (Steiger, 1990).

Qualitative data obtained in this study, both from interviews with patients and from contacts with entities identified as those participating in provision of care and support to stroke survivors were analyzed using the technique of content analysis.

Content analysis is a method for a systematic analysis of text, verbal or communication messages (Cole, 1988) that aims to deepen the understanding and describing a phenomenon rather than to explain it. It is a research technique for making replicable and valid inferences from data to their context (Krippendorff, 1980, p. 21). Neuman (1997) defined it as a "technique for examining information, or content, in written or symbolic material. In content analysis, a researcher first identifies a body of material to analyze (…) and then creates a system for recording specific aspects of it. The system might include counting how often certain words or themes occur" (p. 31). A quantitative criterion for the use of content analysis was clearly emphasized in the earlier phases of its development, when Lasswell, Lerner, & Pool (1952) declared that "there is clearly no reason for content analysis unless the question one wants answered is quantitative" (p. 52). Finally, by means of the method, a scientist records what was found in the studied material. Information is frequently measured in numbers. Content analysis is employed for exploratory and explanatory research but is most often used in descriptive research.

Content analysis went through a couple of notable phases in its development that founded its contemporary background (Mayring, 2000): (a) from interpretations of ancient texts and early newspapers to dream analysis by Freud; (b) communication theoretical foundation established during the 1920s and 1930s of the 20th century, accentuated by a publication of the first book on content analysis; (c) focus on categories as a result of research questions choice and text interpretation; and (d) qualitative critics phase initiated in the middle of the 20th century criticizing analysis that ignores latent contents and contexts.

Methodological concerns are of a great importance in content analysis. Content analysis brings with itself results which can be considered valid when successfully meeting four criteria: objectivity, reliability, replicability and systematic coherence. Objectivity denotes a level of impact a researcher conducting a study has on the classification of records. While Berelson (1952) cited in Rourke et al. (2000) deemed content analysis an objective technique, a number of other scholars have raised concerns on partiality and interpretive bias. In its roots, a qualitative technique, has received a strong emphasis for a quantitative approach turning it a subject of a researcher’s interpretations. Objectivity shall lead to reliability, what in content analysis refers both to intra-rater reliability, i.e. consistency of results of the same researcher time after time, and to inter-rater reliability, i.e. the coherence between a categorization of transcripts of the same text by different researchers. An ability to apply a coding system over time by different research groups in their studies is a criterion of replicability. Finally, indications clearly point out an importance of systematics of the conducted study, hypotheses, assumptions, theories, definitions and ideas (Rourke et al., 2000).

The categorical system developed in this study deriving from the matrix qualitative analysis was based on the methodology of Miles and Huberman (1994). The authors consider a matrix “essentially the ‘crossing’ of two lists, set up as rows and columns” (Miles & Huberman, 1994, p. 3). Columns and rows correspond to concepts, issues or characteristics important to the research questions. Lauri and Kyngäs (2005) point out that an inductive approach is recommended when there is not enough information about the experience which is being investigated or knowledge about it is fragmented. On the other hand, Burns and Grove (2005) claim that a deductive approach is supported on an earlier theory or model. In the present study both approaches were employed.

From interviews conducted with patients, transcripts of interviews resulted in a coding system constructed having under consideration issues emerged from the previous literature review on relevant and recurrent issues relative to patients' positioning toward the system. In interviews conducted with representatives of care and support service providers, the developed categorical matrix applied as a basis for the main categorical system primarily the framework proposed in the study of Valentijn et al. (2013) for its further adaptation for the particularity of the present study. Categories resulted from data deductive and inductive content analysis, once there was not enough previous knowledge about the phenomenon under study, but the main themes were based on the previous study indicated above. For the latter one, data were analyzed and presented using Microsoft Excel for Windows 2010 (Softonic International S.A.) software.

A growing body of literature demonstrating results of the network theory applications in practice has implied a development of a number of indicators allowing for evaluating network analysis. As recognition of network analysis has been growing over time and data collection regarding social relationships has become increasingly accepted, scientific interest has inevitably turned its attention into methods of measurements and its quality (Thaden & Rotolo, 2009).

In the graph theory, the term centrality is used to describe a group of indicators determining the most important vertices (nodes) within a graph. An importance of a vertex depends of a function which that is expected to provide, leading in consequence to a number of definitions of centrality. Two core axes on which these definitions are based include considering it as a type of stream or shift across the network (Borgatti, 2005) and, another approach, considers centrality as involvement in the cohesiveness of the network (Borgatti & Everett, 2006). Since both categorizations cannot be applied at the same time, if the second is taken in use in the research, it becomes evident that existing centrality types follow one logic. A starting point from a certain vertex are counts of a number of walks, differing only in a manner of defining and counting the walks.

A network is a group of nodes connected until a higher or lower extent, with a number of paths. A phenomenon under investigation is told to flow along these paths. Paths existing in the network theory comprise geodiscs – shortest paths, paths – when no vertex is crossed more than once, trails – when vertices are allowed to be crossed several times, although no edge may be crossed more than once, and walks – when vertices and edges are allowed to be crossed over freely and multiple times (Borgatti, 2005).

The second categorization focuses on the proper construction of centrality and can be further divided in two dimensions, radial and medial. Radial centralities count walks that start and finish from the particular vertex. Examples of radial centralities are the degree or the eigenvalue centralities. Medial centralities count walks that pass through the particular vertex. An example of medial centrality is betweenness centrality (Borgatti & Everett, 2006).

Degree centrality is a number of links passing upon a vertex. In analyses of a directed network, two measures of degree centrality are taken into consideration, in-degree centrality and out-degree centrality. In-degree centrality is a count of a number of connections directed to the vertex and out-degree centrality is a number of ties that the vertex directs to others.

Katz Rank is a measure of influence of a relative importance of a node within the network and considered a generalization of degree centrality (Katz, 1953). The measure takes into account the total number of walks between a pair of elements of the network and computes a relative influence of a vertex by measuring a number of first-degree vertices and all other vertices in the network that connect to that vertex through these first-degree vertices. Further connections receive, however, adequate penalization.

PageRank is an indicator used to measure a relative importance, used broadly in the internet environment. It functions as an algorithm assigning a weighting to each element of the network with an objective of estimating its relative relevance within it (Page et al., 1999). An output provided by PageRank is a probability distribution corresponding to the likelihood of randomly choosing a certain vertex or, if considering or World Wide environment it derives from, a webpage. PageRank is then an indicator of the vertex in the whole network, or thinking of its roots, blogosphere. It is presumed that a probability is evenly distributed among all elements of the network. PageRank requires an interactive process in order to reach empirical value to theoretical value and attributes values from 0 to 10 theoretical values from 0 to 1.

Closeness centrality is a measure of distance between vertices and can be regarded as time necessary to spread information from one vertex to all others sequentially (Newman, 2005). The more central, thus closer to the others the vertex is located, the lower the distance to others from its network is.

Betweenness centrality is a measure introduced by Freeman (1977) whose research demonstrated that vertices with a high probability to be placed on a randomly chosen shortest path between two randomly chosen vertices had a high betweenness. Betweenness centrality represents a centrality position of a vertex within a graph. It is a number of times a node functions as a bridge along the shortest path between two other nodes in the network.

Eigenvector centrality indicates strength of influence of a node within the network. This measure allocates relative values to all vertices in the network in order to quantify their influence basing on the idea that vertices with high scores contribute more to the score of the vertex in question than those of lower scores.

Clustering coefficient is a measure of degree to which nodes of the network cluster together. Two variants of this coefficient exist in practice, global (overall) and local (Costa et al., 2006). Global clustering coefficient is the average of densities of the neighborhood of all nodes. It is calculated as a ratio between a number of triangles (here defined as ordered triples of different vertices in which all of them are tied) to a number of connected triplets (ordered triples of different vertices in which successive vertices are tied). Local clustering coefficient is a ratio of a number of edges between its neighbors to the maximum possible number of these edges (Hardiman & Katzir, 2013).

Data collected on the intensity of collaboration between entities constituting the network of care for stroke patients were analyzed using NodeXL version 1.0.1.332 software. NodeXL is a network analysis software package integrated into Microsoft Excel 2007 and 2010. It intends to collect data in a format of class libraries and to analyze and visualize them in an output of networks (Bonsignore et al., 2009). The program makes a diferentiation between directed and undirected networks. An undirected network is a group of vertices and a group of edges with the edge set composed of unordered vertex pair. A directed network is a group of nodes connected by edges where the edges are ordered and have a direction linked to them. NodeXL offers a number of well-known layout algorithms, of which Fruchterman-Reingold and Haren-Korel are one of the most applied. Force-directed algorithms are designed to make all the lines on a graphical visualization of the network of the same length, approximately, and to minimize line crossing what increases readability of the effect. The Frucherman-Reingold algorithm is a force-directed layout algorithm of which objective is to consider strength between two vertices. Vertices are represented by steel rings and edges by springs (Fruchterman & Reingold, 1991). The Harel-Koren multiscale algorithm is a force-directed layout algorithm using optimization in order to make the algorithm computationally efficient. It is designed for generating layouts of large networks in a short time under the condition of accepting an offered output (Fruchterman & Reingold, 1991).

The graph was laid out using the Fruchterman-Reingold layout algorithm. Vertex colors were based on betweenness centrality values and vertex sizes were based on degree values. Vertices were connected to each other with the strength between 0 and 5, according to the Levels of Collaborations Scale proposed by Frey et al. (2006) who based it on Hogue’s (1993) work. Frey et al. (2006) defined 0 as no interaction at all and 5, the highest level, as collaboration, which in their understanding means the strongest organizational relation. Sizes and colors represented collaboration strength in the inscreasing order.

5.7. Summary and conclusions

This chapter has described in detail methodology applied to this study. It starts with a discussion on general methodological issues with a focus on quantitative and qualitative methods. A researcher, bearing in mind study objectives and questions defines research design which encompasses the overall strategy in order to suitably and effectively address the investigated phenomenon.

For achieving general and specific objectives of the study, qualitative and quantitative components were chosen. Quantitative data aimed to provide insights into patients' quality of life, perceived service quality and satisfaction, and perceived network of social support. Interviews conducted six months after discharge from the Stroke Unit of HIP would deepen the understanding of participants' perspective on the network of care. On the other hand, contacts with institutions providing care and assistance for stroke survivors would draw a picture of formal support existing in the community for persons after cerebrovascular accident and reflect the intensity of existing collaboration within members of the network. Finally, with interviews with a group of representatives of the network an institutional perspective to collaboration and the system functioning was gathered.

The chapter includes a comprehensive discussion on the choice and adaptation of quantitative measures for the study, and a broad explanation and description of the employed qualitative methods.

After having discussed methodological issues applied specifically to this study justifying the choice of methods for data collection and further analysis, the next three chapters will provide the results of the empirical part of the work. The empirical study conducted with stroke patients and care providers will be in detail presented taking into account the employed methodology, and analyzed and discussed.

CHAPTER SIX:

RESULTS OF THE EMPIRICAL STUDY: THE NETWORK OF CARE IN THE EYES OF USERS

The analysis of data from the first phase of the study refers to information collected from patients participating in the HOMECARE project carried out between April 2009 and April 2013. Subjects admitted to the study who fulfilled the inclusion criteria and signed informed consent were followed after discharge during the next six months.

From 190 discharged patients 39 were afterwards excluded due to the following reasons: quitted the study after having been admitted and no data other than from the stroke unit were available, was impossible to contact after having left the stroke unit or was still institutionalized in the 6th month thus never left the system in order to allow for data collection. As a result, 151 patients were validated for the study and this number constitutes a number of possible responses obtained to a question on characteristics of participants of the study. As for evaluated variables, a number of responses may eventually differ due to missings since patients might have refused or felt unable to respond a question, or due to any other reason for which a response for an item was missing. Hence, in each variable the total corresponds to the number of patients who provided an answer to a certain question.

6.1. Characteristics of patients

The total group of patients was composed slightly higher by men (53.0%) than women (47.0%). All of them were Caucasians; none of participants was Negroid or Mongoloid, what would be possible bearing in mind the immigration from the former Portuguese African, South-American and India colonies, and an increasing number of the Chinese population (you may also find an interesting discussion about a question of race in Portugal in historical and cultural context in Sobral (2004)).

Respondents were from 35 to 84 years old, with a mean age of almost 66.5 years and the standard deviation of 11.97, pointing out a considerable diversity within the sample. On the other hand, median was 69 years what suggests that exactly a half of patients were over this age (see Table 36). The use of mean would disrupt a picture of the population of the study, turning median a more appropriate measure to describe the subjects. This is not surprising as incidence of stroke increases rapidly with age (The European Parliament and the Council, 2009) and 75% of strokes occur in people aged over 65 years (National clinical guideline for stroke, 2012).

Table 36. Socio-demographic profile of patients (1)

Variable	**Absolute**		**Percentage**		**Total percentage**
	Feminine	**Masculine**	**Feminine**	**Masculine**	
Gender	71	80	47.0	53.0	100.0
Age					
up to 60	20	26	28.2	32.5	30.5
61-74	27	36	38.0	45.0	41.7
over 75	24	18	33.8	22.5	27.8
Marital status					
Married	34	61	48.6	76.3	63.3
Widow/Widower	24	8	34.3	10.0	21.3
Divorced	4	4	5.7	5.0	5.3
Single	5	4	7.1	5.0	6.0
In an unformal relationship	0	3	0.0	3.8	2.0
Separated	3	0	4.3	0.0	2.0
Household situation					
A spouse	22	42	31.0	52.5	42.4
A spouse and other family members	11	22	15.5	27.5	21.9
Family members other than spouse	18	8	25.4	10.0	17.2
Alone	15	6	21.1	7.5	13.9
Spouse and formal caregiver	1	0	1.4	0.0	0.7
Nursing home	0	1	0.0	1.3	0.5
Spouse, other family members and a formal caregiver	0	1	0.0	1.3	0.7
Formal caregiver	2	0	2.8	0.0	1.3
Other	2	0	2.8	0.0	1.3
Average household income (in euro)					
Below 500	30	31	53.6	43.7	48.0
500-750	13	19	23.2	26.8	25.2
750-1000	6	12	10.7	16.9	14.2
1000-1500	4	6	7.1	8.5	7.9
1500-2000	3	1	5.4	1.4	3.1
Over 2000	0	2	0.0	2.8	1.6

Almost 2 on 3 respondents (63.3%) were married; every fifth was a widow/widower (21.3%). A much less numerous were divorced, constituting 5.3% of the total, and single, 6.0%. Concomitantly, and somewhat consequently to the above, the greatest part of respondents lived with a spouse (42.4%) or with a spouse and other family members (21.9%), followed by those who lived with family members other than spouse (17.2%). Noteworthy, especially from the point of view of the further analysis, there was a group of patients that lived alone (13.9%).

Roughly every other (48.0%) interviewee estimated that average household income as below 500 euro per month and approximately one fourth (25.2%) as between 500 and 750 euro. Other possible options, with a higher income, were chosen less frequently. Altogether, only 4.7% of patients had the monthly household income higher than 1500 euro (see Table 36).

Table 37. Socio-demographic profile of patients (2)

Variable	Absolute		Percentage		Total
	Feminine	Masculine	Feminine	Masculine	Percentage
Education level					
None	16	13	23.2	16.3	19.5
Primary – 1st cycle	41	50	59.4	62.5	61.1
Primary – 2nd cycle	5	5	7.2	6.3	6.7
Primary – 3rd cycle	3	5	4.3	6.3	5.4
Secondary	1	1	1.4	1.3	1.3
Professional equivalent to secondary	0	3	0.0	3.8	2.0
Bachelor	3	2	4.3	2.5	3.4
Master	0	1	0.0	1.3	0.7
Occupation					
Manager, responsible for the work of others	2	9	3.0	11.3	7.5
Healthcare professional with responsibilities and authorization	1	0	1.5	0.0	0.7
Other, e.g., attorney, lecturer, researcher, artist	4	3	6.1	3.8	4.8
Healthcare assistant without formal responsibility and no license to practice	2	1	3.0	1.3	2.1
Specialized worker (with formal training)	3	9	4.5	11.3	8.2
Semi-specialized or unspecialized worker	54	58	81.8	72.5	76.7
Professional situation					
Contracted	5	13	7.2	16.5	12.2
Self-employed	2	9	2.9	11.4	7.4
Unemployed	6	4	8.7	5.1	6.8
On sick leave	0	5	0.0	6.3	3.4
Pensioner	44	46	63.8	58.2	60.8
Military service	0	1	0.0	1.3	0.7

Homecare	9	0	13.0	0.0	6.1
Other	3	1	4.3	1.3	2.7
Living comfort					
Luxurious house or floor	2	1	2.9	1.3	2.0
Comfortable and spacious but not luxurious house or floor	15	25	21.4	32.1	27.0
Modest house or floor (bright, with a kitchen and sanitation)	53	51	75.7	65.4	70.3
Poorly constructed cottage with no running water, electricity or sanitation	0	1	0.0	1.3	0.7

The most predominant highest achieved level of education among patients was the primary school level, with almost two third (73.2%) of the total, divided into the first cycle (61.1%), the second cycle (6.7%) and the third cycle (5.4%). Almost one fifth (19.5%) did not have any formal education. The secondary level was concluded by 3.3% and the higher education by 4.1% of subjects.

Subjects declared to be performing unspecialized or half-specialized professions in 76.7% of the cases, followed by much lower number of specialized workers certified by a formal training (8.2%) and managers responsible for the work of others (7.5%). The remaining groups were represented in the study in a very low degree. The largest group of interviewees were pensioners (60.8) or worked as contracted employees (12.2%); other were self-employed (7.4%), unemployed (6.8%), or taking care of the house (6.1%).

The standard of housing was assessed commonly (70.3%) as comfortable but modest: equipped with electricity, water and sanitation. Over one fourth of the sample lived in a comfortable though not yet to be considered a luxurious residence (27.0%). The extreme options were rare: 2.0% of participants of the study assessed their households as luxurious and 0.7% considered to be living without basic conditions (see Table 37).

6.2. Patients’ expectations and experiences with care

6.2.1. Patients’ expectations at discharge from the stroke unit

Expectations of patients were measured at discharge from the stroke unit and encompassed care and support entities they thought to interact with within the following six months. Furthermore, subjects were questioned on general expectations, expectations of informal care to be received and the idea of functioning of the care system.

6.2.1.1. Expectations of contacts with care and support entities

At discharge from the Stroke Unit of HIP, subjects were asked about their expectations toward contacts with existing institutions regarding any issues related with their cerebrovascular accident and its eventual consequences, of any sort, that might arise within the next half year. The intention was to provide a list of entities possibly capable to offer health and social care, financial support, technical aid, transportation services, spiritual support and any other services or assistance from the community that a stroke patient might need. Patients were given a list of such entities that included the following:

- Hospital (understood as an external consultation related with a stroke, with a specialist)
- Rehabilitation unit (convalescence, medium or long-term care unit)
- Health center
- Fire department
- City council
- Parish council
- Private Institution of Social Solidarity
- *Misericórdia* (charitable institution, mercy)
- the Social Security
- Church
- Caregiver
- Some other, not mentioned above (if yes, indicate which).

The last option was left on purpose, hoping to obtain indications on other institutions that could be useful for patients' recovery. This response is especially interesting as it was meant to explore until which extent a patient was able to envisage the everyday life, challenges and possible difficulties in the next months after having been fully cared by professionals in the institutional setting. For that reason, it was left as an open question.

Subjects could rate their opinions as ‘Yes’, ‘Maybe’ and ‘No’ as to expect the interaction with a given entity. The responses are provided in Table 38.

Table 38. Stroke patients' expectations of contacts with institutions at discharge from the stroke unit

	Yes		Maybe		No	
	Absolute	**Percentage**	**Absolute**	**Percentage**	**Absolute**	**Percentage**
Hospital	113	89.7	4	3.2	9	7.1
Rehabilitation unit	72	58.1	11	8.9	41	33.1
Health center	95	76.0	9	7.2	21	16.8
Fire department	82	65.1	11	8.7	33	26.2
City council	14	11.2	13	10.4	98	78.4
Parish council	17	13.5	8	6.3	101	80.2
IPSS	22	17.5	12	9.5	92	73.0
Misericórdia	19	15.1	11	8.7	96	76.2
The Social Security	20	16.0	37	29.6	68	54.4
Church	15	11.9	8	6.3	103	81.7
Caregiver (formal or informal) support	105	83.3	6	4.8	15	11.9
Other	10	7.9	1	0.8	115	91.3

The last option marked as 'Other' led to an interesting outcome as all respondents who provided an answer to that question pointed out the same entity they found relevant for the recovery process and had an intention to establish a contact with. That entity was a physiotherapy clinic. From one hand, this is a positive sign of a prospective capacity of thinking of the future, on the other, only ten participants, from all, considered that possibility. Figure 30 presents graphically expectations of interactions with diverse institutions that participants of the study expressed at discharge.

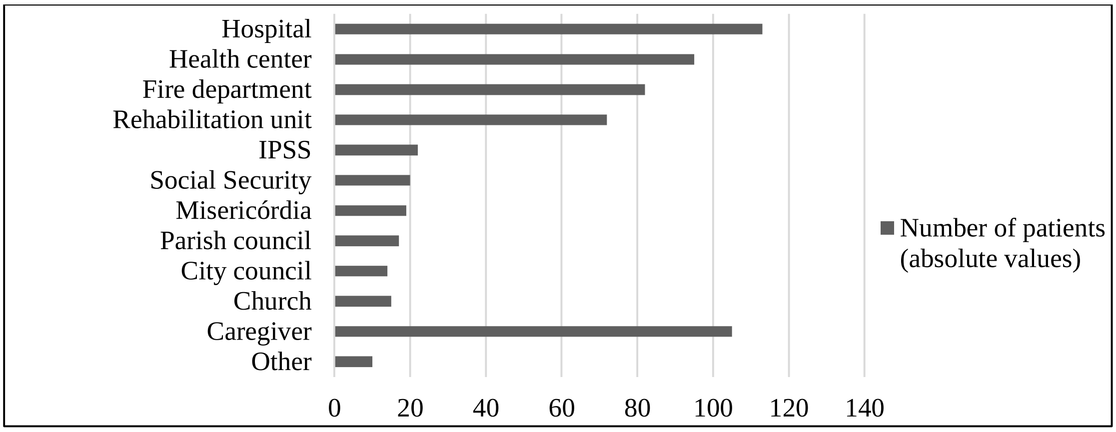


Figure 30. Entities expected to be contacted by patients within the following six months as perceived at discharge from the stroke unit

The above figure presents the responses given by participants of the study in absolute values and allows for a visual inspection of the entities indicated the most frequently by patients as those to hope for and request support from. As such, patients mentioned a hospital, caregiver (who was also considered an ‘entity’ in a sense of care provider), health center, fire department and rehabilitation unit. Other options of the responses were given less repeatedly.

In quest of possible alike groups between patients regarding the expectations to contact entities providing care, services and support, Spearman’s rank correlations were computed since cluster or discriminant function analyses had no application bearing in mind the size and scale of measurement. The correlations identified between entities are provided in Table 39.

Table 39. Spearman correlation ranks between institutions

Spearman’s *rho*	**City council**	**Firemen**	**IPSS**	**Church**	**Parish council**	**Miseric.**	**Rehab. unit**	**Hospital**	**Social Security**	**Caregiver**	**Other**
Health center	.104	.065	.147	.144	.121	.062	.251**	.147	.063	.071	-.003
City council		.239**	.465**	.489**	.623**	.503**	.248**	.125	.237**	.174	-.025
Firemen			.333**	.140	.189**	.327**	.265**	.343**	.141	.407**	.032
IPSS				.561**	.401**	.760**	.288**	.115	.280**	.093	-.017
Church					.671**	.585**	.225**	.104	.251**	.106	.055
Parish council						.445**	.282**	.168	.215*	.162	.058
Misericórdia							.238**	.092	.226**	.015	-.008
Rehabilitation unit								.281**	.241**	.331**	-.228*
Hospital									.155	.135	.009
Social Security										.098	-.137
Caregiver											-.082

**correlation significant at $p<0.05$; **correlation significant at $p<0.01$*

As it turned out, there were considerably more positive than negative correlations. The strongest positive correlations were found between expectations of contacts with a *Misericórdia* and a Private Institution of Social Solidarity (*rho*= .760), a parish council and the Church (*rho*= .671), a parish council and a city council (*rho*= .623), and between a *Misericórdia* and the Church (*rho*= .585).

In turn, the only statistically significant negative correlation, significant at $p<0.05$, was found between the expectation of contact between a rehabilitation unit (of any type) and another, not specified institution ('other') (*rho*= -.228). Concluding, it was difficult to clearly identify fully distinct groups in terms of expectations of contacts with eventual care and support providers. Generally, the higher was the expectation of contact with one entity, the higher the expectation of contact with another. In fact, only the hospital, a health center, a caregiver and the category classified as 'other' were poorly correlated with other variables. For the first three it might be due to the fact to have been indicated by the vast majority of patients, and the last, to have been mentioned, by hardly any of respondents.

6.2.1.2. Expectations of support and general vision of the care system

Subjects were questioned about their current opinion regarding the system as a whole, expectations to obtain support from the health and social care system to find services and treatments that might be beneficial for their recovery and to obtain support to satisfy their specific needs, and the capacity to pay for health and social care services. Their perception of informal support from kins and non-kins was also collected.

Over a half (55.2%) of interviewees expected to receive some sort of support from the health and social care systems in order to seek services and treatments that might be recommendable or necessary to them; 27.2% were not quite sure and the remaining 17.6% did not expect support. A similar pattern of responses was given to the question regarding expectations to receive assistance from the system to satisfy the needs related to stroke. In this manner, 53.6% of respondents expressed such expectation, 32.0% considered that possibility and 14.4% did not expect support in this sphere. These results were straightaway confronted with another, more direct question, concerning the ability to 'navigate' through the system, to find specialized equipment, needful commonly after stroke due to a (diverse) level of disability stroke is associated with. This question provided evidence that while solely 1.6% clearly stated they did not know how to proceed in such situation, a majority (64.3%) deemed able to find out what to do if they found themselves in such need. The remaining 34.1% of patients admitted to be acquainted with information sources.

At the moment of discharge, the perception of subjects about care provided for stroke survivors by the health and social care systems was at an average level, toward a positive tendency: slightly over 78% of patients considered existing care as ‘reasonable’ or ‘good’. As for the number of respondents who assessed the systems as ‘very bad’ and ‘very good’, the results were, interestingly, exactly the same (3.8%).

Opinions on the capacity to pay for health and social care services revealed the highest dispersion. While 34.4% of subjects claimed to be able to afford the care they might need in the nearest future, 24.8% were not sure about it, and 40.8% expressed their concern and deemed themselves unable to pay.

Entirely conversely were distributed answers about the perception of eventuality to count on relatives: family, friends or neighbors (who were often friends), where vast majority of patients (91.2%) had a positive feeling on it, and only 3.2% were not sure and 3.6% deemed to have no kins or non-kins to rely on.

6.2.2. Patients’ experiences six months after discharge from the stroke unit

Six months after discharge, patients were questioned about entities they actually entered in contact with regarding any issue related with their stroke. If the answer about the contact was positive, a number of those contacts and more precise information regarding the institution was collected. The precise name of an entity was sufficient to trace it in a further stage of the study and establish an eventual contact in order to gather other type of information necessary to accomplish defined objectives.

6.2.2.1. Care and support entities effectively contacted by patients

In the 6th-month follow-up each patient was contacted and asked about care and support institutions they had interacted in matters related to cerebrovascular accident. Some participants, however, could not provide accurate data of some of entities. The reason for that was twofold. One was that subjects were predominantly elder and did not remember well some details they did not find relevant (such as the name of the entity they were transported for physiotherapy sessions, or details in case a contact took place a few times). The second reason was that sometimes it was hard for respondents to distinguish some of providers due to their similarities (e.g. firemen) and not much attention might have been given to question of which, precisely, entity provided a certain service at certain moment. Table 40 presents respondents' experiences with institutions six months after their discharge from the Stroke Unit of HIP in terms of interactions that actually took place.

Table 40. Contacts effectively established by patients with care and support providing institutions

Contact with an institution	Responses		Percent of patients who interacted with the entity
	Absolute	Percent	
Contact with a fire department	98	20.10%	74.20%
Contact with the Hospital Infante D. Pedro in Aveiro (outpatient medical appointment)	96	19.70%	72.70%
Contact with another hospital**	7	1.40%	5.30%
Contact with one physiotherapy clinic*	88	18.10%	66.70%
Contact with two physiotherapy clinics*	15	3.10%	11.40%
Contact with a health center	68	14.00%	51.50%
Contact with one rehabilitation unit	40	8.20%	30.30%
Contact with two rehabilitation units*	11	2.30%	8.30%
Contact with a Private Institution of Social Solidarity	26	5.30%	19.70%
Contact with the Social Security	17	3.50%	12.90%
Contact with a private caregiver	10	2.10%	7.60%
Contact with the Church	5	1.00%	3.80%
Contact with a *Misericórdia*	3	0.6%	2.30%
Contact with a parish council	2	0.4%	1.50%
Contact with a city council	1	0.2%	0.80%
Total of all established contacts	487	100.0%	368.90%**

*not included in the Expectations sheet
**percent does not sum up to 100 as participants could interact with unlimited number of institutions

As can be noted, the highest amount of respondents experienced a contact with a fire department and HIP, with 20.10% and 19.70% of interactions respectively, what corresponds to 74.20% and 72.70% of subjcts who interacted with these entities, respectively. The next most frequently used services were those of one physiotherapy clinic with its 66.70% interactions. These results have their logic when taking into consideration the requisite of a medical appointment with a specialist around one month after discharge from stroke unit. That appointment takes place in HIP and is scheduled as a usual outpatient consultation. High results of contacts with transportation services provided by firemen and with a physiotherapy clinic make sense in practice as patients were frequently transported to physiotherapy sessions by the same entity on basis of a credential received from their GP. Consequently, 51.50% of respondents admitted to have gone to the health center for a medical appointment with the documentation they had received from the hospital at discharge requested to be provided to their family doctor. Among other entities, there were also rehabilitation units. These institutions function within the RNCCI and a possible interaction with them does not remain exclusively in hands of the patient, but is conditioned by health status of the patient and the unit availability. In the study, 30.30% of subjects went to one rehabilitation unit and 8.30% to two. Almost one fifth (19.70%) interacted with IPSS. Generally, experiences with remaining care and support providers were limited, making problematic a potential further evaluation. What this study found interesting was that the scope of contacts was not limited to some specific group, but in practice went beyond the list indicated to participants at discharge. Thank to information received from respondents, the final list of entities possibly offering any type of care and assistance to stroke patients (health care, social care, transportation services, spiritual support, technical aid, financial and material support, domiciliary support, etc.) was enlarged with an objective to verify its accuracy and appropriateness for the study purposes in its later stage.

6.2.2.2. Patients' contacts with the care system by entity and care system type

For the analysis of the number of contacts established by patients with each entity, in a subsequent phase care entities were aggregated into either a part of the health care or the system encompassing entities not directly related with health care provision, i.e. elements providing social, financial, material, technical, spiritual support and care and other resources available in the community support.

The analysis of contacts with health and not purely health-related care institutions considered respondents who had at least one contact with a given entity and comprised a comparison of groups of subjects who received and did not receive care after stroke. The final analysis included those groups whose size was sufficiently large to guarantee the conditions necessary for further statistical proceeding.

Mean rank of contacts with a hospital for patients who received care after stroke was 49.35 and without care 46.71 (Z= 0.583, p=0.560). Mean rank of contacts with a health center for subjects who received care after stroke was 35.46 and without care 30.03 (Z= 1.025, p=0.306). Mean rank of interactions with one physiotherapy clinic for patients receiving care after having suffered stroke was 44.60 and without care was 33.56 (Z= 1.635, p=0.102). In average, patients who received care after stroke had more contacts with a fire department (mean rank = 53.06), and those who did not receive care had less contacts (mean rank = 34.83) (Z= 2.890, p=0.004).

The results indicate that, in average, patients with care after stroke had generally more contacts with care entities, although in most of cases, these differences were not statistically significant. The only case in which patients who did not receive care after stroke had effectively more contacts with an institution were interactions with the Social Security, although still not statistically significant (mean ranks = 9.67 and 8.86; Z= -0.314, p=0.859).

Considering the health care system as a whole, with institutions constituting it, mean rank of entities from the health sector (without taking into account rehabilitation units) contacted by patients who received care after stroke was 71.61 while among those who did not receive care after stroke was 56.29 (Z= 2.197, p=0.028). If rehabilitation units were taken into consideration, mean ranks were 73.25 and 52.46, respectively (Z= 2.961, p=0.003). In the remaining, not directly health-related sector, mean rank of contacted entities for subjects who received care after stroke was 74.51 and for those who did not receive care was 49.55 (Z= 3.759, p<0.001). Hence, the results demonstrate that participants of the study who could count on care after having suffered cerebrovascular accident contacted, in average, more care institutions comparing to participants who did not receive care. The (highly) statistically significant difference was found in case of the health sector with and without including rehabilitation units, and in the sector not directly related to health care services provision.

The study explored also the role of a caregiver in establishing contacts with the system and the number of contacted entities. From the list of possible caregivers, some of them could not be included in this specific analysis due to insufficient group sizes which would not assure tolerable robustness. Accordingly, three types of caregivers were deliberated: a spouse, family members other than spouse, and a spouse and other family members. The results demonstrate that mean ranks of contacts with entities from the health sector, without taking into consideration rehabilitation units, were statistically significant (H(2)= 9.69, p=0.005). Comparisons of groups *a posteriori* indicate that this difference resided only between patients who were cared by a spouse (mean rank = 35.42) and patients who were cared by a spouse together with other family members (mean rank = 18.79, p=0.005). Statistically significant differences were not found comparing groups of patients cared by a spouse and family members other than spouse (mean rank = 31.33, p=0.510), and between family members other than spouse and a spouse together with other family members (p=0.080).

If considering the health sector with existing rehabilitation units, the difference remained (H(2)= 6.467, p=0.039). As in the previous situation, comparisons of groups *a posteriori* show that the difference existed solely between patients who were cared by a spouse (mean rank = 35.25) and a spouse together with other family members (mean rank = 22.57, p=0.018). There were no statistically significant differences between a spouse and family members other than spouse (mean rank = 26.17, p=0.510), and between family members other than spouse and a spouse together with other family members (p=0.080).

In the sector of care services not directly related to health care, the difference between a number of contacts of subjects cared by a spouse, participants cared by family members other than spouse and participants cared by a spouse and other family members was not statistically significant (H(2)= 1.14, p=0.565).

6.2.3. Confrontation between patients' expectations and experiences with contacts with care and support entities

A reasonable question was to verify the extent to which patients' experiences with contacts with care and support institutions corresponded to the expectations at discharge. The entity that the largest group of patients expected a contact with at discharge was the hospital (89.7%), followed by a health center (76.0%), transportation services provided by firemen (65.1%) and an inpatient stay in one rehabilitation unit (58.1%). Other listed options (except of 'caregiver') were indicated with a minor frequency. After six months, the predominantly contacted entities were a fire department (74.20%), an outpatient medical consultation in HIP (72.70%), furthermore: a physiotherapy clinic 66.70%, a health center (51.50%) and a contact with one rehabilitation unit (30.30%). Similarly to expectations, interactions with other institutions occurred more rarely. A contrast between expectations and experiences of respondents is provided in Figure 31.

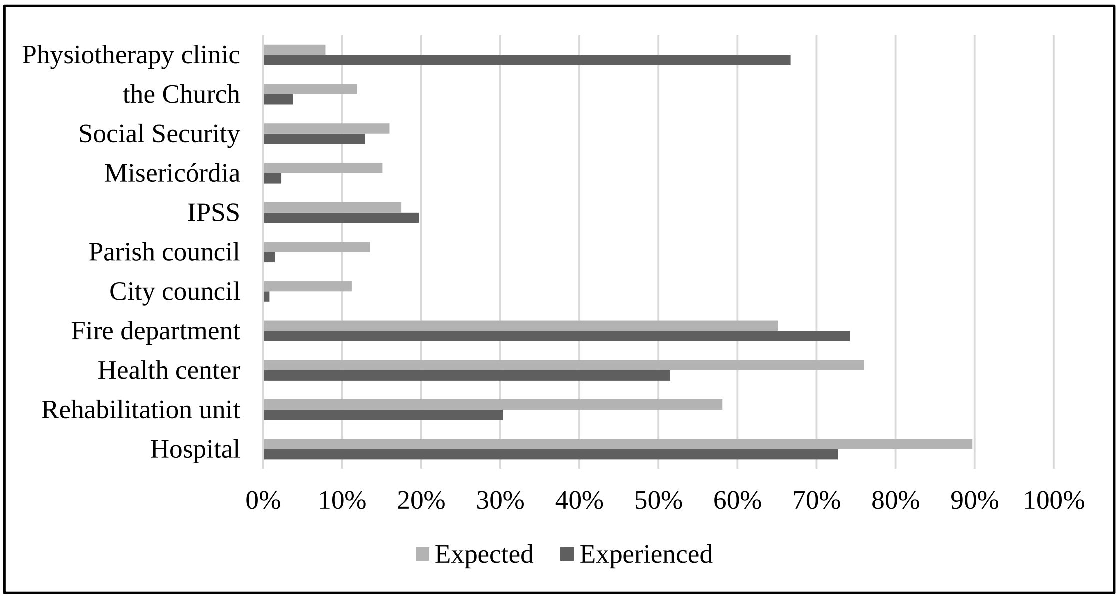


Figure 31. Comparison between expectations at discharge and experiences in the six-month follow-up of respondents of the study

The results demonstrate that, besides the most expectable institutions to be found in the community pursuing care and support after stroke, such as hospital or health center, respondent's awareness about the network of care was limited as limited were their expectations. Having provided a list of options of possible entities at discharge, a very reasonable number of participants considered a rehabilitation unit as an option, as well. Effective contacts established by patients with entities, were, however, considerably lower, from those expected, with a difference clearly visible in cases of city council, parish council and mercy. An extremely low number of contacts was identified with entities of a local government (city council and parish council). On the other hand, institutions in case of which a number of interactions was higher than expected at discharge were also identified. This was the case of fire departments providing transportation services to physiotherapy sessions or medical consultations, and IPSS. Finally, an entity not mentioned at the Expectations sheet was interesting case. Identified by a few subjects, physiotherapy clinic found to be contacted by a considerable group of participants and with an extreme difference between expectations expressed at discharge and actually experienced interactions.

A number of subjects indicated remaining entities from the list of those they expected to possibly contact within the next six months, although numbers of contacts with these entities were even lower. One remark to make at this point is that, with a few general exceptions, patients were not acquainted with institutions functioning within the care system which could support them and their relatives. Furthermore, experiences of participants with the stroke care network in a broader meaning, i.e. with at least two or three from the most indicated entities, were limited, as limited were overall expectations. It seemed that some subjects, when initially presented a list of entities providing an eventual support and thus shown possibilities ahead, became a little enthusiastic, nonetheless, when at the residence, confronted with the reality and difficulties of everyday life amplified by post-stroke limitations, that initial eagerness faded away.

Apart from formal care provided by different means by health and social care entities operating in the care sector in Portugal, and other support and assistance institutions that may turn to be helpful and beneficial for stroke survivors, informal care also exists and plays a significant role. After discharge, patients (and relatives if they are present) face real, physical and/or cognitive, limitations, caused by stroke in the factual life environment. This is a moment when the previous expectations meet the pragmatism and, in fact, informal care appears to play an important part in this stage of patients' life. Literature recognizing the role of informal care in patients' well-being and its contribution to the health and social care systems, together with its estimations of economic value is abundant (Bookman & Harrington, 2007; Dewey et al., 2002; Evers et al., 2004; Hervas-Angulo, Cabases-Hita, & Forcen-Alonso, 2006; Oliva-Moreno et al., 2013). The relevance of informal care has been acknowledged with time and extensively discussed.

As mentioned in the earlier part of this study, the vast majority (over 90%) of respondents were certain they would receive, if necessary, support from their relatives. Before the hospitalization due to stroke, subjects might have been considered as independent in their everyday life. Before cerebrovascular accident, hardly 9.3% of patients had someone to take care of them (for 3.3% of respondents it was family members other than spouse; for 2.0% it was a spouse, for other 2.0% a private caregiver, and 0.7% was cared by either a private care entity, or in a nursing home; by spouse; by private caregiver or by private care entity). Noteworthy mention that 90.7% of participants of the study did not have any caregiver before stroke.

This tendency changed meaningfully after discharge. From all patients, at the time of data collection 68.9% had a caregiver. Within that group, the most frequently mentioned caregiver was a spouse (26.5%), and a spouse and other family members (9.3%), and family members other than spouse (7.9%). A distinct group of responses was that with low occurrences. Hence, 4.0% of respondents were cared by a spouse, other family members and a private care entity; 2.0% stayed in an all-day care center; 2.6% were cared by a private caregiver, 2.6% by family members other than spouse and a day center; other 2.6% received care from a spouse and a private care entity; 1.3% stayed in a nursing home; 2.0% received care by family members other than spouse and a private caregiver; 2.0% received care by family members other than spouse and a private care entity; 1.3% stayed in a day center; 1.3% were cared by a private care entity; 1.3% were cared by a spouse and stayed in a day center. Finally, a scarce 0.7% of respondents received after-stroke care from a spouse, a private caregiver and a private care entity; 0.7% from a spouse, other family members and a private caregiver; and 0.7% from a spouse, a friend and a private caregiver (N=151).

The actual confrontation between patients’ expectations to receive help as formal or informal support from a caregiver and receiving care after stroke is provided in Table 41.

Table 41. Expectations of informal or formal support from a caregiver confronted with actually received care

Care after stroke	Expectation of informal or formal care after stroke						Total	
	Yes		Not sure		No			
	N	Percent	N	Percent	N	Percent	N	Percent
Yes	75	71.4%	3	50%	5	33.3%	83	65.9%
No	30	28.6%	3	50.0%	10	66.7%	43	34.1%
Total	105	100.0%	6	100.0%	15	100.0%	126	100.0%
Chi-2= 9.179, p=0.008								

From 105 patients who expected to obtain care after stroke, 71.4% actually received it. In turn, from those who did not expect support, only 33.3% actually benefited from care. There is, thus, a clear relation between the expectation of care and care after stroke and this is a statistically significant relation (p=0.008, with Monte Carlo simulation).

Before stroke, the study did not identify any subject until the age of 60 who needed care, and among persons over 75 years old 26.2% presented the need of being cared of, indicating, not surprisingly, a higher need of care with age (Chi-2= 20.516, p<0.001, with Monte Carlo simulation). After stroke, among subjects until 60 years old, 52.2% needed care and 47.8% did not; in the group between 61 to 74 years old 71.4% needed care and 28.6% did not, and within subjects of age above 75, 78.6% needed some sort of care and 21.4% did not. The relation between care after stroke and age was statistically significant (Chi-2= 7.721, p=0.021).

Care before stroke was used only by persons who did not work (11.4%) and the analysis showed that they were basically pensioners. The relation between current professional situation and care before stroke was statistically significant (Chi-2= 4.862, p=0.027). As expectable, the tendency shifted after cerebrovascular accident, and 21.2% of subjects who worked and 78.8% of those who did not work were in need of care (Chi-2= 5.530, p=0.019).

Statistical significance was confirmed in case of care after stroke (Chi-2= 7.984, p=0.018), but not before stroke (Chi-2= 3.369, p=0.186) for educational level. Interestingly, the largest portion (53.8%) of subjects who received care had primary education, and the fact of receiving care among respondents with the education higher than primary was uncommon (7.7%). Perhaps it derived from the fact that the education level is correlated with age; the higher the age, the lower the education level, and education level is usually correlated with income. Median age of subjects was in fact 69 with 73.2% subjects with the primary education level concluded. Since the variable ‘care after stroke’ comprised both informal and formal care, it may partially explain these results.

In the next step, possible relationships between socio-demographic variables, a fact of having care after stroke (and eventual type of caregiver after stroke) and contacts with care and support entities were sought. The results found statistically significant, both, for considered variables and respective institutions, are provided below. Table 42 presents the impact of gender on patients' interactions with health centers.

Table 42. Impact of gender on patients' interaction with a health center

Contact with a health center	Gender				Total	
	Female		Male			
	N	Percent	N	Percent	N	Percent
No	32	54.2%	22	34.9%	54	44.3%
Yes	27	45.8%	41	65.1%	68	55.7%
Total	59	100.0%	63	100.0%	122	100.0%
Chi-2= 4.608, p=0.032						

Gender seemed to play a significant role in what contacts with a health center respective to the area of residence of the patient concerned. Significantly more men (65.1%) than women (45.8%) made an appointment with their family doctor in the health center (Chi-2= 4.608, p=0.032). Table 43 presents the impact of age on subjects' interactions with health centers.

Table 43. Impact of age on patients' interaction with a health center

Contact with a health center	Age						Total	
	Until 60 years		From 61 to 74 years		Over 75 years			
	N	Percent	N	Percent	N	Percent	N	Percent
No	16	40.0%	17	33.3%	21	67.7%	54	44.3%
Yes	24	60.0%	34	66.7%	10	32.3%	68	55.7%
Total	40	100.0%	51	100.0%	31	100.0%	122	100.0%
Chi-2=9.691, p=0.008								

Considering age, meaningfully more subjects with the age up to 60 (60.0%) and between 61 and 74 years (66.7%) scheduled an appointment with their family doctor within six months after discharge from the stroke unit than those above 75 years old (32.3%) (Chi-2= 9.691, p=0.008). Table 44 provides evidence of the impact that education level exerted on respondents' contacts with health centers.

Table 44. Impact of education level on patients' interaction with a health center

Contact with a health center	Education level						Total	
	None		Primary		Higher than primary			
	N	Percent	N	Percent	N	Percent	N	Percent
No	8	36.4%	39	41.9%	7	100.0%	54	44.3%
Yes	14	63.6%	54	58.1%	0	0.0%	68	55.7%
Total	22	100.0%	93	100.0%	7	100.0%	122	100.0%
Chi-2= 9.575, p=0.007								

Interestingly, a contact with a health center had 63.6% patients with no formal education and 58.1% patients with the primary education, while no subject with education level higher than primary visited a health center after discharge. The relation between the interaction with a health center and education level was statistically significant (Chi-2= 9.575, p=0.007, with Monte Carlo simulation). Table 45 presents how the type of a caregiver after stroke influenced patients' interactions with health centers.

Table 45. Impact of a type of caregiver after stroke on patients' interaction with a health center

Contact with a health center	Caregiver after stroke								Total	
	None		Spouse		Family member other than spouse		Spouse and other family member			
	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent
No	20	52.6%	8	22.2%	2	22.2%	6	54.5%	36	38.3%
Yes	18	47.4%	28	77.8%	7	77.8%	5	45.5%	58	61.7%
Total	38	100.0%	36	100.0%	10	100.0%	11	100.0%	94	100.0%
Chi-2= 9.454, p=0.022										

More persons cared after stroke by a spouse (77.8%) or a family member other than spouse (77.8%) contacted a health center as compared to those receiving care from a spouse and other family member or not receiving any care (Chi-2= 9.454, p=0.022, with Monte Carlo simulation). Table 46 presents the impact of education level of patients on their interactions with one physiotherapy clinic (as more than one clinic could be contacted throughout the course of the study span).

Table 46. Impact of education level on patients' interaction with one physiotherapy clinic

Contact with one physiotherapy clinic	Education level						Total	
	None		Primary		Higher than primary			
	N	Percent	N	Percent	N	Percent	N	Percent
No	8	34.8%	25	26.0%	5	71.4%	38	30.2%
Yes	15	65.2%	71	74.0%	2	28.6%	88	69.8%
Total	23	100.0%	96	100.0%	7	100.0%	126	100.0%
Chi-2= 6.666, p=0.034								

Taking into account physiotherapy clinics, significantly more respondents with primary education (74.0%) and with no formal education (65.2%) made physiotherapy in one of such institutions comparing to those with education higher than primary (28.6%) (Chi-2= 6.666, p=0.034, with Monte Carlo simulation). Next, Table 47 provides information on how the fact of having care after stroke influenced contacts patients had with one physiotherapy clinic.

Table 47. Impact of having care after stroke on patients' interaction with one physiotherapy clinic

Contact with one physiotherapy clinic	Care after stroke				Total	
	No		Yes			
	N	Percent	N	Percent	N	Percent
No	21	53.8%	17	19.5%	38	30.2%
Yes	18	46.2%	70	80.5%	88	69.8%
Total	39	100.0%	87	100.0%	126	100.0%
Chi-2= 15.046, p<0.001						

The results show that more contacts with one physiotherapy clinic were made by those subjects of the study who received care after stroke (80.5%) than by those who did not receive care (46.2%) (Chi-2= 15.046, p<0.001). Table 48 depicts the impact of a type of caregiver on patients' contacts with one physiotherapy clinic.

Table 48. Impact of a type of caregiver after stroke on patients' interaction with one physiotherapy clinic

Contact with one physiotherapy clinic	Caregiver after stroke								Total	
	None		Spouse		Family member other than spouse		Spouse and other family member			
	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent
No	21	53.8%	4	11.1%	2	22.2%	3	27.3%	30	31.6%
Yes	18	46.2%	32	88.9%	7	77.8%	8	72.7%	65	68.4%
Total	39	100.0%	36	100.0%	9	100.0%	11	100.0%	95	100.0%
Chi-2= 16.389, p=0.001										

Among participants of the study, those receiving care from several caregivers differed significantly between groups (Chi-2= 16.389, p=0.001, with Monte Carlo simulation). In average, a group receiving care from a spouse had the strongest impact on respondents' decision for physiotherapy. Table 49 shows how civil status impacts contacts established by subjects with a fire department.

Table 49. Impact of civil status on patients' interaction with a fire department

Contact with a fire department	**Civil status**				**Total**	
	In a relationship		No relationship			
	N	Percent	N	Percent	N	Percent
No	11	13.4%	12	30.8%	23	19.0%
Yes	71	86.6%	27	69.2%	98	81.0%
Total	82	100.0%	39	100.0%	121	100.0%
Chi-2= 5.171, p=0.023						

Apparently, patients in a relationship (86.6%) used to interact with a fire department more than those currently not in a relation (69.2%) (Chi-2= 5.171, p=0.023). Statistically significant difference in contacting firemen was also found in the fact of a respondent having received care after cerebrovascular accident, of which evidence is displayed in Table 50.

Table 50. Impact of having care after stroke on patients' interaction with a fire department

Contact with a fire department	**Care after stroke**				**Total**	
	No		Yes			
	N	Percent	N	Percent	N	Percent
No	13	34.2%	10	12.0%	23	19.0%
Yes	25	65.8%	73	88.0%	98	81.0%
Total	38	100.0%	83	100.0%	121	100.0%
Chi-2= 8.316, p=0.004						

Patients receiving care after stroke used more (88.0%) transportation services of firemen than those who did not received care (65.8%) and this was a statistically high significant difference (Chi-2= 8.316, p=0.004). Table 51 presents the impact of age on patients' contacts with Private Institutions of Social Solidarity.

Table 51. Impact of age on patients' interaction with IPSS

Contact with IPSS	Age						Total	
	Until 60 years		From 61 to 74 years		Over 75 years			
	N	Percent	N	Percent	N	Percent	N	Percent
No	37	92.5%	42	82.4%	19	57.6%	98	79.0%
Yes	3	7.5%	9	17.6%	14	42.4%	26	21.0%
Total	40	100.0%	51	100.0%	33	100.0%	124	100.0%
Chi-2= 13.886, p=0.001								

The evidence shows that the higher age, the more subjects used to contact IPSS: from 7.5% in a group until 60 years old, through 17.6% for the age between 61 and 74, until 42.4% in a group over 75 years old and this difference between groups was statistically significant (Chi-2= 13.886, p=0.001). Table 52 presents the impact of education level on patients' interactions with Private Institutions of Social Solidarity.

Table 52. Impact of education level on patients' interaction with IPSS

Contact with IPSS	Education level						Total	
	None		Primary		Higher than primary			
	N	Percent	N	Percent	N	Percent	N	Percent
No	13	56.5%	79	84.0%	6	85.7%	98	79.0%
Yes	10	43.5%	15	16.0%	1	14.3%	26	21.0%
Total	23	100.0%	94	100.0%	7	100.0%	124	100.0%
Chi-2= 8.646, p=0.013								

The study reveals that significantly more patients with no formal education (43.5%) than having the primary education (16.0%) or higher than the primary level of education (14.3%) had a contact with a Private Institution of Social Solidarity (Chi-2= 8.646, p=0.013, with Monte Carlo simulation) related to issues of stroke they suffered. Table 53 provides evidence on the way care after stroke influenced interactions with IPSS among subjects.

Table 53. Impact of having care after stroke on patients' interaction with IPSS

Contact with IPSS	Care after stroke				Total	
	No		Yes			
	N	Percent	N	Percent	N	Percent
No	38	100.0%	60	69.8%	98	79.0%
Yes	0	0.0%	26	30.2%	26	21.0%
Total	38	100.0%	86	100.0%	124	100.0%
Chi-2= 14.536, p<0.0001						

The results demonstrate that the contact with IPSS had merely respondents who could count on care after stroke (30.2%) (Chi-2= 14.536, p<0.0001). There was no subject who would not have care after their stroke but interacted with a Private Institution of Social Solidarity within the six months after discharge from the stroke unit. Table 54 presents the impact of age on patients' interactions with a private caregiver.

Table 54. Impact of age on patients' interaction with a private caregiver

Contact with a private caregiver	**Age**						**Total**	
	Until 60 years		From 61 to 74 years		Over 75 years			
	N	Percent	N	Percent	N	Percent	N	Percent
No	39	97.5%	47	94.0%	25	80.6%	111	91.7%
Yes	1	2.5%	3	6.0%	6	19.4%	10	8.3%
Total	40	100.0%	50	100.0%	31	100.0%	121	100.0%
Chi-2= 7.121, p=0.027								

The results indicate that significantly more experiences with a formal caregiver had respondents aged over 75 (19.4%) than those between 61 and 74 (6.0%) and until 60 years old (2.5%) (Chi-2= 7.121, p=0.027, with Monte Carlo simulation). Table 55 presents the impact of gender on patients' interaction with a private caregiver.

Table 55. Impact of gender on patients' interaction with a private caregiver

Contact with a private caregiver	**Gender**				**Total**	
	Woman		Man			
	N	Percent	N	Percent	N	Percent
No	51	86.4%	60	96.8%	111	91.7%
Yes	8	13.6%	2	3.2%	10	8.3%
Total	59	100.0%	62	100.0%	121	100.0%
Chi-2= 4.258, p=0.039						

The impact of gender on the interaction with a private carer was on the limit of statistical significance (Chi-2= 4.258, p=0.050) with exact Fisher test with women being more prone to gave a caregiver (13.6%) than men (3.2%). The impact of housing comfort was not statistically significant, but close to the limit (p=0.06). The results show more subjects with a private caregiver living in households of a medium or low standard than those living in high or luxury conditions.These at first surprising results can be explained by a low number of respondents living in luxurious settings. Table 56 demonstrates the relation between care after stroke and patients' contact with one rehabilitation unit (as patients could be hospitalized in more than one rehabilitation unit of the RNCCI).

Table 56. Impact of care after stroke on patients' interaction with one rehabilitation unit

Contact with one rehabilitation unit	**Care after stroke**				**Total**	
	No		Yes			
	N	Percent	N	Percent	N	Percent
No	42	87.5%	68	66.7%	110	73.3%
Yes	6	12.5%	34	33.3%	40	26.7%
Total	48	100.0%	102	100.0%	150	100.0%
Chi-2= 7.244, p=0.007						

The analysis revealed that statistically more patients who had care after stroke (33.3%) than who did not have care (12.5%) experienced an interaction with one rehabilitation unit (Chi-2= 7.244, p=0.007). Table 57 portrays the impact of a type of caregiver a respondent had after stroke on contacts with one rehabilitation unit.

Table 57. Impact of a caregiver type after stroke on patients' interaction with one rehabilitation unit

Contact with one rehabilitation unit	**Caregiver after stroke**								**Total**	
	None		Spouse		Family member other than spouse		Spouse and other family member			
	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent
No	42	87.5%	27	67.5%	12	100.0%	7	50.0%	88	76.6%
Yes	6	12.5%	13	32.5%	0	0.0%	7	50.0%	26	23.4%
Total	48	100.0%	40	100.0%	12	100.0%	14	100.0%	114	100.0%
Chi-2= 14.457, p=0.002										

The largest amount of respondents who had a contact with a rehabilitation unit were those cared by a spouse with other family member (50.0%) while the lowest in number were those cared by family member other than spouse (0.0%), and differences between all groups under consideration were statistically significant (Chi-2= 14.457, p=0.002, with Monte Carlo simulation). This particular table did not take into account all possible response options which the initial analysis indicated as there were several options with low frequencies of responses; however an additional analysis showed that the statistical significance of the test would not change (Chi-2= 39.946, p=0.002).

A statistically significant relationship existed also between variables 'contact with the Social Security' and 'civil status', and 'contact with the Social Security' and 'housing situation'. Table 58 presents the impact of civil status on patients' contacts with the Social Security.

Table 58. Impact of civil status on patients' interaction with the Social Security

Contact with the Social Security	Civil status				Total	
	In a relationship		No relationship			
	N	Percent	N	Percent	N	Percent
No	66	80.5%	38	97.4%	104	86.0%
Yes	16	19.5%	1	2.6%	17	14.0%
Total	82	100.0%	39	100.0%	121	100.0%
Chi-2= 6.287, p=0.012						

Statistically more persons in a relationship (19.5%) than not (2.6%) sought information or support in the Social Security (Chi-2= 6.287, p=0.012). Table 59 presents the impact of housing situation on the study participants' contacts with the Social Security.

Table 59. Impact of housing situation on patients' interaction with the Social Security

Contact with the Social Security	Housing situation								Total	
	None		Spouse		Family members other than spouse		Spouse and other family members			
	N	Percent	N	Percent	N	Percent	N	Percent	N	Percent
No	19	100.0%	47	85.5%	16	94.1%	19	70.4%	101	85.6%
Yes	0	0.0%	8	14.5%	1	5.9%	8	29.6%	17	14.4%
Total	19	100.0%	55	100.0%	17	100.0%	27	100.0%	118	100.0%
Chi-2= 9.275, p=0.024										

Comparing the experiences of contacts with the Social Security, the findings indicate that the largest group of respondents who contacted the Social Security was the one living with a spouse and other family members (29.6%), followed by the one living only with a spouse (14.5%). For a comparison, no subject living alone contacted the Social Security. Differences between groups were statistically significant (Chi-2= 9.275, p=0.024, with Monte Carlo simulation).

6.3. Perceived service quality and satisfaction with care services

6.3.1. Careperf service quality measure

The starting point of assessing perceived service quality was a specification of the entity from which the evaluation would begin. In this case, it was Hospital Infante D. Pedro in Aveiro, as the institution to which all patients participating in the study were directed after having had a medical condition justifying transportation to the emergency room and, consequently, having been admitted to the Stroke Unit.

The initial Careperf questionnaire employed among subjects regarding their experience with the hospital contained 34 items, which would require at least, around 340 responses. While opinions on the lowest subject to item ratio vary among scholars (Gorusch, 1983; Hatcher, 1994), the rule 10:1 is considered the most reasonable in order to guarantee robustness of results. This amount of responses was not achieved during three years of data collection. Consequently, other approaches had to be taken into consideration and critically evaluated. From those, one solution appeared methodologically correct, fair and robust. It was to conduct principal component analysis applied to new items added to the original SERVPERF questionnaire with an intention to create the Careperf questionnaire, and in the next step, to verify reliability of the entire newly constructed measure as a whole.

Hence, in the present study, PCA was applied to the dimensions proposed additionally for the existing and well established SERVPERF instrument, to form, as a final step, the Careperf questionnaire, a measure of service quality directed specifically to health and social care organizations particularity.

Before performing PCA, the data were checked visually. Missing values were dealt in two ways: full elimination when there was a total absence of observations per line, or missing imputation based on mean replacing. An initial sample size of 151 dropped to 127. Therefore the final analysis included responses of 127 participants. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.77. The Bartlett's test assessing whether the correlation matrix is an identity matrix rejected the hypothesis at $p<0.001$. Therefore, the initial minimum criteria to perform principal component analysis were well satisfied.

Obtaining a factor solution through PCA required repeating a procedure throughout an interactive process to reach the best viable structure of components. The best fitting solution, according to the theoretical assumptions underlying the study was found with the Varimax rotation and it detected, as hoped, three components, confirmed by the Kaiser criterion while graphical inspection of the scree plot suggested rather two components. The Kaiser criterion deems preserving components with eigenvalues over 1 and a scree plot is a simple line segment that allows for a visual judgment based on the highest fraction of total variance explained by a given component. There were, however, a number of issues to cope with. One item correlation (CP_H9 with CP_H5) level was at extremely low level (0.000), a similar situation with CP_H9 was identified in correlation with CP_H23 (0.006), bringing a risk of the variable loading only into the principal component, forming hereby its own principal component. Therefore item CP_H9 was deleted. There was one item (CP_H1) presenting loadings into two components at the same time. This item was also deleted. The last issue, raising continuous discussions among academics and with no conclusive pronouncement so far was the actual possibility of obtaining a dimension composed by two items. This dimension was initially thought to be composed of three items (CP_H2, CP_H5 and CP_H23) and one of them loaded individually into one individual component creating thus a component comprised of one item. This item (CP_H2) was automatically considered for deletion. Deleting the item could be a naturally plausible solution, nonetheless, would bring another dilemma, which was having a component composed of two items considered by some scholars, as such, frail and unstable (Costello & Osborne, 2005). Other two items of the dimension would remain under consideration. Nevertheless, in this case, these items loaded simultaneously into two different components at the same time. Hence, they were considered to be excluded from further analysis.

The final model of the first PCA had two components, of which first component consisted of items CP_H4, CP_H10 and CP_H30, and second component consisted of items CP_H13, CP_H14, CP_H21 and CP_H34 from the Careperf questionnaire. PCA revealed only one item that did not correspond to the initial research assumptions and expectations, which was item CP_H13, hoped to have loaded into the first component.

These two components explained altogether 63.69% of the total variance. First component accounted for 31.87% of the variance and second component for the next 31.82% of the variance in the items, specifically, in the variance-covariance matrix of the items. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.70. The Bartlett's test rejected the hypothesis that the correlation matrix was an identity matrix at $p<0.001$.

The procedure conducted with the PCA methodology led into two conclusions: (a) two components (and not three, as originally assumed) were more adequate for the part of the measure in question, and (b) as PCA was applied to items of the questionnaire appended into the original SERVPERF measure in order to adapt it to the specificity of care organizations, further reliability of the complete questionnaire should be verified. Items revealing as not stable and consistent within a certain dimension were recommended to be deleted.

Conformingly, principal component analysis was applied to the items extracted within the previous PCA which resulted in creating two dimensions and to the items adapted to the Careperf measure from the original SERVPERF instrument, making up five dimensions. The objective of the procedure was to find single-factor solutions for each theoretical dimension considering loadings above 0.45 (Field, 2005), explained variance above 50% for one dimension (Batt & Purchase, 2004) and communalities above 0.40 (Bonsignore et al., 2009).

Reliability for each dimension was measured through Cronbach's alpha with a recommended value above 0.60 (Fruchterman & Reingold, 1991), and item-total correlation above 0.30 (Fruchterman & Reingold, 1991). Therefore, through the use of Cronbach's alpha internal consistency for each dimension was evaluated verifying whether and to which extent items of the instrument measured the same concept or construct (Tavakol & Dennick, 2011). The item-total coefficient, representing the Pearson's correlation coefficient between each item and the total score of the remaining items of the same dimension provided information whether the item was consistent with the domain.

In the dimension of Tangibles, despite initial Cronbach's alpha of 0.57 with four items in the analysis, the result was considered to be satisfactory. That was due to the fact that all loadings were above 0.45 and accumulated explained variance was above 50%. Items of the dimension were correlated with the total score (above 0.30) with an exception of CP_H32 (*'The hospital has up-to-date equipment (e.g. diagnosis equipment)'*), which item-total correlation was 0.22. It was also found out that communality of that item was below 0.4 (0.19) and its eventual removal would increase Cronbach's alpha. The decision was therefore to eliminate the item. The final composition of the Tangibles dimension is provided in Table 60.

Table 60. Reliability and PCA results for the Tangibles dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
CP_H15. Appearance of physical facilities of the hospital keeps with the type of provided service	0.83	0.68	58.06	58.06	0.53	0.62
CP_H26. The hospital professionals are well dressed and appear neat	0.55	0.30			0.26	
CP_H28. The hospital physical facilities are visually appealing (e.g. appointment rooms, waiting rooms, bathrooms)	0.87	0.76			0.61	

KMO=0.55; BTS p<0.001

The Reliability dimension encompassed five items and had Cronbach's alpha 0.65, therefore its result could be assumed as suitable. All questions were correlated with the general construct (above 0.30) and an eventual deletion of one of them would not improve the alpha coefficient. Nevertheless, PCA solution found two distinct factors: CP_H8, CP_H18 and CP_H19 (explaining 44.7% of the variance) and CP_H3, CP_H27 (explaining 20.60% of the variance), both totalizing for 65.35% of the explained variance. Communalities (above 0.40) and loadings (above 0.45) were adequate. Thus, the dimension was split into two in the confirmatory factor analysis, and Cronbach's alpha was 0.67 and 0.51 for each particular factor. The final composition of the Reliability dimension is provided in Table 61.

Table 61. Reliability and PCA results for the Reliability dimension

	Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
Factor 1	CP_H8. When a problem (e.g. doubts) arises, the hospital is sympathetic and reassuring	0.87	0.65	44.77	44.77	0.38	0.67
	CP_H18. The hospital is dependable	0.56	0.77			0.31	
	CP_H19. The hospital provides its service at the time it promises to do so (e.g. makes treatments at scheduled time, delivers meals on time)	0.80	0.51			0.46	
Factor 2	CP_H3. When the hospital schedules a service with a patient at certain time, it does so	0.80	0.74	20.60	65.38	0.57	0.51
	CP_H27. The hospital keeps its records accurately (e.g. realized appointments, medication, exams)	0.76	0.60			0.40	

KMO=0.69; BTS p<0.001

PCA solution for a four-item dimension of Responsiveness found two distinct factors, of which one was composed solely by one item. That item, CP_H24, (*'The hospital does not tell patients exactly when services will be provided'*) was very poorly correlated with the others (0.13), and its deletion would improve the total alpha coefficient, so far of 0.55, what made it below that generally considered as reasonable. An attempt to calculate Cronbach's alpha and item-total correlation without CP_H24 resulted in satisfactory results, with Cronbach's alpha 0.64 and item-total correlations above 0.30. Despite making part of the original SERVPERF questionnaire, the decision fell into eliminating the item from further analysis taking in consideration the improvement its removal would bring to the overall subscale. The final composition of the Responsiveness dimension is provided in Table 62.

Table 62. Reliability and PCA results for the Responsiveness dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
CP_H6. You do not receive prompt service from the hospital employees	0.75	0.67	58.20	58.20	0.43	0.64
CP_H12. Employees of the hospital are not always willing to help patients	0.74	0.55			0.42	
CP_H17. Employees of the hospital are too busy to respond to patients' requests promptly	0.79	0.63			0.49	

KMO=0.65; BTS p<0.001

In the Assurance dimension Cronbach's alpha for the overall subscale was 0.66, a result that can be considered well satisfactory. In case of CP_H22 (*'Employees get adequate support from the hospital to well perform their tasks'*), alpha coefficient would increase when deleting the item in cause. Additionally, it presented poor correlation with the general domain (0.25), low communality (0.17) and loading 0.41. All other values of the items composing the dimension were according to the necessary assumptions so only that item was removed from further analysis. The final composition of the Assurance dimension is provided in Table 63.

Table 63. Reliability and PCA results for the Assurance dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
CP_H7. Employees of the hospital are correct (they treat a patient with courtesy and politeness)	0.82	0.68	77.28	77.28	0.64	0.84
CP_H11. A patient feels safe in contacts with the hospital employees	0.91	0.82			0.75	
CP_H33. One can trust employees of the hospital	0.90	0.82			0.76	

KMO=0.70; BTS p<0.001

The Empathy dimension consisted of five items and its overall Cronbach's alpha was 0.66, which is considered an above satisfactory result. An eventual removal of any item would not improve the value of this coefficient. Item-total correlation was adequate (above 0.30). The explained variance was slightly below the expected 50%, but all loadings (higher than 0.45) and communalities (higher than 0.40) presented satisfactory values within the established criteria. Hence, no changes were made to this subscale. The Empathy dimension results are presented in Table 64.

Table 64. Reliability and PCA results for the Empathy dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
CP_H16. The hospital does not give individual attention	0.87	0.66			0.42	
CP_H20. Employees of the hospital do not comprehend patient's needs	0.56	0.69			0.45	
CP_H25. The hospital does not have patients' interests at heart	0.80	0.71	43.06	43.06	0.46	0.66
CP_H29. Employees of the hospital do not give patients personal attention	0.80	0.57			0.34	
CP_H31. The hospital operating hours are not convenient to all patients	0.76	0.64			0.41	

KMO=0.69; BTS p<0.001

Cronbach's alpha for the Communication dimension was 0.72 what indicates a good level of internal consistency. There was still one question, CP_H4, (*'Professionals of the hospital do not provide information on services and treatments available at other institutions'*) with a potential to increase Cronbach's alpha if deleted. This item also raised issues on item-total correlation (0.25) and communalities (0.23). Despite that fact, the decision was to maintain it since its loading was higher than 0.45. The final composition of the Communication dimension is provided in Table 65.

Table 65. Reliability and PCA results for the Communication dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
CP_H4. Professionals of the hospital do not provide information on services and treatments available at other institutions	0.46	0.23	63.97	63.97	0.25	0.72

CP_H10. Professionals of the hospital inform about entities that might help in the specific case of the patient (e.g. appointments, transportation by firemen, social support, exams, spiritual support)	0.92	0.85			0.74	
CP_H30. Professionals of the hospital put patients in contact with entities that may be useful in their case (e.g. appointments, transportation by firemen, social support, exams, spiritual support)	0.92	0.84			0.73	

KMO=0.54; BTS p<0.001

The dimension of Privacy included four items. Cronbach’s alpha for the dimension was 0.72, what indicated a good internal consistency. All assumptions were accomplished, except those of communalities (CP_H13 and CP_H34 were slightly below 0.40); still, all items remained plausible in this dimension. The final composition of the Privacy dimension is provided in Table 66.

Table 66. Reliability and PCA results for the Privacy dimension

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach’s α
CP_H13. When necessary, the hospital contacts the entity who treated a patient before (e.g. family doctor, fire department)	0.59	0.35	55.67	55.67	0.37	0.72
CP_H14. The hospital has conditions guaranteeing that the patient’s data are not accessed by unauthorized persons	0.87	0.76			0.65	
CP_H21. Professionals of the hospital treat patient information confidentially	0.88	0.77			0.67	
CP_H34. The hospital has conditions to guarantee privacy	0.59	0.35			0.38	

KMO=0.65; BTS p<0.001

Confirmatory factor analysis with structural equation modelling software AMOS v. 21.0 (IBM, Armonk, NY, USA, 2014) was performed. The maximum likelihood method of covariance structure analysis was used and considered to be robust, even in case of absence of multivariate normality (Harel & Koren, 2000). A set of fit indices reflect recommendations about what to report in written summaries of the confirmatory factor analysis (Kline, 2005). These include: (1) model chi-square (χ2) (Field, 2009); (2) Goodness of Fit Index (GFI) (Joreskog & Sorbom, 1984); (3) Comparative Fit Index (CFI) (Hu & Bentler, 1989); (4) Non-Normed Fit Index (NNFI) (Bentler & Bonett, 1980); (5) Incremental Fit Index (IFI) (Bollen, 1989); and (6) the Steiger-Lind root mean square error of approximation (RMSEA) (Steiger, 1990).

The final Careperf instrument contained 21 items divided into seven dimensions, as presented in Figure 32.

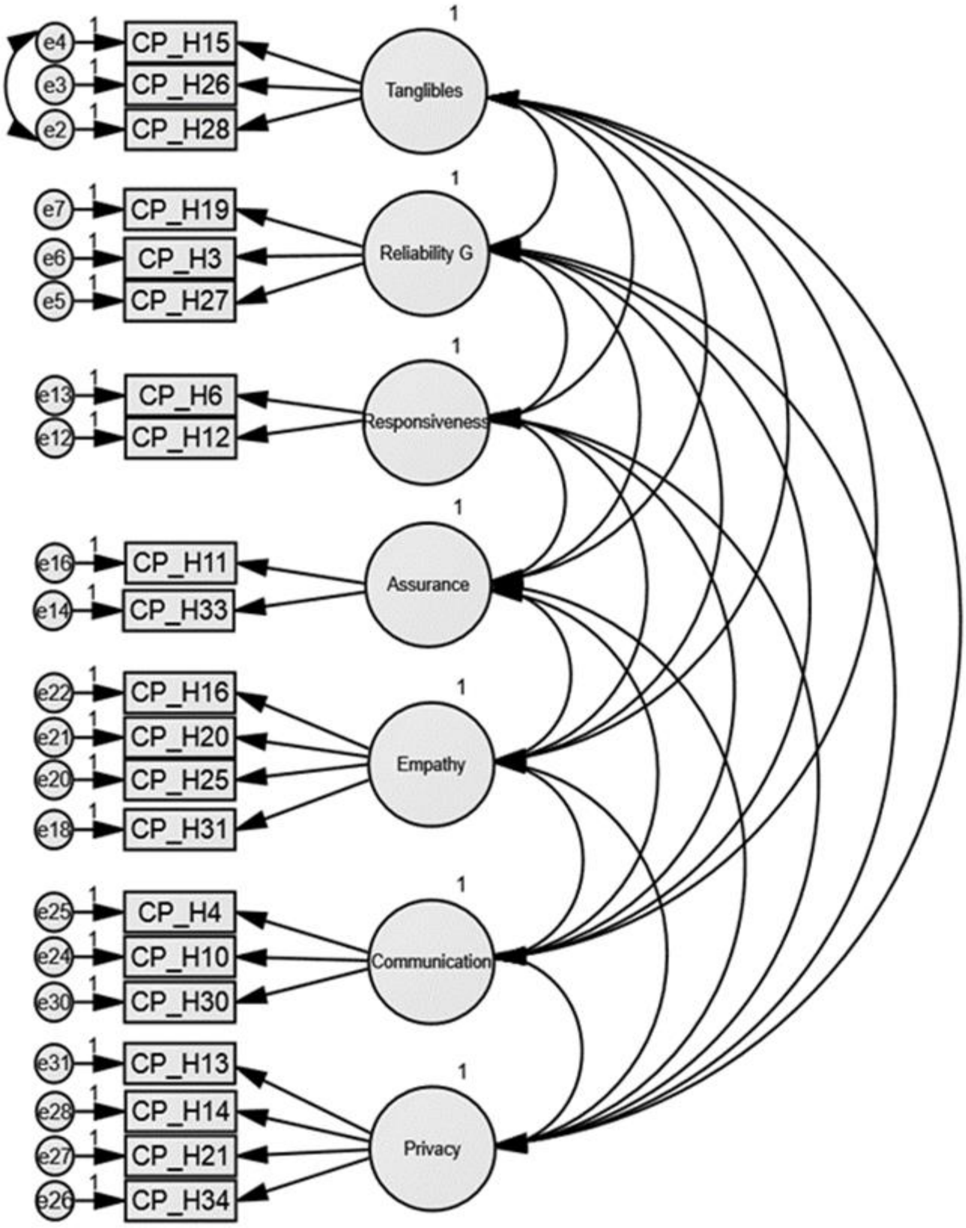


Figure 32. Confirmatory model for the Careperf instrument

Confirmatory model fit was measured according to chi-square (χ^2), GFI, CFI, NNIFI, IFI and RMSEA. Together with previously eliminated items, AMOS modification indices recommended covariance between errors 2 (CP_H28) and 4 (CP_H15) and elimination of items CP_H8, CP_H17 and CP_H18. Estimates were calculated based on the maximum likelihood method, considered to be robust, even in case of absence of multivariate normality (Harel & Koren, 2000). Results of the Careperf confirmatory model fit indices are provided in Table 67.

Table 67. Confirmatory model fit indices

Model-fix index	Recommended value	Confirmatory model
model chi-square χ^2	≥ 0.05	$\chi^2_{(167)}=265.77$; $p<0.001$
GFI	≥0.90	0.84
CFI	≥0.90	0.90
NNFI	≥0.90	0.88
IFI	≥0.90	0.90
RMSEA	≤0.07	0.069

Despite chi-square $p<0.05$, model fit was considered to be satisfactory as several other fit parameters satisfied their criteria. CFI was 0.90 (recommendation ≥0.90), and RMSEA scored 0.069, below the limit 0.07. IFI was 0.90 with its values equal or superior to 0.90 considered as suitable, and robustness towards a sample size (Bollen, 1989). GFI was 0.84 with a recommended value greater than 0.90 and NNFI was 0.88 with the recommendation above 0.90, therefore from these two parameters not satisfying the suggested values, they still approached very closely their fit criteria.

Positive significant coefficient results (β) were also found on all possible relations as presented in Table 68. The highest magnitude relations were identified in the Communication dimension (all coefficients above 1). On the other end, the lowest coefficients were found in the Tangibles dimension.

Table 68. Confirmatory model coefficient statistics

Item		Dimension	Estimate (β)	S.E.	p-value (CR)
CP_H28	←	Tangibles	0.28	0.07	p<0.001
CP_H26	←	Tangibles	0.30	0.05	p<0.001
CP_H15	←	Tangibles	0.35	0.09	p<0.001
CP_H12	←	Responsiveness	0.67	0.15	p<0.001
CP_H6	←	Responsiveness	1.00	0.17	p<0.001

CP_H33	←	Assurance	0.40	0.04	p<0.001
CP_H11	←	Assurance	0.57	0.04	p<0.001
CP_H31	←	Empathy	0.76	0.17	p<0.001
CP_H25	←	Empathy	0.76	0.10	p<0.001
CP_H20	←	Empathy	0.63	0.12	p<0.001
CP_H16	←	Empathy	0.85	0.14	p<0.001
CP_H10	←	Communication	1.73	0.15	p<0.001
CP_H4	←	Communication	1.09	0.17	p<0.001
CP_H30	←	Communication	1.72	0.15	p<0.001
CP_H34	←	Privacy	0.37	0.08	p<0.001
CP_H21	←	Privacy	1.02	0.08	p<0.001
CP_H14	←	Privacy	0.96	0.09	p<0.001
CP_H13	←	Privacy	0.50	0.11	p<0.001
CP_H19	←	Reliability	0.41	0.05	p<0.001
CP_H3	←	Reliability	0.49	0.09	p<0.001
CP_H27	←	Reliability	0.62	0.10	p<0.001

CR= Critical ratio for Z-Distribution; S.E.-standard error

Table 69 provides basic statistics obtained for all items of the Careperf measure.

Table 69. Statistics of all items proposed for the Careperf measure reached in the hospital setting

Variable	Min	Max	Mean	SD
CP_H 1	2	7	5.00	1.53
CP_H2	2	7	6.02	0.65
CP_H3	1	7	5.72	1.05
CP_H4	1	7	3.47	1.98
CP_H5	1	7	4.37	1.93
CP_H6	1	7	5.57	1.40
CP_H7	3	7	6.07	0.68
CP_H8	2	7	5.96	0.80
CP_H9	1	7	5.55	1.51
CP_H10	1	7	3.39	1.95
CP_H11	3	7	6.08	0.59
CP_H12	1	7	5.48	1.49
CP_H13	1	7	4.41	1.26
CP_H14	2	7	4.98	1.17
CP_H15	1	7	5.69	0.93
CP_H16	1	7	5.35	1.52
CP_H17	2	7	5.56	1.30
CP_H18	2	7	6.01	0.66
CP_H19	3	7	5.98	0.64
CP_H20	1	7	5.59	1.25

CP_H21	2	7	5.13	1.09
CP_H22	2	7	5.24	1.08
CP_H23	1	7	3.68	2.14
CP_H24	1	7	5.35	1.46
CP_H25	2	7	5.63	1.10
CP_H26	3	7	6.09	0.49
CP_H27	2	7	5.30	1.12
CP_H28	1	7	5.87	0.75
CP_H29	2	7	5.75	1.11
CP_H30	1	7	3.46	1.93
CP_H31	1	7	4.79	1.75
CP_H32	1	7	5.60	1.01
CP_H33	4	7	6.03	0.50
CP_H34	2	7	5.77	0.92

Means of variables proposed for the Careperf were generally at average or high level. Means of only a few items situated between 3 and 4, in a 7-point Likert scale, with all remaining with higher values. This tendency found confirmation in means of factors associated to service quality in the final model of the Careperf instrument as well (Figure 33). Factor with the highest mean was Assurance (6.06), followed by Tangibles and Reliability, with means 5.88 and 5.66 respectively. Conversely, factor with distinctively lower mean from the others was that of Communication (3.44).

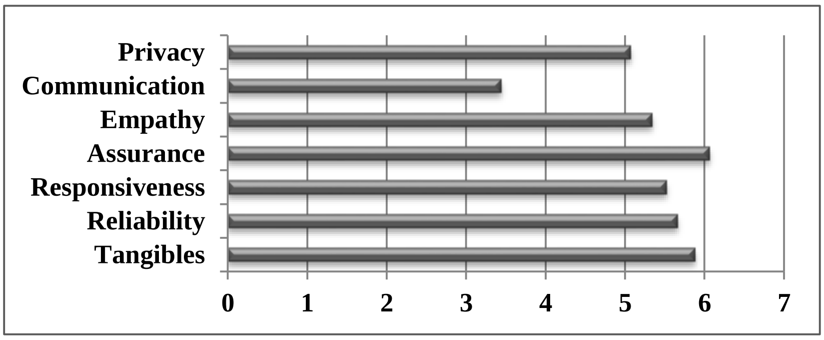


Figure 33. Means of factors associated to service quality in the hospital setting measured by the Careperf

6.3.2. Service quality of stroke support and care entities assessed by the Careperf

Having initiated the data collection at the Stroke Unit of HIP, patients were asked to evaluate their experience with entities providing care and support services. However, employing the Careperf measure for each entity a patient interacted with was not considered feasible at the study design phase, due to a number of factors, that is: (a) multiplicity of institutions to possibly contact with of which exact number was impossible to predict; and (b) burden that such application would constitute for the participant. For that reason, a decision fell into employing the Careperf solely for entities thought to be contacted by a higher number of respondents allowing for making eventual further statistical manipulations with gathered data. In this manner, experience with the hospital services (HIP), health centers, rehabilitation units and physiotherapy clinics was evaluated by means of the Careperf measure.

6.3.2.1. Service quality of the hospital

The first step in the analysis of the service quality was a definition of descriptive statistics of the dimensions composing the Careperf measure. Given that the instrument is composed of seven dimensions where each one contains different number of items, it turned compulsory to recalculate the results into percentage of the possible maximum score to be achieved. The results of the Careperf instrument application for hospital services are provided in Table 70.

Table 70. Results of the individual dimensions of the Careperf measure applied for hospital services

	N	Min	Max	Mean	SD	Percent of the max. possible score
Tangibles	127	8	21	17.65	1.68	84.06%
Reliability	128	11	21	17.01	2.10	80.99%
Responsiveness	128	2	14	11.07	2.36	79.07%
Assurance	128	8	14	12.11	1.02	86.50%
Empathy	125	9	28	21.36	3.96	76.29%
Communication	128	3	21	10.38	5.03	49.44%
Privacy	127	8	28	20.28	3.28	72.41%

The results demonstrate that the best scores were attributed to the dimensions of Assurance (86.50%), Tangibles (84.06%) and Reliability (80.99%). The scores of the dimensions of Responsiveness and Empathy did not diverge much from the ones rated the highest having attained 79.07% and 76.29% of a potential maximum value, respectively. The weakest dimension of the measure, as seen by respondents, was that of Communication, reaching 49.44% of the possible maximum score.

A general perception of service quality of the hospital was predominantly assessed as ‘good’ (6 on a 7-point Likert scale), what was a case of 74.0% of respondents. A range of responses varied from 4 to 7, indicating that there were no participants whose evaluation of service quality of the hospital was bad. Median was 6. Figure 34 presents distribution of responses regarding general perception of service quality of the hospital.

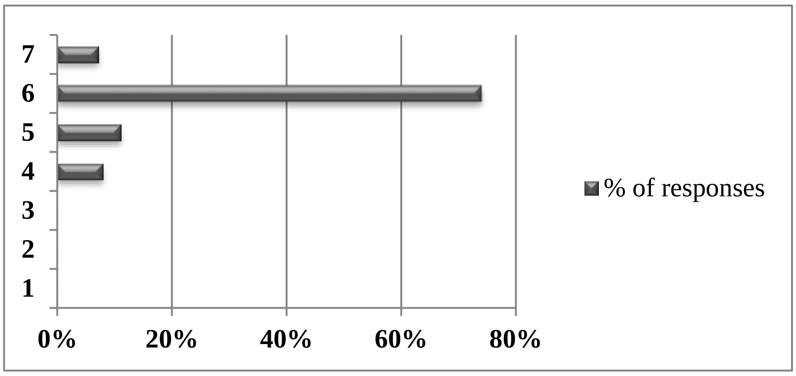


Figure 34. Assessment of overall service quality provided by the hospital

6.3.2.2. Service quality of rehabilitation units

A combined analysis of all rehabilitation units involved in the study would be methodologically improper, however, an individual analysis was impossible due to a limited number of subjects. In fact, there were few more patients who remained in long-term rehabilitation units and contact with them became impossible so they were excluded from the study. Patients remaining in medium-term and long-term units typically represented a more serious level of cognitive and/or physical impairments, or were found to have no or not adequate social response in their residence. Those patients could not count on informal care and social support. Significantly more respondents were directed into short-term units.

While convalescence units provide treatment and clinical and rehabilitative care following the acute phase of the hospitalization are quite easy to distinguish in the system, the same cannot be said about medium and long-term units. However, the RNCCI allows for existing two typologies within one entity, making thus impossible, a clear division between them and conducting a distinctive analysis. For that reason, it was decided to present the information as two groups: convalescence (short-term) units, and medium and long-term units. As it happened in case of use of the measure of service quality for the hospital services, it was necessary to recalculate individual subscales in order to compare the results bearing in mind they had different number of items. Table 71 provides statistics of the dimensions of the Careperf measure applied to rehabilitation units in general. The first part presents results of the applications of the instrument to convalescence units and the second to medium-term and rehabilitation units jointly with long-term and maintenance units.

Table 71. Results of individual dimensions of the Careperf measure applied to the RNCCI convalescence, and medium and long-term units

	N	Min	Max	Mean	SD	Percent of the max. possible score
Convalescence units						
Tangibles	34	8	21	18.03	2.86	85.85%
Reliability	34	9	21	17.47	2.64	83.19%
Responsiveness	35	2	14	5.46	3.44	39.98%
Assurance	35	3	14	11.86	2.73	84.69%
Empathy	34	4	24	9.88	5.19	35.29%
Communication	34	3	18	11.32	4.18	53.92%
Privacy	35	7	28	20.60	4.43	73.57%
Medium and long-term units						
Tangibles	7	10	19	16.57	3.36	78.91%
Reliability	7	8	21	14.57	4.24	69.39%
Responsiveness	7	2	12	7.43	3.99	53.05%
Assurance	7	5	14	9.00	3.65	64.29%
Empathy	7	4	24	16.57	7.30	54.18%
Communication	7	5	18	11.29	4.15	53.74%
Privacy	7	13	25	18.14	3.89	64.80%

In convalescence units, respondents evaluated the highest the dimensions of Tangibles (85.85%), Assurance (84.69%) and Reliability (83.19% of the possible maximum result). Two most problematic dimensions, with the lowest scores were Responsiveness and Empathy, with 39.98% and 35.29% of the highest achievable score, with Responsiveness representing a high variability (mean=5.46, SD=3.44).

In medium and long-term units, the Careperf measure dimensions with the highest appraisal from patients were those of Tangibles (78.91%), Reliability (69.39%) and subsequently, at a similar level, Privacy (64.80%) and Assurance (64.29%). The lowest score, on the other hand, was registered in Responsiveness (53.05%), although differences between the maximum possible scores achieved by both remaining dimensions, namely Empathy and Communication, were in fact trivial. Nonetheless, these results require especial caution. While the number of responses from convalescence units reached at least a minimum to allow for making statistical inferences, the number of seven subjects from medium-long term units is absolutely below any acceptable minimum to take statistically valid conclusions from this specific section. In this case, the objective was simply to illustrate the general situation with a perspective to results of convalescence units.

When questioned about overall perception of service quality provided by convalescence units, subjects expressed high consideration for these entities in the district. Results of that evaluation are presented in Figure 35.

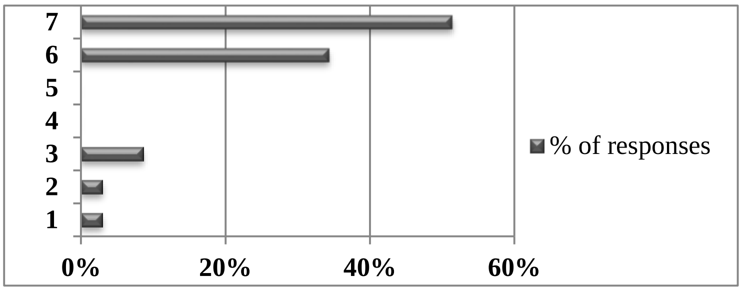


Figure 35. Assessment of overall service quality provided by convalescence units

Responses received from patients varied from 1 to 7. As the distribution was highly skewed, median was considered to better represent patterns of the phenomena and it was 7, the maximum of the scale. Over a half (51.4%) of patients assessed the quality of convalescence units as 'very good' (the highest possible answer on the provided Likert scale). When comparing groups of different convalescence units in what perceived service quality concerned, the institution of Anadia was registered as the one with the highest mean rank, followed by Ovar and Cantanhede (12.50, 9.50 and 6.63, respectively), however these differences were not statistically significant (H(2)= 3.863, p=0.145).

In medium and long-term rehabilitation units responses were from 1 to 7, and median was 3.50. However, bearing in mind a very low number of cases, making any statistical inferences was impossible in such case and above values are provided only for descriptive purposes.

6.3.2.3. Service quality of health centers

The Careperf was administered to subjects who made a medical appoinment related to stroke with their family doctor within six months after discharge. Under the term 'health center' the study assumed a traditional health center and its extension into a less inhabited zone. As respondents resided in the district of Aveiro, they were geographically associated to respective health centers from that district. From all health of the district, participants of the study made their medical appointment in Aveiro, Águeda, Albergaria-a-Velha, Anadia, Estarreja, Mealhada, Ílhavo, Oliveira de Azeméis, Oliveira do Bairro, Murtosa, Sever do Vouga, and Vagos.

With such high number of different entities, performing statistical inferences for each of the institution became meaningless since, at the end, the number of cases to work with would be exceptionally low. This fact allowed merely for presenting a description of the data. Therefore, the objective was to provide a broad view that subjects had on the service quality provided by health centers. As in previous cases, given that the measure consisted of dimensions with different number of items which participants could rate from 1 to 7, it became essential to recount the results into the percentage of the results possible to achieve. Apparently, patients appreciated the most the dimensions of Tangibles (81.90%) and Assurance (78.03%), followed by Reliability (74.57%), and least of all, Empathy, having reached 44.47% of the maximum score. Table 72 presents statistics of the Careperf measure dimensions employed to health centers services provided to stroke patients.

Table 72. Results of individual dimensions of the Careperf measure applied to health centers in the district of Aveiro

	N	Min	Max	Mean	SD	Percent of the max. possible score
Tangibles	53	10	21	17.21	2.60	81.90%
Reliability	53	9	21	15.66	2.75	74.57%
Responsiveness	53	3	14	7.25	2.63	51.75%
Assurance	53	4	14	10.93	2.02	78.03%
Empathy	53	4	24	12.45	4.34	44.47%
Communication	53	3	19	11.42	3.86	54.36%
Privacy	53	14	25	19.26	2.75	68.80%

Patients were asked to evaluate overall service quality of their health center by means of one item, measured, as the rest of the instrument in a 7-point Likert scale. Distribution of responses obtained from participants is presented in Figure 36.

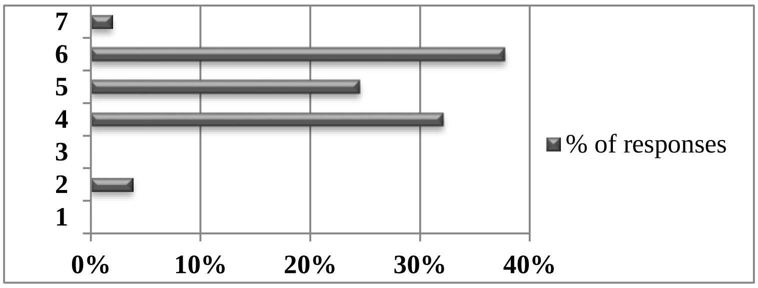


Figure 36. Assessment of overall service quality provided by health centers

Overall service quality of health centers as perceived by participants of the study was rated high. Solely two respondents appeared with a clear opinion of low perceived service quality. Together, two top response options were given by 39.6% of all respondents. Answers varied between 2 and 7, with median 5.

6.3.2.4. Service quality of physiotherapy clinics

The Careperf measure was also employed to patients performing physiotherapy treatments in clinics spread throughout the Aveiro district. In these specific interactons however there was a quite substantial group of patients who admitted to have used rehabilitations services of more than one entity and whose elimination restricted the scope of analysis. This turned computing descriptive statistics impossible.

Individual dimensions of the Caperf applied to physiotheraphy clinic were computed merely for exploratory reasons for comparing service quality between different types of care providers. As it was found out, the pattern of appreciation was very similar to that of hospital services. Respondents appreciated the most the dimension of Assurance (84.30%), followed by Reliability (82.77%) and Tangibles (82.14%), with the only difference residing in an inverse order of the latter two. The lowest were scored the dimensions of Responsiveness and Empathy, having obtained 37.48% and 40.87% of the possible maximum. The statistics of the Careperf dimensions applied to physiotherapy clinics services are provided in Table 73.

Table 73. Results of individual dimensions of the Careperf measure applied to physiotherapy clinics in the district of Aveiro

	N	Min	Max	Mean	SD	Percent of the max. possible score
Tangibles	80	9	21	17.25	2.32	82.14%
Reliability	81	7	21	17.38	2.61	82.77%
Responsiveness	81	2	12	5.25	2.73	37.48%
Assurance	81	4	14	11.80	1.66	84.30%
Empathy	81	4	23	11.44	4.93	40.87%
Communication	81	3	18	9.90	3.20	47.15%
Privacy	81	12	26	18.90	2.84	67.50%

6.3.3. Service quality in stroke support and in care entities assessed qualitatively

Six months after discharge from the stroke unit, semi-structured interviews were conducted with patients participating of the study. Interviews took place from June 2010 to July 2012. Altogether, 102 interviews with patients were concluded. Participants were informed about the objectives of the study and confidentiality of the data and only under the condition of obtaining the patient’s consent to record the interview, the procedure might have been performed. No patient refused recording the interview.

The guide of the interview was designed in order to explore respondents’ perspectives of the health and social systems functioning in practice, their care transitions and experiences with care entities they had after discharge from the stroke unit. A group of questions regarding service quality referred only to entities with which a given participant had interacted but to which the Careperf instrument had not been previously applied. These were based on the Careperf dimensions reckoned to catch their quintessence although not as extensive as the Careperf measure itself. Open-ended questions intended a greater thematic depth and expanding and exploring the meaning of the topic under investigation until the point allowing to admit data saturation (Legard, Keegan, & Ward, 2003).

Interviews were recorded and transcribed. The average duration of an interview was 13 minutes. The codification of interviews with the purpose to ensure privacy and confidentiality was carried out subsequently.

Content of interviews was analyzed with a selection of concepts to be examined and evaluation of the frequency of their occurrence within the recorded data. The use of this systematic analysis method was an excellent tool to establish inferences about the transcribed material (Bardin, 2006).

The transcripts were analyzed thematically with the intent to identify segments of data with similar concepts with particular attention turned into the themes in the interview guide. Different categories made possible establishing a coding system, where similar codes were grouped into more inclusive categories. Each category was compared and reformulated so that a clear definition of the coding was conceivable at the final stage. The findings of the analysis of interviews with patients are presented bearing in mind the themes defined in the final codification system. The analysis of transcripts led to the conclusion that information they contained was rich and profound in some situations but spread among several aspects making challenging the process of coding construction.

6.3.3.1. Service quality of first aid

The topic on the provision of first aid refers to the element that respondents identified as relevant as to the moment when cerebrovascular accident occurred. This theme used to bring emotional recalls and sensations related to that situation in the past in case of almost all interviewees. The first contact with the emergency services tended to be established by a member of patient’s family (n=45), eventually by other related persons such as a neighbor (n=2) or a boss (n=1). Three respondents went to the emergency room on their own. The INEM/fire department provided transportation service and enhanced support in emergency care (n=63).

Experiences of patients regarding first aid were limited to those of them who remembered the time after having suffered cerebrovascular accident. Those interviewees who were able to remind the period between first symptoms, of a different kind, and giving an entry to the emergency department admitted having had a perception they had never felt before, a prickling sensation of a different degree of intensity to the point to lose consciousness or pass out. Not necessarily, however, the symptoms of stroke were obvious:

> *"After my daughter, my son-in-law came as well and he said to me: "You will go to Aveiro and what you think you will do tomorrow, you will do today". He had had stroke in the past; he had problems with speech as I was having at that moment, so I went to the doctor in the same day and he said it was not stroke. I was given medication for osteoporosis and (...) on Sunday I started having serious problems with balance, I was falling on one side. It was when my daughter and son-in-law took me immediately to the hospital and I stayed there since then."* (ID026).

The first contact with emergency services was established through the national emergency number or a fire department. In Portugal, two types of entities provide formal transportation in such cases: ambulances of the National Institute of Medical Emergency or fire departments on basis of protocols signed with the ARS. Several patients did not use the emergency number as the first option, having called directly a local fire department unit (those admitted to know that fire department telephone number). In a few cases (n=3), a health center or a pharmacy was contacted for advice. It is common in Portugal to have a linkage with a fire department, as an associate or by an informal way:

> *"I already knew some of them, we are neighbors; inclusively, my son is a fireman."* (ID077);

> *"Actually, what happened was that my friend called her sister who is a fireperson."* (ID086).

On the other hand, a few patients were able to make a distinction between a professional fire department team and the INEM during the interviews. After informing about symptoms over the telephone, transportation had an objective to verify the patient's actual condition. Respondents reminded in interviews efforts to determine their health condition. The experience with entities providing formal transportation for patients was, in all cases of patients able to remember it very satisfactory. Professionals were considered neat and adequately dressed, in an easily identifiable way. Patients described vehicles and equipment as modern and up-do-date:

> *"Modern it was, I know (...), at least to me and for my case. Now, if it was for a baby, it would not go in this particular car, because they ask a reason to sort out if a nurse is needed, if paramedics are needed."* (ID037).

Interviewees admitted the sensation of the time passing by. Nevertheless, in their perception, in the vast majority, the transport arrived promptly. Professionals were characterized by readiness and willingness to help. Patients used to describe them as approachable, responsive, and receptive while caring. Looking back in time, when remembering themselves in the situation they found themselves six months before, these qualities were deemed highly relevant. On the way to the hospital, patients felt secure as professionals were considered to convey aptitude and confidence. Their behavior was polite, correct and considerate. Some of the opinions were even enthusiastic:

> *"They were wonderful, magnificent to me."* (ID037).

With a perspective of a six-month period of time, several patients reminded their desperate attempts to try to communicate with firemen or paramedics and other persons present on place, without success. Those of them realized during the interview that professionals had sometimes actually tried to transmit tranquility while explaining the situation and further procedures to the nearest person. Professionals seemed to understand very well the condition the patient, the stress to be passing through and the anxiety related with a sudden incapacity:

> *"I was not quite well and he was there always talking to me."* (ID055).

In general terms, patients pointed out personal attention and empathy of professionals. However, when asked a view on the service provided, there were two different groups to be distinguished. One group openly discussed feelings regarding the experience and was not afraid to express their belief in skills of care professionals they had interacted with. The second group of respondents was somewhat afraid to judge aptitudes of first aid professionals they had had contact with, justifying it by lack of knowledge of standards of service that should have had been provided. At the end, however, they used to give themselves permission to speak about their own experience, positive in all cases, yet accentuating, continuously, it could only be limited only to their example.

6.3.3.2. Service quality of fire departments

From all entities discussed with participants of the study during interviews, evidence regarding their experience with transportation services to rehabilitation treatments and medical consultations was the most diversified. While commonly positive, opinions went from one extreme to another, in a number of domains.

Firemen provided transportation services for patients to physiotherapy sessions, medical appointments or medical exams. A contact was widespread within interviewees (n=100), not only in terms of quantity but also its quality. It was however found that some patients used services of more than one fire department, in which case they were excluded from further analysis. For further analysis n=81 patients were validated.

During transportation to the emergency department a number of patients remained at least partially unconscious, having limited their full-sensorial experience. More frequent transportation, particularly the one performed a number of times per week to rehabilitation treatments, gave foundation for richer and more realistic verdicts. Noteworthy to mention, however, that transportation means for medical emergencies and for planned medical interventions are not the same considering human resources and equipment. As such, this study did not intend making comparisons between these two distinct services but to describe patients' experiences bearing in mind the previously set up framework.

The service was usually arranged in two ways. One was through a family doctor providing a credential for the service and that was then delivered to a fire department. Another way was contacting a fire department directly. The second option was chosen mostly in case of households where one of the family members was an associate of the firemen.

Most of participants gave a positive opinion about vehicles and equipment used by the fire department. Views varied from 'modern' and 'up-do-date' to 'satisfactory'. Men were found to be more critical in this subject. Those of patients who were transported by two different fire departments were able to make a comparison regarding vehicles and staff.

Patients reported the firemen to have been arriving late, in a few cases too late to be attended in medical appointments and on time to their physiotherapy sessions. This was caused by the fact they had a daily route to carry patients from diverse localizations to diverse entities for their exams, appointments and treatments. An example of an explicitly intense (emotional) reaction was:

> *"They did not stick to the timetable at all. They could appear at 9, as well as at 11."* (ID095).

A great majority of interviewees appeared, however, comprehensible to delays since these were caused by incapacities of the proper system and lack of its organization and not fault of individual persons. Several patients acknowledged help they received in leaving the house and entering into the car, when still not capable to walk. Shortly after the first contact, a relation of trust was established:

> *"The other day my daughter did not bring a credential she did not have; Sir, please… you will not come to pick me up? I will, I will. It was a good man, very considerate, and at the beginning, when I was not able, he used to help me come down'."* (ID026).

From the analysis of interviews, only one opinion about a professional attitude appeared to be extremely negative:

> *"He obliged me to call a lawyer, a lawyer who is a man in front of them all, to make a complaint of him, I said to him 'You do not transport cattle but people."* (ID015).

That interview stood out from others, where firemen were described as generally polite, friendly and correct toward persons they were carrying. Interviewees globally emphasized to be regularly asked about their health condition and mood, and found it a pleasant aspect. While in journey, some professionals used to talk:

> *"They actually distract people (...) there are some more serious cases or the elder on wheelchairs and they try to cheer them up, they play and joke with them. They happen to be a cool team."* (ID047),

yet some did not:

> *"They did not use to talk. They were always in a rush trying to pick all those people up and be on time."* (ID053).

A fire department was actually the only entity clearly indicated by patients to have ever spoken (even if a few times, as accounted) about other services available in the geographic proximity that they might use for their better recovery:

> *"I really needed physiotherapy and on the way [to the medical consultation] they told me there was a clinic specialized in physiotherapy (...) and another time they actually took us there (...)."* (ID010).

6.3.3.3. Service quality of Private Institutions of Social Solidarity

From interviewed patients, a number used a private non-profit care provider (n=27). The findings revealed that patients received information about IPSS from their relatives (who often, as denoted, had their own experiences with that specific entity or another entity of such type), and these were relatives who established the first contact with the entity and made all arrangements on behalf of a patient. Not in all cases one contact was sufficient to conclude the arrangement but those constituted a majority. Eventual further contacts were done as a rule over a phone, and were mentioned a few times. One participant reported, however:

> *"Even to pay, I had to go back there three times."* (ID043).

A Private Institution of Social Solidarity may provide two distinct types of service. One is domiciliary support aid, which involves a range of in-home personal care and support services to individuals such as meals, hygiene, washing, cleaning, or assistance with medication intake. Another is a local structure, whether a resident or non-resident facility that allows a person to satisfy nutritional, daily living, health and social needs. Within these structures, several social responses function on the market specifically for potential users such as stroke survivors, namely, social centers, day centers, night centers and nursing homes. The most used social responses in the current study were found to be domiciliary care and day centers but other social responses also had their participation. An exception was a night center setting, not used by any of participants. Among such diversity, different aspects were noticed and deemed relevant by patients.

In case of domiciliary care, the findings clearly confirmed the overall contentment with services. None of interviewees stated any aspect to be at any level clearly negative. Professionals were recognized by their professional abilities, together with gentleness and joyfulness. Such skills should be the especially acknowledged as certain services, such as hygiene, require intimacy between a caregiver and a care receiver. As for the price paid for services, patients rated it as rather reasonable, emphasizing service quality they felt they received.

In day centers, patients had a possibility to see the facilities of the entity regularly. The main form of spending time in a day center was watching television, reading, playing games or cards.

What was important and recurrently mentioned, was the time spent with and around other people, sharing it on conversations or in silence, all this considered a relevant factor and a great benefit for well-being. The facilities were assessed from 'good' to 'very good' (a few of them were almost new). Professionals were found mostly informed about the current situation of the patient (including, for instance, medication the patient was taking). One respondent concluded:

> *"The doctor was more or less aware of my weakness."* (ID019).

Interviewees often emphasized the understanding they felt from professionals for limitations they presented, particularly the physical ones, as well as the emotional weight of having lost independence as a formerly active person.

6.3.3.4. Service quality of charitable institutions

Very few (n=3) participants recorded an interaction with a *Misericórdia*. A scope of activities, considering specifically needs of persons who suffered cerebrovascular accident, since mercies provide an enormous amount of different services to the community, is, until some extent, analogous to private non-profit care institutions. Charitable institutions offer domiciliary care (personal care in domicile of a person; hygiene (giving a bath), washing, cleaning, delivering meals with a pre-established frequency) and day centers. Furthermore, they create and manage nursing homes, and may deliver other services to the community (for instance, *Santa Casa de Misericórdia* in Aveiro organized physiotherapy sessions for persons with physical limitations and incapacities). Similarly to IPSS, an initiative of the contact with charities came from a relative of the patient (daughter, wife):

> *"A social assistant told me to enroll him in an institution because he would not walk again."* (ID139).

Professionals providing domiciliary care and those from a day center were found neat and pleasant. As in case of IPSS, particularly warm opinions regarded attention and gentleness of professionals delivering domiciliary care. A patient attending day center also said:

> *"There is a chapel and a holy mass, on Friday a priest comes by and prays with us. I really like it there. Oh, and I like the swimming-pool."* (ID001).

As can be seen, there are similarities between services offered by Private Institutions of Social Solidarity and charitable institutions. The analysis was conducted taking in consideration only those entities clearly identified, at least by type, if not by name, by patients at the follow-up, having excluded a number of them due to impossibility of their identification. Such situations were recurrent. In the specific case of charitable organizations, a low quantity of interactions may be motivated by two factors: (a) confusion with Private Institutions of Social Solidarity due to similarity of provided services; and (b) a number of unknown service providers of that type which could not be identified by any means and which were, therefore, excluded from further analysis. In a similar way, until some extent respondents could not remind which fire department transportation services they used, in which physiotherapy clinic they made physiotherapy treatments, or even in which rehabilitation unit (typically convalesce) they had been hospitalized. In cases where data could be traced through other sources that challenge was overcome, nonetheless, a number of unidentified entities remained.

6.3.3.5. Service quality of the Church

The study found a very limited number (n=5) of patients who sought a contact with the Church. Participants received not only spiritual and emotional support (yet one patient strongly and repeatedly stressed out its significance in her life), but also meals and, eventually, a little amount of grocery products to take home. In case of one participant, help from the Church, more precisely from the initiative of a local vicar, allowed him to reside in the local religious community, moving from the current place of residence with no basic conditions to live. That participant considered himself blissful with such a change in his life, with work for the community and meals he could have every day, and even with simple things such as domestic tasks he could do for his own using a washing machine. Furthermore, as he emphasized, he was surrounded by other people from the community, not alone anymore, a situation he was found when he suffered stroke and was still, in some way, frightening him. The patient revealed:

> *"I feel happy; here I am safe, because father Zé does not want me to think about other things."* (ID012).

The findings of the study might therefore indicate a very limited level of reliability of spiritual and religious institutions, nevertheless, in later conversations with participants at the end of the study, several of them admitted not to have indicated the Church as an entity they sought support after stroke, since it always had been part of their life and they did not consider it a specific institution to mention in that case.

6.3.3.6. Service quality of city councils

Only one participant surveyed in the 6th month admitted having contacted the city council adequate to the place of residence in what issues regarding stroke concerned. The patient pointed out it was the daughter who was dealing with all ‘bureaucracy’ and seeking for support where possible. From the information obtained, the daughter contacted the city council personally and no specific support was proposed as a solution for the patient by the institution.

6.3.3.7. Service quality of parish councils

A very few participants (n=2) had experience with a local parish council. Similarly to some other institutions, these contacts were established help of a relative (the single patient who contacted a city council was also one of the two who sought support in the local parish council). Another patient admitted not have searched any specified help, but simply orienting oneself in the system to better know ways which could eventually be helpful.

6.3.3.8. Service quality of the Social Security

The Social Security was sought by participants (n=17) since they heard from their relatives and acquaintances or had already known about a chance to obtain support for some specific purposes while meeting certain requirements. This support might encompass financial subvention (in case of sick leave due to incapacity to work after stroke), subsidy to purchase diapers or subsidy for ‘the third person assistance’ attributed, among others, to descendants who financially depended on the patient while providing the one effective care to ensure basic needs for at least six hours a day. For that reason, contacts with the Social Security were of two types: informing oneself about any achievable financial aid and being called by a medical board for the assessment (alone or accompanied by a caregiver). A telephone contact with the entity was reported only once.

Particularly in case of this institution, participants seemed lost in the system and confused how to proceed. A few confessed not have understood the meaning of the answer they received but felt embarrassed to have to ask once more, thus decided to wait and eager the situation to be solved, what did not happen. On the other hand, respondents complained about a lack of a promised return contact. In particular, one patient reported to had been seeking for estimations of costs for diapers in seven places so far in order to make it cheaper for the family budget, yet, a response from the Social Security regarding the subsidy never came:

> *“They did not say anything else anymore.”* (ID011).

The same participant suggested that for the Social Security suppliant's time was irrelevant as the waiting time was, at times, unacceptable, especially for persons with worse health condition and that employees expected patients to come back over and over again:

> *"Otherwise, please come here again', I heard."* (ID030).

In particular, one patient pointed out:

> *"Nobody advised me, nobody said anything (...) they forget when it comes to giving but not when it is about receiving."* (ID011).

A more proactive behavior from part of the institution was found absent but desirable, and employees, yet correct, not necessarily expressed comprehension and interest. An example of this attitude was a respondent who said:

> *"I felt she was indifferent."* (ID013).

Patients' opinions were strongly influenced by the result of their application. All interviewees who did not received help they were hoping for emanated disappointment and sorrow; one good example of that reaction was:

> *"They did nothing."* (ID030).

6.3.3.9. General assessment of care provision after discharge

The issue of assessment of care provision after discharge in general terms resulted from participants' narratives during interviews and refers to the analysis of different aspects and facts of the convalescence process after stroke. This topic focuses on the perception of health condition that participants felt they had at the time they were discharged from the acute care unit and presents advantages and disadvantages of their recovery in domicile. It discusses availability of information needed to find and access rehabilitation services, support, and proper monitoring by health professionals during the therapeutic process. The following aspects comprised this part of the analysis, globally denominated as Assessment of Situation and Care Provision after Discharge and which encompassed analysis that the patient makes on certain aspects regarding the recovery process after the occurrence of stroke:

a) Perception of Physical Condition – identification of patients' physical health state at the time of discharge

  - Positive – Physical condition perceived as positive
  - Negative – Physical condition perceived as negative

b) Advantages of Recovery at Home – observations that patients had about benefits that recovery at residence could bring to them and their health, in a general meaning

  - At-will/freedom of movement – reference to the patient freedom of movement and an increased feeling at-will when recovery occurs at home
  - Relatives – reference to the importance of the relationship with family for the enhancement of the recovery at home

c) Disadvantages of Recovery at Home – patients' observations on possible difficulties and harmful effects that recovery at residence could bring to them and their health, in a general meaning

  - Lack of health care on place – identifying medical resources in supporting the patient's recovery

d) Information on Rehabilitation and Support Services – awareness and identification of courses of action alluding to rehabilitation support and services

  - Difficulties of access – obstacles necessary to recognize practices necessary for acquiring access to services needed for the patient's recovery

e) Monitoring by Health Professionals – recognition and supervision of patients' health condition by health professionals

  - Family doctor supervision – identification of a role of a family doctor in supervising the patient's health state

f) Community Support – identification of support provided to patients' by community institutions
  - Appreciation of community support – expression of importance of community entities in the rehabilitation process of the patient.

The described aspects were used for interviews codification purposes and resulted in creating a matrix of categories and subcategories for the further analysis. A system of partial codification of interviews related specifically to the assessment of situation and care provision after discharge as perceived by patients is provided in Table 74.

Table 74. Partial codification system and representative citations from the interviews with patients

Category	Subcategory	Citation
Perception of the Physical Condition	Positive (n=52)	“I was, I was slimmer a little, because the things were different but I was better” (ID170) “I was much better than when I left the hospital of Aveiro, yes, I was able to make some steps (…)” (ID165)
	Negative (n=39)	“No, I did not feel very well, but… well….” (ID012) “I am not even today in conditions yet” (ID187)
Advantages of Recovery at Home	At-will/freedom of movement (n=52)	“Advantages of staying at home is to feel more free, obviously, you are also more comfortable in your home than in mine” (ID052) “I am at ease and I have a bath every day and I wear my cloths” (ID174)
	Relatives (n=35)	“At home, it is another thing, when we are well, when our family is our friends, we are fine at home. There are a lot of people who did not like to come back home; in my specific case, I like the fact of staying at home with my family” (ID057) “The boy and my Fernanda, they are my company, day and night. Fernanda is with me at night always by my side (…)” (ID186)
Disadvantages of Recovery at Home	Lack of health care on place (n=18)	“The house has disadvantages because, obviously, if anything happened, doctors would be there instantaneously, here they are not (…)” (ID030) “What you can do there, you cannot do at home, they do there what they do, if you want to do it at home, you have no equipment” (ID043)
Information on Rehabilitation and Support Services	Difficulties of access (n=51)	“It is not really easy, you need to run a lot, you need to ask a lot” (ID142) “I do not think so, I think you don’t find it, you have to knock at many doors and nothing” (ID009)
Monitoring by Health Professionals	Family doctor supervision (n=49)	“Yes. Even last week I went there” (ID087) “Yes, yes, he even gave me a number of instructions and advice when I delivered a document from the Hospital of Aveiro. I went there with the results and he was very considerate and respectful to me” (ID111)

Community Support	Appreciation of community support (n=32)	"There surely should be more, should be more support" (ID022) "Help should be better, you know, anything, because after all, we become dependent on everything and everyone" (ID156)

Over a half of respondents believed that they had a physical capacity to return to their residence upon discharge from the hospital (n=52). On the other hand, interviews detected another significant group (n=39) of patients who considered themselves certainly unable to return home, desiring to extend they stay in the hospital stroke ward. Recurrent limitations pointed out by patients were: physical incapacities of movements, recurrent pain in one part of the body (arm or leg, or both), headaches, and forgetting to take prescribed medication.

When evaluating their stay at the residence, interviewees generally felt that after the initial phase of adaptation after discharge, feeling tension and anxiety, and demanding to face a new reality with burden of physical and/or cognitive limitations, a domicile was an adequate place for recovery after stroke, for instance thank to a greater freedom of movement, feeling unrestricted and comfortable (n=52) and thank to the presence of relatives who they missed when admitted into an inpatient unit and from whom they were receiving support at home they valued a lot (n=35). In terms of disadvantages, respondents emphasized the fact of not having a direct and immediate access to health care, what they could count on in a health care institution, what was concerning in case of any other serious health situation, especially requiring medical assistance (n=18). Access to information about rehabilitation services and any support existing in the community was perceived as difficult, with a conclusion that participants had difficulties with identifying courses of action (n=51). In this way, information about support existing in the community for post-stroke patients was not considered by patients either visible or easily accessible. Also, they did not find it easy to move through the system to find assistance if such was necessary.

However, patients reported that in what medical monitoring after stroke concerned, including accompanying by their family doctor, was effectively taking place, facilitating their recovery process (n=49) and services provided to them during the therapeutic process in general (including physiotherapy, medication) were satisfactory and suitable (n=54). Within this topic, participants' narratives referred to their experiences with care and support entities they interacted with and which had not been previously evaluated by the Careperf measure of service quality. Since the pathway of each patient was unique, the composition and a number of entities varied from patient to patient.

Information about experiences with rehabilitation units was provided by respondents who were referred to at least one unit existing within the RNCCI (n=50). It was found out that patients adquired information about rehabilitation units predominantly in HIP during the hospitalization (from a nurse, social worker, a doctor), or through the Social Security. Most of patients admitted not had been aware earlier about the rehabilitation unit they stayed in for the recovery purpose after stroke. There were cases of patients who knew about the unit as a health care institution; although without more information as on a typology of care and services it delivered to the community. A few patients did, however, know about the entity before quite well:

> *'Yes, from four years, but personally I was there three months only, my daughter knows better, she is more familiar with this environment.'* (ID019).

Generally, participants were rather pleased with their stay in the unit, acknowledging especially kindness and compassion of professionals but pointing out insufficient equipment and staff. Hence, diversified opinions were registered:

> *'A doctor attended me immediately; he reviewed all medication I used to take every day. I cannot say better of this place, of the nurses, doctors, auxiliaries (….)'* (ID040).

> *'No, no nurses, no doctors (…). Really, if I was about to die, I would die in my home and I was there the whole night, I called a nurse twice or three times and she did not appear, neither she nor anyone else.'*(ID039).

32 of interviewees felt that social support from the community was effectively provided to them.

6.3.4. Satisfaction with stroke support and care services

Analysis of participants' satisfaction was carried on basis of a number of entities, namely: the hospital, fire department, convalescence unit, city council, parish council, IPSS, charitable institution, the Church, the Social Security and health center. A reduced number of observations of some of variables restricted statistical analysis. Descriptive statistics of the variables in analysis are provided in Table 75.

Table 75. Descriptive statistics of variables related to satisfaction with services of support and care providers

Variable	Min.	Max.	Mean	SD	Median
Satisfaction with hospital services (n=127)	4	7	5.92	0.66	6
Satisfaction with fire department services (n=81)	2	7	5.93	0.95	6
Satisfaction with convalesce unit services (n=35)	1	7	5.94	1.59	6

Satisfaction with city council services (n=1)	4	4	4	-	4
Satisfaction with parish council services (n=2)	4	4	4	0.00	4
Satisfaction with IPSS services (n=21)	2	7	5.29	1.42	5
Satisfaction with charitable institution services (n=3)	4	6	4.67	1.16	4
Satisfaction with the Church (n=5)	4	7	6	1.41	7
Satisfaction with the Social Security services (n=12)	2	7	4.08	1.44	4
Satisfaction with health center services (n=53)	2	7	5.23	1.07	5

The data point out a reduced number of observations in six variables. Still, it is possible to observe that in four of these variables the minimum of responses was 4 indicating that participants did not demonstrate themselves dissatisfied. In variables with a higher number of responses, mean was always higher than 5, revealing satisfaction with services, and a low standard deviation indicated few dispersion of data.

6.3.4.1. Satisfaction with hospital services

Regarding overall satisfaction with hospital services, from 127 responses, vast majority was found to be situated in the upper part of the provided Likert scale. The minimum response was 4 and the maximum was 7. Median of received answers was 6. Figure 37 presents a distribution of frequencies of responses.

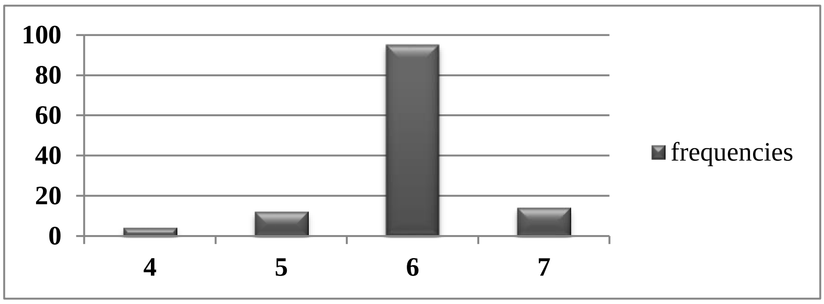


Figure 37. Satisfaction with hospital services perceived by patients

As can be verified in the above figure, a major part of responses was situated on 6 in a 7-point Likert scale. The lowest option on the scale was not registered. The lowest provided response was 4, with a limited number of frequencies.

Respondents, when questioned about a likelihood of a similar situation repeating in the future and their willingness to receive treatment in the hospital, in 78.6% of the cases agreed and in 9.5% definitely agreed with such possibility. Responses for this item varied from 1 to 7, with median 6.

For the question concerning the capacity to pay more for services of the hospital, if such need arose, the responses provided by patients varied from 1 to 7, with median 6, and, the frequencies were, only in case of this question, slightly more equally distributed. Still, the predominant response achieved 44.4% of the cases.

The last question concerned a willingness to recommend the entity in question to a relative that was in a similar situation to the respondent's. Again, the distribution of the responses to the item was particularly asymmetric. The responses varied from 1 to 7, with median 6.

Comparison of groups was carried out with nominal or ordinal variables and with the variable of satisfaction with the hospital services treated in a quantitative way. No statistically significant differences were found between men (mean rank = 64.59) and women (mean rank = 63.40) in what satisfaction with services of HIP concerned (Z= -0.238, p=0.812). The same was found relatively to civil status: no differences existed between participants in a relationship (mean rank = 65.68) and those not in a relationship (mean rank = 61.42) (Z= -0.836, p=0.403). Housing situation did not reveal to constitute a relevant variable in this matter, either (H(3)= 2.065, p=0.559). When considering a profession, significant differences were detected between participants performing specialized and half or non-specialized work (Z= -1.986, p=0.049), with the second proven to have mean rank lower (59.10) than first (mean rank = 69.60). A comparison between respondents currently employed and non-employed resulted in absence of significant differences, with mean ranks 63.32 and 60.20, respectively (Z= -0.587, p=0.557). Patients who had care before stroke (mean rank = 65.20) and those who did not have need for such care (mean rank = 63.90) were not different when it came to perceived satisfaction with hospital services (Z= -0.141, p=0.888). The situation remained relatively to the need of care after stroke. Mean rank of those who needed and received care after cerebrovascular accident was 63.76 and of those who did not 64.48. This relation was not statistically significant (Z= -0.137, p=0.891).

When quantitative variables were compared, Spearman correlation results indicated absence of any significant correlation with satisfaction with hospital services, namely age (*rho*= -.096, p=0.281), income (*rho*= .061, p=0.530) and education (*rho*= .095, p=0.289).

6.3.4.2. Satisfaction with rehabilitation units services

Similarly to what happened to perceived service quality provided by rehabilitation units, considering satisfaction with service of those institutions, performing analysis was possible only in case of convalesce units due to a very limited number of observations in medium and long-term units. As explained, some patients remained in the institutional setting in the 6th month. Moreover, while some institutions had status of medium-term and some of long-term units, there were units combining both of these typologies in one entity. Distribution of data relative to satisfaction with convalesce units is presented in Figure 38.

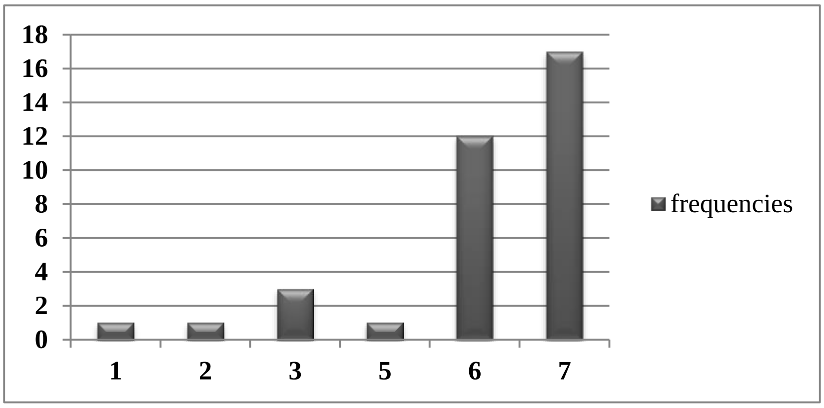


Figure 38. Satisfaction with convalesce units services perceived by patients

From respondents who provided opinion on perception relative to satisfaction with their experience with interaction with convalescence units services, vast majority evaluated this experience very positively, reaching 82.9% of participants who provided two highest answers to that question. Responses varied from 1 to 7, with median 6. A comparison of groups between different convalescence units revealed statistically significant differences on how participants perceived their satisfaction (H(2)= 7.348, p=0.025), with convalescence unit of Anadia having reached the highest mean rank (13.43), followed by Ovar (9.06) and Cantanhede (5.88).

6.3.4.3. Satisfaction with health centers services

Patients were generally satisfied with services provided by health centers respective to their residence zone. The highest two options of responses in the questionnaire were given by 48.2% of subjects. The minimum response was 2 and the maximum was 7, which was the highest on the provided scale. The median was 5. Distribution of the variable of satisfaction with health centers services is provided in Figure 39.

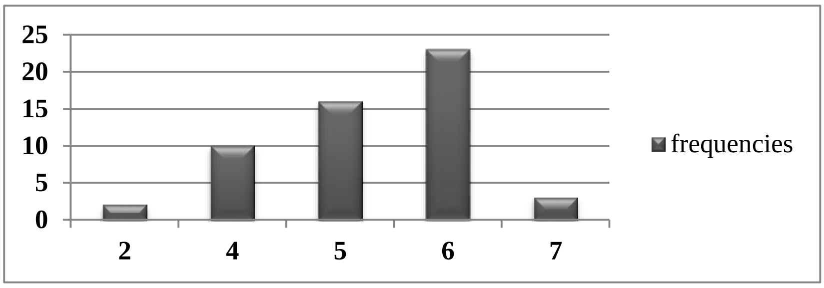


Figure 39. Satisfaction with health centers services perceived by patients

Most of patients wished to continue using services of the same health center in the future (three highest options provided by vast majority of respondents accumulated into 79.2%), when 1.9% would definitely not like to continue to be attended in their health center. The results point out a very interesting distribution of responses regarding the promptness to eventually pay more for services of a health center. The range of responses varied from 1 to 7. Responses supporting lack of agreement with the statement were given by 22.6% of patients and, on the other side, 64.2% of patients felt able to pay more for services of the health center. A major consensus between respondents existed also when questioned about a possible recommendation of services of a given health center to a relative: 67.9% would do so, while 15.1% did not agree with the others.

In comparison of groups, gender appeared to not be a relevant factor in what satisfaction with health center services concerned, with mean rank of men of 28.39 and women of 26.10 (Z= -0.555, p=0.579), neither was civil status, with mean ranks of respondents in a relationships higher than those not in a relationship (28.00 and 26.07, respectively), although not statistically significant (Z= -0.418, p=0.676). Housing situation did not reveal to be a factor differentiating groups (H(3)= 3.956, p=0.266). Bearing in mind profession, no significant differences were observed between participants performing half and non-specialized work and other participants, with mean ranks 26.61 and 28.50 respectively (Z= -0.384, p=0.701). A comparison between respondents currently employed and not employed resulted in absence of statistically significant differences (mean ranks 28.69 and 26.45, respectively; Z= -0.481, p=0.631). Patients who were in need of care already before stroke and could count on such care, and those who did not receive care did not differ significantly between each other in perception of satisfaction with health centers services (Z= -1.844, p=0.065), however the first group mean rank was higher from another (46.50 to 26.77). The situation after stroke remained not statistically significant. Mean rank of patients who had care was 25.86 and of those who did not 31.77 (Z= -1.310, p=0.190).

Spearman correlation results did not indicate any significant correlation between satisfaction with health centers services in age (*rho*= .190, p=0.169), income (*rho*= .168, p=0.243), either education (*rho*= -.169, p=0.221).

6.3.4.4. Satisfaction with physiotherapy clinics services

Considerations on satisfaction with services provided by physiotherapy clinics faced the same challenges as the ones on perceived overall service quality related to those entities. Due to a possibility of interaction with more than one institution, a number of statistical manipulations were impossible.

6.3.4.5. Satisfaction with fire departments services

Similarly to what was observed in satisfaction with hospital services, satisfaction with transportation services provided by fire departments represented high mean with a low dispersion of data. Figure 40 demonstrates the distribution of this variable.

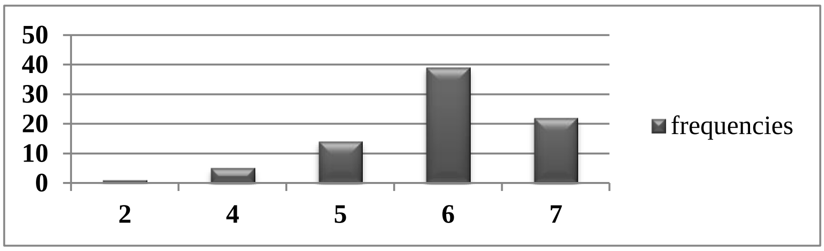


Figure 40. Satisfaction with transportation services of fire departments perceived by patients

Less than a half of responses were situated in their median (6), with the next most frequently given answer constituting the maximum from the provided 7-point Likert scale.

Comparisons between groups were carried out through the use of tests for comparisons of means or distributions, and correlations (Spearman). In gender, when comparing men and women regarding satisfaction with transportation services provided by fire departments, the results proved absence of significant differences (Z= -1.349, p=0.177) despite slightly higher mean ranks from those of women (43.79 and 37.15, respectively). Relatively to civil status, no statistically significant differences were detected, nevertheless patients in a relationship registered mean ranks higher (42.55) than those not in a relationship (35.95) (Z= -1.152, p=0.249). Evidence did not show differences in what housing situation concerned (H(3)= 3.434, p=0.329), either. The same was verified in comparison between groups according to profession, given that no statistically significant differences could be proven between respondents performing specialized work and those whose work was half or non-specialized (Z= -1.148, p=0.251); and to current professional situation. A comparison between those who worked and who did not resulted in absence of significant differences, with mean ranks 33.83 and 40.58, respectively (Z= -1.216, p=0.224). Significant differences were, however, registered between patients with care before stroke (mean rank = 17.75) and those to whom care was not provided before cerebrovascular accident (mean rank = 42.21) (Z= -2.182, p=0.029). The situation changed when it comes to comparison of participants of the study with and without care after stroke. Mean rank of those who had care was 41.21 and of those who did not was 40.28, and that was not statistically significant difference (Z= -0.159, p=0.874).

In association of satisfaction with transportation services with quantitative variables , namely age, income and education, the results of Spearman correlation demonstrated inexistence of significant results (age: *rho*= -.146, p=0.194; income: *rho*= -.138, p=0.236; education: *rho*= -.050, p=0.657).

6.3.4.6. Satisfaction with Private Institutions of Social Solidarity services

In spite of a limited number of responses relative to satisfaction with services provided by Private Institutions of Social Solidarity (n=21), distribution of the variable is provided in Figure 41.

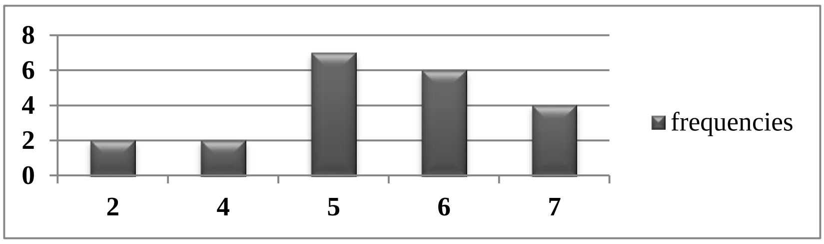


Figure 41. Satisfaction with services of Private Institutions of Social Solidarity perceived by patients

Majority of responses provided by patients fell into higher levels of the Likert scale, with solely two respondents expressing a much reduced level of satisfaction. The minimum of responses was 2 and the maximum was 7, with median 5.

6.3.4.7. Satisfaction with charitable institutions services

Three participants provided responses on their level of satisfaction with charitable institutions. The minimum response was 4 and the maximum was 6 in a 7-point Likert scale, with median 4. From these responses, computed mean was 4.67 with standard deviation 1.16.

6.3.4.8. Satisfaction with the Church

Five respondents provided their opinion on perceived satisfaction with the experience with the Church. The minimum response was 4 and the maximum was 7, with median 7. Mean of responses for this variable was 6 with standard deviation 1.41.

6.3.4.9. Satisfaction with city councils services

Only one respondent used services of a city council in matters related directly to cerebrovascular accident. The respondent evaluated the level of satisfaction with the service in 4 in a 7-point Likert scale.

6.3.4.10. Satisfaction with parish councils services

There were solely two participants who consulted their local parish council seeking support in matters related to stroke they had suffered. Both respondents evaluated their satisfaction level with that experience in 4 in a 7-point Likert scale.

6.3.4.11. Satisfaction with the Social Security services

From the total of participants of the study, 12 respondents pronounced themselves regarding satisfaction with the Social Security services they had had the experience with. In a 7-point Likert scale, the minimum response was 2 and the maximum was 7, with median 4. Mean of responses was 4.08 with standard deviation 1.44.

6.3.4.12. Overall satisfaction with the care system

The study verified whether the intensity of contact with a certain institution had a significant influence on satisfaction with the whole system of care existing for stroke patients. At the beginning, each entity with which respondents had a contact was taken into consideration, leading to the first conclusion that analysis in such form could not proceed due to insufficient number of observations. The calculations excluded those of entities in which the number of subjects in one of the groups was lower than five.

Statistical procedure comprised institutions satisfying that condition, i.e. the hospital, health center, transportation services by fire departments, IPSS, the Social Security, and physiotherapy clinics in total. The distinction between groups (high versus low intensity of contact) was based arbitrary but not random, as no other reasonable manner was found: the quantity of contacts between entities varied significantly and, due to this fact, neither a fix number for all of them nor mean nor median could constitute a uniform solution. The key that seemed feasible was to look at patients' pathways and typical behaviors during six months after discharge. The quantity of interactions with the entities in consideration had a tendency to oscillate around some number or level.

In case of the hospital, the cut point was made on basis of medical practice to schedule an appointment for control purposes with a neurologist a month after discharge. This took place in HIP as an outpatient consultation. Hence, it would be desirable to have minimum that one contact with the hospital within the six months. The medical information regarding cerebrovascular accident a patient had gone through, most important indicators, results of medical exams, and medication currently taken is collected into a document and given to a patient with a recommendation to be delivered to their family doctor. This implies patient's visit in the health center. Consequently, this number was considered for the health center. As for the Social Security, a high level was defined for more than one interaction. The specification of the intensity for the fire department was based on the assumption that in most cases subjects arrived to the emergency department of the hospital either calling the emergency number or a local fire department unit. The estimate was later confirmed during interviews with patients. In case of physiotherapy clinics, an average number of sessions was decided to be taken as a cut point (there were patients who had short periods of physiotherapy experiences, due to several reasons, and others, whose interaction with an entity was durable). For IPSS, as entities that (depending evidently on a need) provide a range of services for stroke patients which require to contact the entity for setting up, more than one contact was considered a higher level. That was because one contact can be established in order to obtain information and clarify doubts after which a decision to use or not the services of a given IPSS is further made.

The tendencies observed between satisfaction with the whole care system and intensity of contacts with the entities which fulfilled conditions for this specific part of the analysis are presented below. Table 76 presents a relation between satisfaction with the care system and the intensity of contact with the Hospital Infante D. Pedro.

Table 76. Satisfaction with the care system and intensity of contact with the hospital

Satisfaction with the system	Intensity of contact with the hospital				Total	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	0	0.0%	1	1.2%	1	1.0%
Bad	0	0.0%	7	8.6%	7	7.0%
Neither bad nor good	12	63.2%	28	34.6%	40.0	40.0%

Good	5	26.3%	42	51.9%	47.0	47.0%
Very good	2	10.5%	3	3.7%	5.0	5.0%
Total	19	100.0%	81	100.0%	100	100.0%

In satisfaction between the care system as a whole and the intensity of contact with the hospital, no statistically significant difference was found (Z= -0.592, p=0.554). Respondents with a lower intensity of contact had, however, mean rank slightly lower from those of a higher intensity of interactions (i.e. who had more than one medical appointment in HIP related strictly to their stroke) (49.95 and 50.91, respectively). Table 77 presents a relation between satisfaction with the care system and the intensity of contact with a health center.

Table 77. Satisfaction with the care system and intensity of contact with a health center

Satisfaction with the system	**Intensity of contact a health center**				**Total**	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	1	1.8%	0	0.0%	1	1.0%
Bad	6	10.9%	1	2.2%	7	7.0%
Neither bad nor good	18	32.7%	22	48.9%	40	40.0%
Good	29	51.7%	18	40.0%	47	47.0%
Very good	1	1.8%	4	8.9%	5	5.0%
Total	55	100.0%	45	100.0%	100	100.0%

While patients with a higher intensity of contacts with a health center – at least two contacts – presented mean ranks higher than those with a lower intensity (respective mean ranks = 51.56 and 49.64), that difference was not statistically significant (Z= -0.361, p=0.718). Table 78 presents a relation between satisfaction with the care system and the intensity of contact with a fire department.

Table 78. Satisfaction with the care system and intensity of contact with a fire department

Satisfaction with the system	**Intensity of contact with firemen**				**Total**	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	1	2.0%	0	0.0%	1	1.0%
Bad	3	6.0%	4	8.0%	7	7.0%
Neither bad nor good	17	34.0%	23	46.0%	40	40.0%
Good	25	50.0%	22	44.0%	47	47.0%
Very good	4	8.0%	1	2.0%	5	5.0%
Total	50	100.0%	50	100.0%	100	100.0%

In the relationship of the intensity of interactions with a fire department and patient satisfaction with the system as a whole, no statistically significant difference was determined (Z= -1.266, p=0.205). Subjects with a lower intensity of contacts with fire department had mean rank 53.85 and those of a higher intensity (twice or more) 47.15. Table 79 presents a relation between satisfaction with the care system and the intensity of contact with IPSS.

Table 79. Satisfaction with the care system and intensity of contact with a Private Institution of Social Solidarity

Satisfaction with the system	Intensity of contact with an IPSS				Total	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	0	0.0%	1	5.3%	1	1.0%
Bad	5	6.2%	2	10.5%	7	7.0
Neither bad nor good	31	38.3%	9	47.4%	40	40.0%
Good	40	49.4%	7	36.8%	47	47.0%
Very good	5	6.2%	0	0.0%	5	5.0%
Total	81	100.0%	19	100.0%	100	100.0%

No statistically significant difference, although not much far distant from it (Z= -1.811, p=0.070) could be confirmed in the relationship of the intensity of interactions with IPSS and patient satisfaction with the system as perceived by respondents of the study. Subjects with a lower intensity of contacts with a Private Institution of Social Solidarity had, however, higher mean rank from those with higher (more than once) intensity of contacts with that entity (52.82 and 40.61, respectively). Table 80 presents a relation between satisfaction with the care system and the intensity of contact with the Social Security.

Table 80. Satisfaction with the care system and intensity of contact with the Social Security

Satisfaction with the system	Intensity of contact with the Social Security				Total	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	0	0.0%	1	5.3%	1	1.0%
Bad	5	6.2%	2	10.5%	7	7.0%
Neither bad nor good	31	38.3%	9	17.4%	40	40.0%
Good	40	49.4%	7	36.8%	47	47.0%
Very good	5	6.2%	0	0.0%	5	5.0%
Total	81	100.0%	19	100.0%	100	100.0%

In the relationship of the intensity of interactions with the Social Security and patient satisfaction with the system, no statistically significant difference was verified (Z= -0.500, p=0.617). Mean rank of respondents with a lower intensity was 51.08 and with a higher intensity (more than one) 47.47. Table 81 presents a relation between satisfaction with the care system and the intensity of contact with physiotherapy clinics.

Table 81. Satisfaction with the care system and intensity of contact with physiotherapy clinics

Satisfaction with the system	Intensity of contact with physiotherapy clinics (total)				Total	
	Low		High			
	N	Percent	N	Percent	N	Percent
Very bad	1	1.9%	0	0.0%	1	1.0%
Bad	2	3.8%	5	10.9%	7	7.1%
Neither bad nor good	18	34.6%	21	45.7%	39	39.8%
Good	28	53.8%	19	41.3%	47	48.0%
Very good	3	5.5%	1	2.2%	4	4.1%
Total	52	100.0%	46	100.0%	98	100.0%

Considering the relationship between the intensity of interactions with physiotherapy clinics and patient satisfaction with the system, a situation analogous to the above was confirmed and no statistically significant difference was found (Z= -1.711, p=0.087). Respondents with a lower intensity of interaction with physiotherapy clinics had mean rank 53.70 and those with a higher intensity (defined as more than 34 times) had mean rank 44.75.

Evidence shows that the number of entities participants interacted with did not influence significantly the assessment of the system as a whole from the perspective of the user. The situation recurred when satisfaction with the system as a whole was examined. Table 82 presents these results.

Table 82. Correlations between perceived quality of the care system, satisfaction with the system as a whole and a number of institutions contacted by the patient

Spearman's *rho*	Assessment of perceived quality of health and not health-related care entities	Satisfaction with the system as a whole
A number of contacted health care entities (excluding rehabilitation units)	-.007	-.010
A number of contacted health care entities (including rehabilitation units)	-.011	-.010
A number of contacted not health-related care entities	-.127	-.131

**correlation significant at p<0.05*; ***correlation significant at p<0.01*

6.3.5. Service quality and satisfaction with the system versus perceived health status

Findings indicate an average or good level of satisfaction with the system as a whole apparently independent from health status. All respondents who rated their health status as very good presented an average level of satisfaction and no statistically significant correlation was found between these variables (*rho*= .110, p=0.274).

The same appeared to arise from the analysis of the assessment of service quality of the whole system and health status. Majority of subjects (85.7%) considered quality of provided care ‘neither good nor bad’ or ‘good’. A correlation between the variables was not statistically significant either (*rho*= .183, p=0.083).

6.3.6. Regression analyses

Initially, simple and multiple linear regressions were applied in order to test the relation between the dimensions of service quality measured by the Careperf instrument and the overall perception of service quality, between the dimensions of service quality and overall satisfaction with the service, between overall service quality and overall satisfaction with the service, between the willingness to come back to the entity in the future and overall satisfaction with the service, between the readiness to pay more for the service and overall satisfaction with the service, and between the willingness to recommend the services of the entity in question to a relative and overall satisfaction with the service.

Before running regressions, the Careperf dimensions based on the items means which emanated from the confirmatory structure were created. We intended to model:

Model 1:
Overall satisfaction (CP_H36) = $\beta 0+ \beta 1$ Tangibles + $\beta 2$ Reliability + $\beta 3$ Responsiveness + $\beta 4$ Assurance + $\beta 5$ Empathy + $\beta 6$ Communication + $\beta 7$ Privacy + ε

Model 2:
Overall service quality (CP_H35) = $\beta 0+ \beta 1$ Tangibles + $\beta 2$ Reliability + $\beta 3$ Responsiveness + $\beta 4$ Assurance + $\beta 5$ Empathy + $\beta 6$ Communication + $\beta 7$ Privacy + ε

Model 3:
Overall satisfaction (CP_H36) = $\beta 0+ \beta 1$ Overall service quality (CP_H35) + ε

Model 4:
Overall satisfaction (CP_H36) = $\beta 0+ \beta 1$ Willingness to come back (CP_H37) + ε

Model 5:
Overall satisfaction (CP_H36) = $\beta 0+ \beta 1$ Willingness to pay (CP_H38) + ε

Model 6:
Overall satisfaction (CP_H36) = $\beta 0+ \beta 1$ Willingness to recommend (CP_H39) + ε

Model 7:

Overall satisfaction (CP_H36) = β0+ β1 Willingness to come back (CP_H37) + β2 Willingness to pay (CP_H38) + β3 Willingness to recommend (CP_H39) + ε

Statistical analyses for regression were performed with SPSS v. 21.0 (SPSS Analytics, IBM, Armonk, NY, USA, 2013). The first hypothesis was to model the relationships via linear regression. Hence, descriptive measures, means, standard deviations, and correlations - these in particular, were calculated to verify the assumption of correlation between dependent (DV) and independent variables (IV), necessary condition to select predictors to the prior regression model.

Table 83 provides sample means, standard deviations (SD) and correlations between all observed variables.

Table 83. Descriptive statistics and the correlation matrix

	Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12
1 CP_H35	5.79	0.68	1	.83***	.54***	.15	.45***	.39***	.34***	.33***	.58***	.44***	.04	.31***
2 CP_H36	5.90	0.66		1	.58***	.25***	.53***	.27***	.36***	.40***	.57***	.44***	.14	.40***
3 CP_H37	5.83	0.91			1	.33***	.84***	.27***	.38***	.36***	.54***	.43***	.14	.30***
4 CP_H38	4.99	1.58				1	.40***	.07	.19*	.06	.16	.13	.26***	.24**
5 CP_H39	5.76	1.02					1	.31***	.43***	.35***	.50***	.46***	.15	.34***
6 Tangibles	5.88	0.57						1	.51***	.30***	.59***	.25***	.07	.38***
7 Reliability	5.66	0.69							1	.22***	.53***	.47***	.34***	.61***
8 Responsivess	5.49	1.21								1	.35***	.47***	.05	.20*
9 Assurance	6.05	0.51									1	.33***	.13	.42***
10 Empathy	5.32	1.00										1	.12	.36***
11 Communication	3.48	1.66											1	.37***
12 Privacy	5.08	0.81												1

*p<.05; **p<.01; ***p<.001

All specified models fulfilled the assumption of correlation between dependent variables and the independent variable, except for Communication in Models 1 and 2. Therefore the variable was excluded from those models.

The first regression procedure for multiple regressions followed the *backward* method, in which non-significant variables are withdrawn step-by-step, based on higher p-value criteria, i.e. the variable that less contributes in each step for the total explained variance is eliminated and a new model is created. This follows an algorithmic process that stops when all independent variables have a significant contribution ($p<0.05$) to explaining the dependent variable.

However, when checking residuals for a normal distribution, this assumption failed on all specified models. This issue resisted to several attempts such as logarithmic transformation of variables and outliers (observations outside mean±3SD) elimination. Therefore a multiple logistic regression procedure was decided to be adopted. It based on the following criteria for both CP_H35 and CP_H36 (as dependent variables): 0 to 4 = 0; 5 to 7 = 1; so 1 stands for better results on both Overall service quality and Overall satisfaction (CP_H35 was maintained in its original form when applied as an independent variable). A similar procedure (*backward Wald*) to the one used in linear regression (first attempt) was followed. Hosmer-Lemeshow (2000) goodness-of-fit assumption was verified and satisfied in all considered models.

Table 84 provides results of multivariate logistic regressions carried out to model intended relationships. Model 1 indicates that Assurance and Empathy higher results were related with higher levels of Overall satisfaction. For each unit of Assurance (which scores varied from 1 to 7, as all the other dimensions of the Careperf instrument) the odds ratio of having higher levels of Overall satisfaction increased 5.14 more [1.51 – 17.50 95% CI, p<0.001] and the same occurred for Empathy which was 3.54 more likely of having higher levels of Overall satisfaction [1.56 – 8.03 95% CI, p<0.001].

Regarding Overall quality (Model 2), Empathy and Privacy were the significant predictors, with 3.82 more chance of better Overall service quality results for each unit increase of Empathy [1.21 – 12.08 95% CI, p=0.02], and 4.11 [1.23 – 13.71 95% CI, p=0.01] for Privacy.

Model 3 results suggested the impossibility of estimating odds ratio but, on the contrary, when Overall satisfaction was a predictor of Overall quality, OR was 24.69 [5.66 – 107.66 95% CI, p<0.001] proving a strong relation between respondents with high Overall satisfaction and their perception of Overall quality.

Model 4 indicated that the more subjects were willing to come back for future treatments in the hospital, the higher level of Overall satisfaction they felt. In other words, the evidence showed that patients were 1.81 more likely of scoring higher in Overall satisfaction for each unit of increase in Willingness to come back [1.04 – 3.13 95% CI, p=0.04].

Model 5, testing whether there was a relation between Willingness to pay more for services of the hospital and Overall satisfaction did not appear to be statistically significant.

The same situation happened while testing Model 6, that is, Willingness to recommend services of the hospital to a relative or a friend and Overall satisfaction. That model did not find to be statistically significant, either.

Model 7 which included Willingness to come back to the hospital in the future in case a need for that arose, Willingness to pay more for services of the hospital and Willingness to recommend services of the hospital to a relative or a friend showed in a multivariate analysis that only Willingness to come back was statistically significant, with odds ratio 1.81, therefore representing 1.81 more likely of scoring higher levels of Overall satisfaction for each unit increase of Willingness to come back, as previously recognized [1.04 – 3.13 95% CI, p=0.04].

Table 84. Multivariate logistic regression models results

Model	B	SE	Wald	df	OR	95% CI	p-value
Model 1 Overall satisfaction (step 6)							
Constant	-13.17	4.09	10.34	1	0		p<0.001*
Assurance	1.64	0.63	6.86	1	5.14	1.51 – 17.50	p<0.001*
Empathy	1.27	0.42	9.19	1	3.54	1.56 – 8.03	p<0.001*
Model 2 Overall service quality (step 6)							
Constant	-9.70	3.81	6.49	1	0		p<0.001*
Empathy	1.34	0.59	5.21	1	3.82	1.21 – 12.08	p=0.02*
Privacy	1.41	0.61	5.30	1	4.11	1.23 – 13.71	p=0.01*
Model 3 Overall service quality (step 1)							
Constant	-15.02	0.75	18.20	1	0		p<0.001*
Overall satisfaction	3.03	0.75	18.20	1	24.69	5.66 – 107.66	p<0.001*
Model 4 Overall satisfaction (step 1)							
Constant	-0.30	1.53	0.04	1	0.74		p=0.84
Willingness to come back	0.59	0.28	4.45	1	1.81	1.04 – 3.13	p=0.04*
Model 5 Overall satisfaction (step 1)							
Constant	1.95	1.17	2.80	1	7.02		p=0.09
Willingness to pay	0.22	0.24	0.83	1	1.24	0.7 – 1.99	p=0.36
Model 6 Overall satisfaction (step 1)							
Constant	0.40	1.42	0.08	1	1.50		p=0.78
Willingness to recommend	0.47	0.26	3.23	1	1.60	0.96 – 2.68	p=0.07
Model 7 Overall satisfaction (step 3)							
Constant	-0.30	1.54	0.04	1	0.74		p=0.84
Willingness to come back	0.59	0.28	4.45	1	1.81	1.04 – 3.13	p=0.04*

*statistically significant

6.4. Quality of life and informal support for stroke patients

6.4.1. Quality of life after cerebrovascular accident

Quality of life was measured twice, in the 2nd and in the 6th month, using the Stroke Specific Quality of Life Scale. The instrument allows for assessing both, patients' individual dimensions of quality of life and overall quality of life. The purpose of its employment was to verify quality of life of stroke patients at certain moments of the study and to measure whether any differences existed between the 6th and the 2nd month in this respect, in specific dimensions of quality of life and in overall quality of life. The interest fell also into investigating differences between certain groups of respondents.

6.4.2. Quality of life in the 2nd and 6th month after discharge

The results indicate that in the 2nd month, participants of the study obtained the highest average scores in the dimensions of Language, Vision and Thinking what suggests the best quality of life is these domains. The lowest scores were registered in the dimensions of Work/Productivity, Energy, Mobility and Upper Extremity Function.

In the sixth month, respondents were questioned again about their quality of life, and the dimensions of the highest mean scores were Vision, Language and Thinking, and the lowest were Energy, Work/Productivity, Mobility and Upper Extremity Function (two last dimensions with the same mean). In both measurement moments, the most problematic dimensions of life quality and those in which patients felt the strongest remained the same.

Table 85 provides mean scores of the SS-QoL dimensions and tests for a statistical difference between them.

Table 85. Differences between patients' quality of life after stroke in the second and the sixth month after discharge

Dimension/application time		Statistics		t-Student test	
		Mean (M)	SD	t	p
Self-care	2nd month	3.84	1.09	-3.091	0.002*
	6th month	4.00	1.07		
Vision	2nd month	4.60	.74	-1.919	0.057
	6th month	4.72	.57		
Language	2nd month	4.62	.66	-1.401	0.164
	6th month	4.69	.57		
Mobility	2nd month	3.57	1.23	-3.183	0.002*
	6th month	3.76	1.10		
Work/Productivity	2nd month	3.24	1.29	-2.745	0.007*
	6th month	3.46	1.28		
Upper Extremity Function	2nd month	3.62	1.31	-1.888	0.061
	6th month	3.76	1.21		
Thinking	2nd month	4.31	.94	-1.156	0.250
	6th month	4.41	.86		
Personality	2nd month	3.88	1.33	0.390	0.697
	6th month	3.83	1.33		
Mood	2nd month	3.90	1.09	-1.023	0.308
	6th month	3.99	1.03		
Family Roles	2nd month	3.99	1.21	-1.629	0.106
	6th month	4.14	1.06		
Social Roles	2nd month	3.70	1.39	-1.862	0.065
	6th month	3.89	1.28		

Energy	2nd month	3.38	1.46	-0.415	0.679
	6th month	3.43	1.45		
Overall quality of life	2nd month	3.89	.87	-2.755	0.007*
	6th month	4.02	.78		

*significant p-value

The results show the improvement of quality of life in all dimensions of the SS-QoL except of Personality (a decline from 3.88 to 3.83). Statistically significant differences were identified in the dimensions of Self-care, Mobility and Work/Productivity. Considering the standard significance levels, Vision (0.057), Upper Extremity Function (0.061) and Social Roles (0.065) approached also the statistical significance. Overall quality of life improved from the 2nd to the 6th month and this, importantly, was a statistically highly significant result (t= -2.755, p=0.007).

In order to compare the results of quality of life between the 6th and the 2nd month, a One-Way Repeated Measures ANOVA for each dimension was computed. Within-subjects factor was quality of life in two moments of evaluation and several variables were chosen as between-subjects factor, namely: gender (male/female), age (<65; ≥65 years), housing situation (living alone/living with someone), civil status (in a relationship/not in a relationship) and current professional situation (professionally active/professionally inactive). Greenhouse-Geisser correction was used to calculate p-value when variances sphericity was not assumed. Missing values were handled by case elimination (several missing observations) or by replacing by mean.

Table 86 provides comparisons by gender (females, n=67; males, n=59). Significant p-values for moment (6th-2nd) in dimensions of Self-care, Language, Mobility, Work/Productivity, Upper Extremity Function and Overall quality of life demonstrate that quality of life increased regardless the effect of gender, meaning that both, males and females registered a raise of quality of life in the second moment of evaluation. No significant p-values for interaction (gender*moment) were found. Finally, significant p-values for gender in the Mood and Energy dimensions indicate that males had higher average levels in these dimensions in both evaluation moments.

Table 86. One-Way Repeated Measures ANOVA for comparing quality of life by gender

Dimension	Gender	2nd month		6th month		p-value (moment)	p-value (gender)	p-value (gender*moment)
		M	SD	M	SD			
Self-care	Female	3.87	1.15	4.02	1.12	p<0.001*	0.97	0.49
	Male	3.84	1.05	4.06	0.99			
Vision	Female	4.63	0.75	4.77	0.51	0.07	0.45	0.54
	Male	4.59	0.69	4.67	0.62			
Language	Female	4.57	0.71	4.75	0.51	0.047*	0.85	0.07
	Male	4.63	0.64	4.64	0.60			
Mobility	Female	3.54	1.27	3.71	1.15	0.003*	0.55	0.81

	Male	3.64	1.20	3.85	1.06			
Work/ Productivity	Female	3.27	1.31	3.34	1.32	0.01*	0.70	0.053
	Male	3.20	1.28	3.58	1.26			
Upper Ext. Function	Female	3.70	1.31	3.80	1.33	0.03*	0.59	0.48
	Male	3.54	1.34	3.74	1.11			
Thinking	Female	4.13	0.99	4.36	0.91	0.25	0.11	0.053
	Male	4.50	0.80	4.44	0.81			
Personality	Female	3.84	1.31	3.87	1.26	0.47	0.98	0.33
	Male	3.95	1.35	3.75	1.40			
Mood	Female	3.69	1.17	3.81	1.14	0.43	0.03*	0.58
	Male	4.11	0.93	4.13	0.94			
Family role	Female	3.81	1.28	4.08	1.12	0.17	0.14	0.11
	Male	4.22	1.05	4.20	1.03			
Social roles	Female	3.78	1.35	3.99	1.21	0.08	0.48	0.71
	Male	3.66	1.43	3.80	1.34			
Energy	Female	3.05	1.45	3.18	1.41	0.84	0.02*	0.44
	Male	3.67	1.41	3.60	1.48			
Overall quality of life	Female	3.83	0.88	3.99	0.79	0.01*	0.56	0.42
	Male	3.95	0.84	4.03	0.78			

*significant p-value

Table 87 shows comparisons by age (<65 years, n=57; ≥65 years, n=69). Significant p-values for moment (6th-2nd) and age were found in Self-care, Mobility, Work/Productivity, Upper Extremity Function dimensions and Overall quality of life indicating that quality of life improved the 6th month and was higher for patients younger than 65 years, in both moments. No significant p-values for interaction (age*moment) were identified.

Table 87. One-Way Repeated Measures ANOVA for comparing quality of life by age

Dimension	Age	2nd month		6th month		p-value (moment)	p-value (age)	p-value (age*moment)
		M	SD	M	SD			
Self-care	<65 years	4.22	0.87	4.35	0.79	p<0.001*	p<0.001*	0.31
	≥65 years	3.55	1.17	3.79	1.16			
Vision	<65 years	4.63	0.73	4.73	0.61	0.80	0.72	0.92
	≥65 years	4.59	0.70	4.70	0.55			
Language	<65 years	4.64	0.60	4.75	0.44	0.06	0.39	0.52
	≥65 years	4.58	0.73	4.64	0.65			
Mobility	<65 years	3.97	1.03	4.07	0.95	0.01*	0.01*	0.18
	≥65 years	3.28	1.29	3.55	1.16			
Work/ Productivity	<65 years	3.62	1.21	3.79	1.17	0.01*	0.01*	0.42
	≥65 years	2.91	1.27	3.21	1.32			
Upper Ext. Function	<65 years	4.03	1.15	4.13	0.97	0.03*	0.01*	0.46
	≥65 years	3.26	1.36	3.47	1.31			
Thinking	<65 years	4.27	1.00	4.40	0.88	0.31	0.66	0.41
	≥65 years	4.39	0.83	4.41	0.84			
Personality	<65 years	3.74	1.42	3.68	1.29	0.43	0.21	0.73
	≥65 years	4.04	1.25	3.90	1.37			
Mood	<65 years	4.03	0.99	4.13	1.04	0.44	0.17	0.72
	≥65 years	3.83	1.12	3.86	1.04			
Family role	<65 years	4.23	0.97	4.19	1.03	0.28	0.23	0.14
	≥65 years	3.88	1.31	4.11	1.10			
Social roles	<65 years	3.79	1.40	3.99	1.22	0.09	0.46	0.86
	≥65 years	3.65	1.39	3.81	1.34			
Energy	<65 years	3.49	1.46	3.62	1.48	0.84	0.22	0.39

	≥65 years	3.31	1.45	3.23	1.43			
Overall quality of life	<65 years	4.07	0.79	4.17	0.70	0.01*	0.03*	0.68
	≥65 years	3.74	0.89	3.88	0.83			

*significant p-value

Table 88 provides comparisons by housing situation (alone, n=18; living with someone, n=108). Significant p-values for moment (6th-2nd) were found in Self-care, with better quality of life results in the 6th month. A significant p-value for interaction (housing situation*moment) was found in Vision, with positive progression of quality of life in patients who lived with someone, and negative progression in patients who lived alone. No significant p-value for housing situation was identified.

Table 88. One-Way Repeated Measures ANOVA for comparing quality of life by housing situation

Dimension	**Housing situation**	**2nd month**		**6th month**		**p-value** (moment)	**p-value** (housing situation)	**p-value** (housing situation *moment)
		M	SD	M	SD			
Self-care	Alone	4.00	1.11	4.19	1.05	0.01*	0.52	0.99
	Living with someone	3.83	1.09	4.02	1.05			
Vision	Alone	4.83	0.35	4.59	0.75	0.64	0.67	0.02*
	Living with someone	4.57	0.75	4.73	0.54			
Language	Alone	4.48	0.65	4.60	0.56	0.14	0.38	0.75
	Living with someone	4.63	0.67	4.71	0.56			
Mobility	Alone	3.68	1.23	3.70	1.16	0.18	0.99	0.27
	Living with someone	3.58	1.23	3.80	1.09			
Work/ Productivity	Alone	3.54	1.37	3.46	1.33	0.34	0.57	0.11
	Living with someone	3.18	1.27	3.47	1.29			
Upper Ext. Function	Alone	3.76	1.27	3.85	1.14	0.19	0.66	0.74
	Living with someone	3.59	1.34	3.75	1.22			
Thinking	Alone	4.33	0.88	4.20	1.04	0.89	0.55	0.26
	Living with someone	4.34	0.92	4.44	0.82			
Personality	Alone	4.31	0.99	4.06	1.16	0.33	0.19	0.58
	Living with someone	3.83	1.37	3.76	1.37			
Mood	Alone	4.24	1.15	3.93	1.01	0.43	0.51	0.07
	Living with someone	3.87	1.05	3.99	1.05			
Family role	Alone	4.07	1.23	4.15	0.98	0.46	0.93	0.87
	Living with someone	4.03	1.17	4.15	1.09			
Social roles	Alone	4.04	1.05	4.01	1.15	0.54	0.40	0.41
	Living with someone	3.66	1.43	3.87	1.31			
Energy	Alone	3.50	1.46	3.20	1.41	0.52	0.87	0.31
	Living with someone	3.37	1.46	3.44	1.47			

Overall quality of life	Alone	4.06	0.83	4.04	0.79	0.35	0.56	0.19
	Living with someone	3.86	0.86	4.01	0.79			

*significant p-value

Table 89 shows comparisons by civil status (in a relationship, n=85; not in a relationship, n=41). Significant p-values for moment (6th-2nd) were found in Self-care, Mobility, Work/Productivity, Upper Extremity Function and in Overall quality of life. All these dimensions scored better in the 6th month. A significant p-value for civil status was found in Personality; in this dimension, patients not in a relationship presented higher average results in both moments from those in a relationship. No significant p-values for interaction (civil status*moment) were identified.

Table 89. One-Way Repeated Measures ANOVA for comparing quality of life by civil status

Dimension	**Civil status**	**2nd month**		**6th month**		**p-value** (moment)	**p-value** (civil status)	**p-value** (civil status *moment)
		M	SD	M	SD			
Self-care	In relationship	3.84	1.10	4.02	1.06	p<0.001*	0.76	0.72
	Not in relationship	3.88	1.10	4.10	1.03			
Vision	In relationship	4.64	0.70	4.75	0.55	0.11	0.32	0.85
	Not in relationship	4.54	0.74	4.63	0.62			
Language	In relationship	4.58	0.71	4.68	0.58	0.13	0.63	0.59
	Not in relationship	4.66	0.59	4.71	0.52			
Mobility	In relationship	3.54	1.25	3.77	1.12	0.01*	0.65	0.44
	Not in relationship	3.69	1.18	3.82	1.05			
Work/ Productivity	In relationship	3.17	1.27	3.49	1.29	0.02*	0.09	0.17
	Not in relationship	3.36	1.33	3.44	1.29			
Upper Ext. Function	In relationship	3.60	1.35	3.77	1.24	0.046*	0.99	0.81
	Not in relationship	3.62	1.28	3.76	1.16			
Thinking	In relationship	4.44	0.87	4.49	0.81	0.33	0.06	0.78
	Not in relationship	4.13	0.95	4.23	0.94			
Personality	In relationship	3.76	1.41	3.64	1.37	0.52	0.03*	0.70
	Not in relationship	4.19	1.10	4.15	1.21			
Mood	In relationship	3.87	1.08	3.98	1.01	0.70	0.68	0.38
	Not in relationship	4.02	1.04	3.98	1.12			
Family role	In relationship	4.03	1.20	4.16	1.07	0.31	0.99	0.73
	Not in relationship	4.06	1.15	4.12	1.07			
Social roles	In relationship	3.63	1.50	3.84	1.34	0.15	0.40	0.65
	Not in relationship	3.88	1.13	3.99	1.17			
Energy	In relationship	3.39	1.49	3.40	1.47	0.89	0.99	0.96

	Not in relationship	3.39	1.38	3.41	1.45			
Overall quality of life	In relationship	3.86	0.90	4.00	0.81	0.02*	0.64	0.65
	Not in relationship	3.95	0.76	4.05	0.74			

*significant p-value

Table 90 presents comparisons by current professional situation (professionally active, n=37; professionally inactive, n=84). Significant p-values for moment (6th-2nd) were identified in Self-care, Language, Mobility, Work/Productivity and in Overall quality of life. All these dimensions scored better in patients' quality of life in the 6th month. No significant p-values for interaction (professional situation*moment), or professional situation alone were found.

Table 90. One-Way Repeated Measures ANOVA for comparing quality of life by professional situation

Dimension	Professional situation	2nd month		6th month		p-value (moment)	p-value (Professional situation)	p-value (Professional situation *moment)
		M	SD	M	SD			
Self-care	Active	4.11	0.92	4.16	0.99	0.01*	0.16	0.07
	Inactive	3.72	1.12	3.98	1.07			
Vision	Active	4.61	0.69	4.71	0.65	0.20	0.73	0.78
	Inactive	4.67	0.65	4.73	0.53			
Language	Active	4.58	0.73	4.69	0.57	0.04*	0.83	0.90
	Inactive	4.61	0.66	4.71	0.54			
Mobility	Active	3.82	1.08	3.91	1.04	0.01*	0.20	0.21
	Inactive	3.45	1.26	3.72	1.12			
Work/ Productivity	Active	3.50	1.21	3.71	1.25	0.01*	0.10	0.72
	Inactive	3.07	1.29	3.35	1.28			
Upper Ext. Function	Active	4.05	1.13	4.03	1.09	0.13	0.83	0.08
	Inactive	3.39	1.35	3.64	1.23			
Thinking	Active	4.28	0.95	4.36	0.89	0.26	0.50	0.91
	Inactive	4.37	0.89	4.47	0.79			
Personality	Active	4.11	1.22	4.04	1.24	0.45	0.18	0.83
	Inactive	3.83	1.38	3.69	1.39			
Mood	Active	4.21	0.95	4.09	1.05	0.78	0.13	0.14
	Inactive	3.78	1.11	3.95	1.04			
Family role	Active	4.17	1.00	4.18	1.06	0.44	0.60	0.49
	Inactive	4.00	1.22	4.14	1.07			
Social roles	Active	3.98	1.26	3.99	1.20	0.25	0.25	0.28
	Inactive	3.58	1.44	3.84	1.33			
Energy	Active	3.71	1.34	3.71	1.48	0.90	0.08	0.90
	Inactive	3.26	1.48	3.30	1.42			
Overall quality of life	Active	4.10	0.74	4.13	0.77	0.046*	0.12	0.17
	Inactive	3.79	0.89	3.97	0.77			

*significant p-value

6.4.3. Informal network of care and perceptions of its importance in post-stroke recovery

Measures related to perceptions of support were applied to subjects at discharge and in the 6th-month follow-up. At the first measurement point, patients were asked about their expectations toward likelihood to obtain support from kins and non-kins. In the 6th month, the Lubben Social Network Scale-18 (Boston College, 2014) was employed (n=108) to evaluate quality of received social support and additional interviews (n=102) were conducted.

Regarding the perception of eventuality to count on relatives, friends and neighbors after discharge, the answers of patients were entirely one-sidedly distributed, with vast majority (91.2%) expressing a positive feeling on it. Only 3.2% were not sure and 5.6% deemed to have no kins or no-kins to rely on. Hence, globally, respondents were certain they would receive, if necessary, support from persons who used to be the closest to them before stroke and that they could rely on them.

In the studied population, mean of all items of the LSNS-18 was 51.72 (SD=19.31). The minimum overall score was 2 and the maximum was 89. The family subscale received the highest scores in the study, with mean 22.65 and standard deviation 5.81 (min=2, max=30) indicating therefore the highest importance of family support in respondents' lives. Support of friends (mean=15.24, SD=9.20; min=0, max=30) and neighbors (mean=13.83, SD=8.20; min=0, max=30) was comparatively of less significance.

Three subscales of the LSNS-18 were then tested for differences between groups expected to distinguish levels of social support. The analysis indicated a number of variables which significantly discriminated them. The results are provided in Table 91.

Table 91. Differences between groups in the subscales of the LSNS-18

The Lubben Social Network Scale-18					
Family t=-1.174, p=0.243		**Neighbors** t=-1.419, p=0.159		**Friends** t=-2.367, p=0.020	
women 21.98 (SD=5.51) n=53	men 23.29 (SD=6.06) n=55	women 12.70 (SD=8.41) n=53	men 14.93 (SD=7.92) n=55	women 13.15 (SD=9.94) n=53	men 17.25 (SD=8.01) n=55
Family t= 2.887, p=0.005		**Neighbors** t= 1.437, p=0.154		**Friends** t= 0.525, p=0.601	
in a relationship 23.77 (SD=4.55) n=71	not in a relationship 20.49 (SD=7.26) n=37	in a relationship 14.65 (SD=7.37) n=71	not in a relationship 12.27 (SD=9.51) n=37	in a relationship 15.58 (SD=8.91) n=71	not in a relationship 14.59 (SD=9.83) n=37
Family		**Neighbors**		**Friends**	

t= -2.323, p=0.022		t= -0.795, p=0.429		t= 0.094, p=0.926	
living alone 19.89 (SD=6.62) n=19	living with someone 23.24 (SD=5.48) n=89	living alone 12.47 (SD=9.54) n=19	living with someone 14.12 (SD=7.92) n=89	living alone 15.42 (SD=10.37) n=19	living with someone 15.20 (SD=8.99) n=89
Family t= 1.901, p=0.060		**Neighbors** t= 0.838, p=0.404		**Friends** t= 2.251, p=0.026	
with private caregiver 19.11 (SD=8.04) n=9	no private caregiver 22.90 (SD=5.49) n=98	with private caregiver 11.56 (SD=9.13) n=9	no private caregiver 13.95 (SD=8.12) n=98	with private caregiver 8.67 (SD=10.39) n=9	no private caregiver 13.95 (SD=8.12) n=98
Family t= 2.575, p=0.011		**Neighbors** t= 1.212, p=0.228		**Friends** t= 1.596, p=0.113	
used an IPSS 19.65 (SD=6.99) n=20	did not use an IPSS 23.25 (SD=5.30) n=87	used an IPSS 11.75 (SD=8.25) n=20	did not use an IPSS 14.21 (SD=8.16) n=87	used an IPSS 12.20 (SD=10.58) n=20	did not use an IPSS 15.80 (SD=8.75) n=87

Men, in average, had a perception to be receiving more social support than women from family (mean=23.29 vs. 21.98), neighbors (mean=14.93 vs. 12.70) and friends (mean=17.25 vs. 12.15); however statistically significant difference was found only in perceived support received from friends (p=0.020). Civil status of respondents, dichotomized as in a relationship/not in a relationship, was also associated with a level of received support. Individuals in a relationship scored averagely higher for all groups (family, neighbors and friends) from those who were not in a relationship at the time (mean=23.77 vs. 20.49; 14.65 vs. 12.27; 15.58 vs. 14.59, respectively). Statistically significant difference was identified in social support available from family (p=0.005). The data show that for subjects living with somebody, perceived social support of family (mean=23.24 vs. 19.89) and neighbors (mean=14.12 vs. 12.47) was higher but that of friends was slightly lower (mean=15.20 vs. 15.42) than for subjects living alone (while the statistical significance for the difference between the groups could be assumed only in case of family, p=0.022). Very interesting findings demonstrate a relation between employing a private caregiver and its effects on perceived social support. Those of participants of the study who counted on help of a private carer reported, in average, lower levels of perceived social support in all subgroups, where perceived social support of friends appeared to be statistically significant (p=0.026). A lower level of support prevailed among respondents using services of Private Institutions of Social Solidarity than among those who did not use services of such entities. It reached statistical significance for support received from family (p=0.011). Table 92 presents statistically significant differences identified between groups for overall support.

Table 92. Significant differences between groups in overall support in the LSNS-18

The Lubben Social Network Scale-18	
Overall support for women	**Overall support for men**
t= -2.089, p=0.039	
47.83 (SD=19.57) n=53	55.47 (SD=18.46) n=55
Overall support for subjects with care before stroke	**Overall support for subjects without care before stroke**
t= 1.993, p=0.049	
36.67 (SD=8.98) n=6	52.61 (SD=19.41) n=102
Overall support for subjects with private caregiver	**Overall support for subjects without private caregiver**
t= 2.008, p=0.047	
39.33 (SD=22.02) n=9	52.57 (SD=18.65) n=98
Overall support for subjects who used an IPSS	**Overall support for subjects who did not use an IPSS**
t= 2.061, t= 0.042	
43.60 (SD=22.38) n=20	53.26 (SD=18.06) n=87

In overall support, statistical difference existed between men and women (p=0.039). Subjects receiving care before having suffered cerebrovascular accident had a perception to receive less overall social support than those who did not have such care, and this difference was statistically significant (p=0.049). Similar feelings expressed those who were cared by a contracted person (p=0.047) as well as patients using services of IPSS (p=0.042).

Six months after discharge from the stroke unit, the extent to which initial convictions about support from kins and non-kins were right was measured. From patients who claimed at discharge that could count on support of family, the opinion of effectively received support was rated in 47.6% as ‘very good’ and in 35.4% as ‘good’. Patients who initially believed in eventual neighbors’ support rated it later as ‘very good’ (30.3%) and ‘good’ (44.7%). Among subjects who felt at discharge they could rely on their friends, support was assessed as ‘very good’ by

40.8% and as ‘good’ by 39.5%. The assessment of perceived support of family, neighbors and friends is presented in Figure 42.

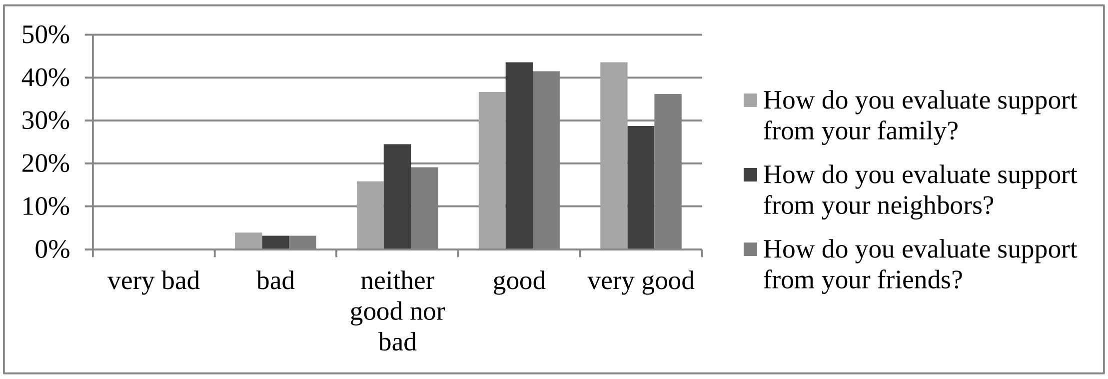


Figure 42. Assessment of support received from family, neighbors and friends six months after discharge

Overall, 43.6% subjects said that support they actually received from their family members was very good and this was the predominant response class, while there was no one who found it very bad and only a marginal part of respondents (3.7%) evaluated it as bad, leading to a very positive perception of family support as seen by stroke patients. Support of neighbors was assessed by the largest group (43.6%) of patients as ‘good’ and, again the lowest rating level was ‘bad’, with 3.2% responses. Participants of the study found friends a mainly ‘good’ source of social support (41.5%). No ‘very bad’ response was reported.

Analysis of the assessment of social support received from family, friends and neighbors revealed that age and current professional situation were factors differentiating the level of perceived quality of social support. The results are provided in Table 93.

Table 93. Differences between groups in the assessment of perceived quality of social support received from family, neighbors and friends

Assessment of social support received in the post-stroke recovery period					
Family t= -2.027, p=0.045		**Neighbors** t= -0.768, p=0.444		**Friends** t= -1.058, p=0.293	
age below median 4.36 (SD=0.811) n=53	age above median 4.02 (SD=0.863) n=48	age below median 4.04 (SD=0.841) n=49	age above median 3.91 (SD=0.793) n=45	age below median 4.02 (SD=0.946) n=49	age above median 4.20 (SD=0.661) n=45
Family t= 1.682, p=0.096		**Neighbors** t= 2.601, p=0.011		**Friends** t= 0.340, p=0.734	

professionally active	professionally inactive	professionally active	professionally inactive	professionally active	professionally inactive
4.40	4.09	14.65	3.83	4.14	4.08
(SD=0.675)	(SD=0.910)	(SD=7.37)	(SD=0.808)	(SD=0.891)	(SD=0.789)
n=30	n=68	n=27	n=64	n=28	n=63

Available support measured by the LSNS-18 individually for each subscale (family, neighbors and friends) was positively correlated with the subjective assessment of quality of that support. The respective correlation coefficients are presented in Table 94. Statistically significant relationships occurred between availability of family support and quality of actual support, between availability of neighbors support and quality of actual support, and availability of friends support and quality of that support. The strongest correlation existed between support received from neighbors and its perceived quality (*rho*= .616).

Table 94. Relation between availability of social support and patients' assessment of that support

Spearman's *rho*	**Support from family**	**Support from neighbors**	**Support from friends**
How do you evaluate support you received after stroke from your family?	.452**	.269**	.283**
How do you evaluate support you received after stroke from your neighbors?	.490**	.616**	.399**
How do you evaluate support you received after stroke from your friends?	.338**	.256*	.519**

**correlation significant at p<0.05*; ***correlation significant at p<0.01*

Findings from interviews (n=102) conducted with patients in the 6th month of the study confirmed the results of quantitative data analysis. Identified categories, subcategories and illustrative quotations extracted from interviews are presented in Table 95. The highest number of participants acknowledged family support (n=82). Respondents frequently mentioned kins' help in daily tasks and activities and emotional support to guarantee the best conditions for the recovery. Appreciation of family support did not differ considerably from the other two groups; neighbors' support was appreciated by 75 respondents and friends' support was esteemed by 70 patients. Almost one fifth (19.6%) of patients did not formulate a positive opinion about support from family in their post-stroke recovery, expressing their disappointment with such situation. Analyzing closer their cases from socio-demographic data, it was found out that those were patients with a limited first line family network, therefore, the scope of family support they could count on was *a priori* restricted. Regarding support of neighbors, the study distinguished two types of respondents: those with casual or even reserved relationships with neighbors, and those in close and intimate relations with their neighbors, for whom neighbors were as relevant as family (often in case of its inexistence or unavailability). Thus, while not sharing the same household, respondents admitted to value shared everyday routines, conversations, help received with performing tasks, and, importantly, the feeling of ‘not being left alone’. Findings indicate that the level of proximity with friends differed substantially, therefore, contentment with the friends’ visit at the stroke ward varied and stress related to it affected interviewees in some cases. However, in vast majority, support of friends was evaluated positively.

Table 95. Interview categories and subcategories with representative quotations within the topic ‘Perceived Social Support’

Category	Subcategory	Quotation
Family Support	Appreciation of family support (n=82)	“It has been good. The whole work there is to be done and I cannot do, they do for me” (ID159) “I am. I am very satisfied and quiet as I like. I see that everyone treats me so good” (ID183)
Neighbors Support	Appreciation of neighbors support (n=75)	“I speak with that [neighbor]; I speak with the one living in front, who is for me almost like a family. She was coming here to check if I was fine. If I wanted, I was going there to have meals with her and her husband” (ID101) “Everything, everything here, the neighbor from downstairs was coming (…) she is a policewoman and her husband is a policeman as well, and she even called me to say ‘If anything happens, you call me, I will take you to the hospital by myself’. It’s just I didn’t want to bother people around…(…)” (ID127)
Friends Support	Appreciation of friends support (n=70)	“Some of them [friends] went even to the Hospital of Aveiro thinking I was there to visit me and I was already in Ovar” (ID001) “Yes, they came to the hospital to see me, but only after some time, I tried not to have the mobile phone by my side” (ID139)

6.4.3.1. Relation between informal social support and the quantity of interactions in the care sector

The results indicate that there were no statistically significant correlations between perceived support that subjects received from family, neighbors, friends and support as a whole, and the number of entities they interacted with (Table 96). An eventual tendency of interest can be seen in entities providing care and support not directly related to health care, where all correlations were negative, suggesting a relation of stronger social support, whether partial or overall, with less frequent contact with entities from the sector.

Table 96. Correlation between the type of informal support and a number of institutions contacted by patients

Spearman's *rho*	Support from family	Support from neighbors	Support from friends	Overall support
A number of contacted health care entities (excluding rehabilitation units)	.130	.107	.054	.101
A number of contacted health care entities (including rehabilitation units)	.070	.141	-.019	.075
A number of contacted not health-related care entities	-.187	-.114	-.148	-.159

**correlation significant at p<0.05*; ***correlation significant at p<0.01*

6.4.3.2. Health status of patients and received informal social support

Patients (n=102) were asked about their perceived health status six months after discharge from the stroke unit. A little over a half (52.0%) did not find it either good or bad. More respondents found their health condition positive ('very good' or 'good, 2.9% and 34.3% respectively) than negative ('very bad'- 2.9% and 'bad'- 7.8%). A part of interviews regarding that issue focused on the topic denominated 'Assessment of Current Health Status' – a perception that the participant of the study had on health state in a given moment, which comprised health status – current health condition of the patient. That could be:

- Positive – health condition perceived by the patient as favorable;
- Negative - health condition perceived by the patient as unfavorable;
- Variable - health condition perceived by the patient as oscillating.

The codification system resulting from the data analysis led to creating the categories provided in Table 97 with their representative citations.

Table 97. Partial codification system and representative citations from the interviews with patients within the topic 'Assessment of Current Health Status'

Topic	Category	Subcategory	Citation
Assessment of Current Health Status	Health Status	Positive (n=55)	"And, as I have already told you, I am not a 100%, but it's almost, I am absolutely sure that the rest will reach a 100%, just a little more patience" (ID032) "I feel lighter, better, day after day, thank God" (ID185)

		Negative (n=15)	"It is nothing good, I suffer a lot from my back and everything together (…)" (ID026) "Mine? I don't think it is fine, it's not going away (…), not getting better, there are complications… I don't know" (ID018)
		Variable (n=23)	"I am more or less, and with this condition I am already very thankful to God (…)" (ID116) "There are days in which it is better, and others in which it is very bad" (ID006)

The topic regarding health condition of the patient and referring to the current perception of that condition (which varies over time and is subject to a number of factors) suggested that most of interviewees considered their health status as positive (n=55), more than those with variable (n=23) and negative (n=15) health state.

The results indicate that perceived health condition was statistically dependent on gender. Considerably more women (mean rank = 41.69) considered their health status 'very bad' or 'bad' (22.7%) as compared to men (1.7%) (mean rank = 58.94) and substantially more men (46.6%) than women (25.0%) assessed their health as 'very good' or 'good'. This was a statistically significant difference (Z= -3.222, p=0.001).

A significant impact on perceived health condition played civil status. More respondents not in a relationship at the time considered their health status as 'very bad' or 'bad' (mean rank = 43.53, 21.6%) than those remaining in a relation (mean rank = 54.98, 5.6%). In line with these results, significantly more participants in a relation (40.8%) than without a partner (29.0%) judged their health status as 'very good' or 'good' (Z= -1.986, p=0.047).

The relationship of perceived health status and assessment of support received from family, neighbors and friends was verified separately. No correlation was found in case of family. There might have been, indeed, identified a tendency of one group of patients with a general negative-moderate attitude, whose assessment of health status and social support from family was bad or at most average, and another group with a general positive-moderate attitude. Nonetheless, when analyzed a relation of the assessment between support of neighbors and friends (separately) and perception of health condition, these appeared to be statistically significant. The assessment of support from neighbors was very strongly associated with the perception of health status. The better the opinion of support from neighbors, the better the perception of the own health condition (*rho*= .351, p=0.001). As an example, from the group of subjects who assessed neighbors' support as bad, 100.0% perceived their own health condition as 'very bad'. In contrast, respondents who assessed support from neighbors as 'very good', considered in 63.0% their health status 'good' or 'very good'. This situation was similar to what happened in the analysis of support from friends and perceived health condition. The more positive evaluation of support from friends, the better the perception of own health condition. The correlation was, a little weaker than in the case of neighbors, but still statistically significant (*rho*= .232, p=0.024).

6.4.3.2.1. Dimensions of the Lubben Social Network Scale-18 verified in the Portuguese stroke patients

The LSNS-18 was tested for a number of factors associated with its original structure in the sample of the Portuguese stroke patients participating in the study. Principal axis factoring which analyses shared variance was chosen as a method of factor extraction. The method was used as it is common for theoretical exploration of the underlying factor structure and that was specifically the objective of its application.

The factor structure was tested on the eigenvalues-basis using Kaiser's rule of including solely factors with eigenvalues greater than 1 together with a scree plot graphical indication. The best achieved solution with the original version of the LSNS-18 applied the Varimax rotation. The Kaiser-Mayer-Olkin measure of sampling adequacy was 0.852, and the Bartlett's test of sphericity was 1259.417 rejecting the hypothesis that the correlation matrix was an identity matrix at p<0.001. Communalities of the variables were from 0.300 to 0.812. More importantly, each of the items loaded evidently into one factor and no cross-loadings were observed. In this solution, factor one corresponded to friends' social support items, factor two corresponded to neighbors' support-related items and factor three loaded with the family support item. This solution presented a clear advantage to the previously tested as to be more easily interpretable.

Three items represented the lowest communalities in the solution, each one in a different LSNS-18 subscale, namely:

- *'How many relatives do you feel at ease with that you can talk about private matters?'* (communality=0.366);
- *'How many neighbors do you feel at ease with that you can talk about private matters?'* (communality=0.373); and

- *'How many friends do you feel at ease with that you can talk about private matters?'* (communality=0.300)

Bearing in mind the problematic communalities were related to the same item applied into running an additional test excluding those variables. Factor analysis for the final instrument as applied for the Portuguese group of stroke survivors was conducted in order to confirm the final structure of the measure. The solution applied the Varimax rotation. The KMO measure of sampling adequacy was 0.855. The Bartlett's test of sphericity provided result 1077.489 ($p<0.001$). The lowest observed communalities now registered were at the level 0.4 (three variables) reaching the level 0.8 (one variable). Three factors of the solution accounted for 62.38% of the total variation.

Reliability tests of the instrument were conducted by the use of Cronbach's alpha and item-total coefficients (Tavakol & Dennick, 2011) for the family, neighbors and friends subscales individually, and, at the concluding stage, also to the global score of the instrument, as the LSNS-18 allows for calculating the overall score of social support. Following Kline's (1999) recommendations, values of Cronbach's alpha below 0.6 were considered unsatisfactory, between 0.6 and 0.7 acceptable, between 0.7 and 0.9 good to very good, and over 0.9 exceptional.

Internal consistency measured by Cronbach's alpha for the LSNS-18 in its original version applied for the Portuguese stroke survivors was 0.920 and situated on a very suitable level within parameters suggested for health measurement instruments by Streiner and Norman (1995). All three subscales presented high levels of Cronbach's alpha (family=0.844; neighbours=0.884; friends=0.900). The final measure was still composed by three subscales, with an exception of one missing item in each of them (*'How many relatives/neighbors/friends do you feel at ease with that you can talk about private matters?'*). The factors associated to social support that resulted from factor analysis and respective statistics are provided in Table 98.

Table 98. Factors associated to social support

Factor	Loading	Communalities	Explained Variance (%)	Accumulated Explained Variance (%)	Item-total correlation	Cronbach's α
Factor 1						
A13. How many of your friends do you see or hear from at least once a month?	0.76	0.69			0.78	

A14. How often do you see or hear from the friend with whom you have the most contact?	0.78	0.67	22.22	22.22	0.77	0.92
A16. How many friends do you feel close to such that you could call on them for help?	0.69	0.64			0.76	
A17. When one of your friends has an important decision to make, how often do they talk to you about it?	0.71	0.67			0.75	
A18. How often is one of your friends available for you to talk to when you have an important decision to make?	0.86	0.84			0.86	
Factor 2						
V7. How many of your neighbors do you see or hear from at least once a month?	0.74	0.62	21.59	43.81	0.75	0.89
V8. How often do you see or hear from the neighbor with whom you have the most contact?	0.78	0.69			0.78	
V10. How many neighbors do you feel close to such that you could call on them for help?	0.69	0.59			0.72	
V11. When one of your neighbors has an important decision to make, how often do they talk to you about it?	0.67	0.53			0.65	
V12. How often is one of your neighbors available for you to talk to when you have an important decision to make?	0.74	0.65			0.75	
Factor 3						
F1. How many relatives do you see or hear from at least once a month?	0.87	0.77	18.57	62.38	0.73	0.83
F2. How often do you see or hear from relative with whom you have the most contact?	0.62	0.41			0.56	
F4. How many relatives do you feel close to such that you could call on them for help?	0.75	0.69			0.70	
F5. When one of your relatives has an important decision to make, how often do they talk to you about it?	0.57	0.45			0.65	
F6. How often is one of your relatives available for you to talk to when you have an important decision to make?	0.56	0.44			0.64	

Factor 1 constituted items related to support from friends and explained 22.22% of variance. The friends social support subscale demonstrated the Cronbach’s alpha 0.915, hence, indicating an excellent consistency. Item-total Pearson’s correlation coefficients were sound and correlated with the total score of the subscale (0.75-0.86).

Factor 2 was composed of items related to social support received from neighbors and explained additional 21.59% of variance. Cronbach’s alpha of the subscale reached 0.887 constituting an excellent result and indication that five items in cause in fact measured the same concept or construct. All items were well correlated with the total score (0.65-0.78).

Factor 3 explained 18.57% of the variance and included items related to support received from family. With five items, Cronbach's alpha was 0.832 indicating a very good extent to which the subscale managed to measure the same concept of construct as defined by Tavakol and Dennick (2011). Item-total correlation coefficients between each item and the total score of the remaining items of the subscale presented also very good levels (0.56-0.73).

Considering the overall social support as measured by the Lubben Social Network Scale-18 with the adjusted number of items, Cronbach's alpha was 0.917 indicating an outstanding internal consistency of the total measure what is not surprising after excellent results of the individual subscales. Therefore, the analysis suggests that the adjusted LSNS-18 with 15 items better suits the Portuguese population of stroke survivors revealing excellent reliability levels. Hence, further studies are obviously recommended to confirm these findings among different populational groups.

Table 99 provides statistics of all items constituting the LSNS-18 applied to patients participating in the study. As can be confirmed, apart from a few means presenting high values, generally the statistics situate at average level. Three items of the measure proposed to eliminate in the study over the Portuguese population represent lower means and high standard deviations. Furthermore, it is clear that means the family subscale present higher scores than two other subgroups.

Table 99. Statistics of all items of the Lubben Social Network Scale-18 applied to Portuguese stroke survivors

Item	Min.	Max.	Mean	SD
F1	1	5	4.32	0.98
F2	1	5	4.65	0.79
F3	0	5	2.33	1.48
F4	0	5	3.62	1.43
F5	0	5	3.53	1.55
F6	0	5	4.19	1.34
V7	0	5	3.24	1.73
V8	0	5	2.94	1.68
V9	0	5	0.84	1.41
V10	0	5	2.35	1.89
V11	0	5	1.69	1.68
V12	0	5	2.76	1.88
A13	0	5	3.53	1.95
A14	0	5	2.54	1.68
A15	0	5	1.23	1.73

A16	0	5	2.71	2.04
A17	0	5	2.26	1.83
A18	0	5	2.98	2.00

As a confirmation of a visual inspection of the previous table, the factor associated to social support of family (Factor 3) demonstrates the highest mean, 4.06. Factor 1, relative to support of friends indicates mean 2.8, followed by Factor 2, combining items relative to social support of neighbors, with mean 2.6 (Figure 43).

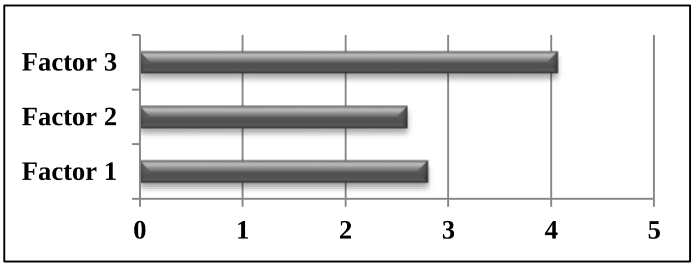


Figure 43. Means of factors associated to social support measured by the Lubben Social Network Scale-18

6.4.4. Patients' quality of life and received social support

An important component of quality of life of a patient with any level of dependency is support received from the closest relatives and a subjective feeling to be able to count on it. In case of stroke patients, dependency is one of consequences that, at a lower or higher degree, leads to worsening quality of life. Some of post-stroke frequent limitations included in the SS-QoL dimensions are those of Self-care, Language, Upper-Extremity Function or Mobility. Impairments in these abilities may have a negative impact on other spheres of person's life, affecting Mood or Family Roles, followed by Social Roles or reducing Energy. Overall quality of life without appropriate support may deteriorate meaningfully over time.

An impact of social support on quality of life was therefore investigated. The interest focused on quality of life patients represented in the 6th month of the study and the difference in quality of life between the 6th and the 2nd month. Social support comprised support from family, neighbors and friends separately, and the general level of support as understood by the Lubben Social Network Scale-18. An objective was to contrast two groups of participants: those with a very low level of social support and those who received very high scores of social support in the understanding of the LSNS-18. Questionnaires were screened for that purpose. The boundaries between groups originated from performed statistical analysis and in a way to maximize the differences between the groups and the decision was taken arbitrary.

In the subscale of Family support, scores from 2 to 9 were considered to be very low levels (5 respondents achieved such results), and score 30 was considered a very high level (achieved by 7 respondents). In the subscale of Neighbors, as a very low level a score of 0 was considered (that score was achieved by 13 respondents), and scores from 26 to 30 were deemed very high (9 respondents were included). In the subscale of Friends, a score of 0 was considered a very low level (18 subjects achieved that result) and a very high level was that from 28 to 30 (8 respondents met that criterion). Overall social support (90 was the total possible score to accomplish), a very low level of support was a range from 0 to 22 (taking into account 10 respondents) and a very high level of support was between 75 and 90 (13 respondents were included to the analysis).

In the 6th month, in the group with the lowest social support from family, the highest mean was 4.80 (SD=0.28) and it was recorded in the dimension of Language, and the lowest mean was 3.13 (SD=1.61) reached in the dimension of Energy. Among respondents with the highest social support, the dimension with the highest mean, 4.90 (SD=0.25), was Thinking, and with the lowest was Work/Productivity, 3.57 (SD=1.32). Respondents who received very low social support from family had lower scores in most of the dimensions of quality of life than respondents who could count on a very high level of support. This becomes the most apparent in the dimensions of Upper Extremity Function, Thinking, Personality, Mood, Family Roles and Energy.

In case of support from neighbors, subjects with very low support achieved lower scores than those with the highest support. The discrepancy was the most explicit in the dimensions of Language, Thinking, Personality, Mood and Energy. The highest mean in the group of the lowest support, 4.79 (SD=0.32), was in the dimension of Vision and the lowest, 3.18 (SD=1.62), in the dimension of Energy. In the group of the highest support, the highest mean was recorded in the dimension of Language, 4.98 (SD=0.07), and the lowest in the dimension of Work/Productivity, 3.59 (SD=1.61).

In turn, patients receiving very strong support from friends relatively to those with very weak support achieved considerably higher scores in the dimensions of Work/Productivity, Upper Extremity Function, Personality, Mood, Family Roles, Social Roles and Energy. In the groups with the lowest level of support, the highest mean was 4.78 (SD=0.34) and that was in the dimension of Language, and the lowest was 2.93 (SD=1.57), in the dimension of Energy. Mean scores for the highest of support did not vary in most of cases with the highest registered in the dimension of Thinking, 4.96 (SD=0.12), and the lowest in the dimension of Work/Productivity, 3.67 (SD=1.55). In all three subscales of the LSNS-18, Overall quality of life was higher for persons with the highest social support.

The analysis of overall social support and quality of life in the 6th month showed that higher scores of quality of life were more commonly noticed among patients with the highest social support. That occurred in the dimensions of Mobility, Work/Productivity, Upper Extremity Function, Thinking, Personality, Mood, Family Roles, Social Roles, Energy, Self-care and Language, what indicates an improvement in 11 from 12 of quality of life dimensions of the measure. Bearing in mind Overall quality of life score, that was also at a clearly higher level for subjects with the highest level of support (mean=4.27, SD=0.75) than for patients receiving the lowest social support (mean=3.59, SD=0.82).

Comparing quality of life between the 6th and the 2nd month in patients with a very high support from family quality of life in the dimensions of Vision, Language, Thinking, Personality, Mood and Energy improved considerably. Interestingly, subjects with a very low level of family support, made substantial achievements in quality of life in Mobility, Work/Productivity, Upper Extremity Function and Social Roles. Moreover, and what is also remarkable, among respondents with a very low level of social support from family, a fairly resilient drop of quality of life in the dimension of Energy was registered (Table 100).

Table 100. Differences observed in quality of life dimensions between the 6th and the 2nd month of the study among groups of patients with very high and very low support from family

Difference in quality of life between the sixth and the second month	**Support from family**					
	Very low			Very high		
	N	Mean	SD	N	Mean	SD
Self-care	5	.120	.363	7	.143	.395
Vision	5	.130	.506	7	.190	.813
Language	5	-.040	.219	7	.314	.832
Mobility	4	.875	.250	7	.405	.810
Work/Productivity	5	.467	1.261	7	.286	.989
Upper Extremity Function	5	.240	1.252	7	-.057	.737
Thinking	5	-.067	.548	7	.476	1.215
Personality	5	-.067	2.565	7	.571	1.101
Mood	5	-.120	1.119	7	.543	.838
Family Roles	5	-.067	1.402	7	.143	1.086
Social Roles	5	.520	1.262	7	.057	.321
Energy	5	-.200	2.142	7	.714	1.254
Overall quality of life	4	.158	.319	7	.297	.580

Respondents who could count on very strong support from neighbors progressed much in terms of quality of life in the dimensions of Mobility, Work/Productivity, Thinking, Personality, Mood, Social Roles, Family Roles and Energy, that is in seven of twelve of the instrument dimensions. More specifically, while the results of patients receiving very high perceived social support from neighbors made a significant improvement in the domains of Personality, Mood and Family Roles, they worsened in case of patients with the lowest support from neighbors (Table 101).

The fact of such strong support from neighbors may not only be derived from cultural values and principles but also from the structure of the proper LSNS-18 questionnaire. The questions regarding neighbors come before friends and, as recurrently happened during interviews, respondents had difficulties in distinguishing who was considered a neighbor and who was a friend if, as they felt, both belonged to the same category. Eventually, after a more precise explanation by the interviewer, also provided at the original questionnaire by the authors (*'who do not live in your neighborhood'*), this ambiguity could be clarified. Still, the risk of uncertainty remained due to the characteristics and specificity of participants of the study.

Table 101. Differences observed in quality of life dimensions between the 6th and the 2nd month of the study among groups of patients with very high and very low support from neighbors

Difference in quality of life between the sixth and the second month	**Support from neighbors**					
	Very low			Very high		
	N	Mean	SD	N	Mean	SD
Self-care	13	.169	.730	8	.075	.354
Vision	13	.410	.696	8	.292	.881
Language	13	.138	.699	8	.225	.446
Mobility	13	-.333	.844	8	.375	.749
Work/Productivity	13	-.179	1.199	8	.375	.967
Upper Extremity Function	13	-.046	.833	8	.150	.424
Thinking	13	-.205	.908	8	.917	1.330
Personality	13	-.385	1.261	8	1.042	1.474
Mood	13	-.708	1.057	8	.575	.871
Family Roles	13	-.538	.948	8	.500	1.141
Social Roles	13	-.138	.918	8	.450	1.140
Energy	13	-.231	1.022	8	1.042	1.240
Overall quality of life	13	-.170	.596	8	.452	.631

The analysis of the LSNS-18 Friends subscale led to the conclusion that patients with the strongest support from friends had, in average, much higher improvement in the dimensions of Thinking, Personality, Mood, Family Roles and Social Roles. Conversely, among subjects with the lowest support from friends, considerably higher scores were achieved in the dimensions of Mobility and Upper Extremity Function. Remarkably, a reasonably strong decrease in the dimensions of Personality, Social Roles and Family Roles of quality of life was registered in case of respondents with a very low level of social support (Table 102).

Table 102. Differences observed in quality of life dimensions between the 6th and the 2nd month of the study among groups of patients with very high and very low support from friends

Difference in quality of life between the sixth and the second month	Support from friends					
	Very low			Very high		
	N	Mean	SD	N	Mean	SD
Self-care	18	.100	.424	5	-.125	.385
Vision	18	.167	.618	5	.083	.812
Language	18	.189	.681	5	.050	.233
Mobility	18	.352	.743	5	.167	.895
Work/Productivity	18	.185	1.133	5	.083	1.035
Upper Extremity Function	17	.259	.624	5	.000	.414
Thinking	18	.185	.752	5	.458	1.097
Personality	18	-.426	1.520	5	.500	1.098
Mood	18	-.067	1.293	5	.400	.962
Family Roles	18	-.222	1.288	5	.357	1.133
Social Roles	18	-.233	1.534	5	.100	.239
Energy	18	.204	1.535	5	.375	1.768
Overall quality of life	17	.062	.575	5	.179	.594

Respondents receiving very high overall social support improved their quality of life in a much higher degree in the dimensions of Mobility, Work/Productivity, Thinking, Personality, Family Roles, Mood and Social Roles from those with very low overall support. Conversely, in case of patients with very low overall support, reasonably strong decrease of quality of life was registered in the dimensions of Mood, Thinking, Personality and Family Roles. A slight increase of Overall quality of life was identified in participants with very strong social background and a minor decrease of Overall quality of life was observed along with very low overall social support (Table 103).

Table 103. Differences observed in quality of life dimensions between the 6th and the 2nd month of the study among groups of patients with overall very high and very low support

Difference in quality of life between the sixth and the second month	Overall support					
	Very low			Very high		
	N	Mean	SD	N	Mean	SD
Self-care	10	.000	.550	12	.000	.381
Vision	10	.233	.832	12	.139	.758
Language	10	-.120	.286	12	.033	.187
Mobility	10	-.100	1.155	12	.194	.735
Work/Productivity	10	-.167	1.390	12	.194	.858
Upper Extremity Function	10	.080	1.034	12	.050	.383
Thinking	10	-.333	.846	12	.333	.899

Personality	10	-.600	1.955	12	.389	1.023
Mood	10	-.420	1.456	12	.250	.801
Family Roles	10	-.700	1.271	12	.472	1.087
Social Roles	10	-.080	1.418	12	.317	.765
Energy	10	.200	1.416	12	.250	1.422
Overall quality of life	10	-.151	.751	12	.199	.494

An eventual relationship between a number of entities a patient interacted with after discharge from the stroke unit and perceived quality of life was also examined. Inquiry comprised both, quality of life in the 6th month and the difference in quality of life between the 6th and the 2nd month. In the 6th month, the more contacts with some entities, the lower quality of life was observed in some of its dimensions, but the higher in others, thus no conclusive results were reached. The analysis of differences of quality of life between the 6th and the 2nd month indicated no association between the quantity of contacted entities and quality of life, either.

CHAPTER SEVEN:

RESULTS OF THE EMPIRICAL STUDY: THE NETWORK OF CARE IN THE EYES OF SERVICE PROVIDERS

In order to determine the current network of care existing for stroke patients in the district of Aveiro, a contact with previously identified institutions was established with an objective to confirm their activity status and question about how they collaborate with other members of the network. Additional interviews were conducted with a sample of key informants of those entities, hence providers of health care, social care, support, technical aid, financial help, transportation services and any other support that a stroke survivor might be in need of. Interviews took place within two months (May-July 2014) and included a representative of each type of institution who agreed to be part of the study. Initial contacts were set up with 11 types of entities in total. The first contacted medium/long-term rehabilitation unit refused recording the interview making it unfeasible for further analysis. As a solution, other two medium and/or long-term rehabilitation units could be contacted. One refused to participate in the study. A decision on participation of another institution remained without final response. An interview with the Social Security was not possible for reasons independent on the researcher.

As a result, nine interviews were conducted with nine entities, namely with a hospital, a health center, a convalescence unit, a fire department, a city council, a parish council, a physiotherapy clinic, a Private Institution of Social Solidarity and a charitable institution.

7.1. Entities in the network of care

Information regarding fire departments and city councils was considered relatively feasible, although still necessary to be verified. As to IPSS, all institutions in the district were screened and solely those offering social response adequate to stroke survivors were extracted. *Misericórdias* existing in Portugal are subject to formal yet voluntary registration and those formally registered were taken into account as part of this work. In their case, information was easily available and up-to date. Some *Misericórdias* had a status of IPSS, in which case were included in the first category in order to avoid the duplication.

Some uncertainties arose in case of parish councils due to a recent change which decreased a number of parishes from 4260 to 3091, diminishing automatically the number of corresponding parish councils but introducing a concept of a union of parishes, therefore these entities had to be localized. Physiotherapy clinics needed to be confirmed one by one, also verifying whether a typology of provided services was adequate for stroke patients.

Still, a composition of the care providers' record was subject of modifications over time as a number of those initially thought to constitute a core changed their status or terminated the activity. This happened in case of rehabilitation units of the RNCCI, one *Misericórdia*, numerous IPSS and several physiotherapy clinics. Hence, for setting up the final list of the care providers, an elevated and much higher than initially envisaged quantity of contacts with entities was necessary to establish. The final list of entities comprised 509 institutions.

Interviews with representatives of entities providing care and support to stroke patients, in a broad understanding of this term, took place between May and July 2014 and had an average duration time of almost 46 minutes.

Results of this part of the study are based on content analysis employing data matrices of nine interviews with entities representing different types of care service activities, related either to health care or and other, not directly health-related care services (presented in Table 104), in order to understand, identify and quantify structural and functional patterns of collaborative relations types and levels between organizations.

Table 104. Sample description from the interviews with care and support entities

Organization	Type of service provider
Rehabilitation unit	Health care
Hospital	Health care
Fire department	Other care service providers
Charitable organization	Other care service providers
Physiotheraphy clinic	Health care
Private Institution of Social Solidarity	Other care service providers
Health center	Health care
City council	Other care service providers
Parish council	Other care service providers

The categorical system developed in the study originating from the matrix qualitative analysis was based on the methodology of Miles and Huberman (1994). The developed categorical matrix within the main categorical system presented in Table 105 used in the initial stage the framework proposed by Valentijn et al. (2013) as a basis for a further adaptation. The categories resulted from data deductive and inductive content analysis once there was not enough previous knowledge about the investigated phenomenon under study, but the main themes were based on the previous study indicated above.

Table 105. The main categorical system for institutional analysis

Collaboration Level	Types of Collaboration
Macro Level	System Integration
Meso Level	Organizational Collaboration
	Professional Collaboration
Micro Level	Clinical Collaboration

‘Collaboration level’ represents the literature theme or the main categorical organization of data and ‘types of collaboration’ correspond to the second level of categorical organization data system. Each ‘type of collaboration’ generic category is split into several categories and subcategories.

7.2. Categorization

7.2.1. Macro Level

The emphasis of the Macro Level is placed on systemic characteristics. Figure 44 demonstrates the way Macro Level was categorized.

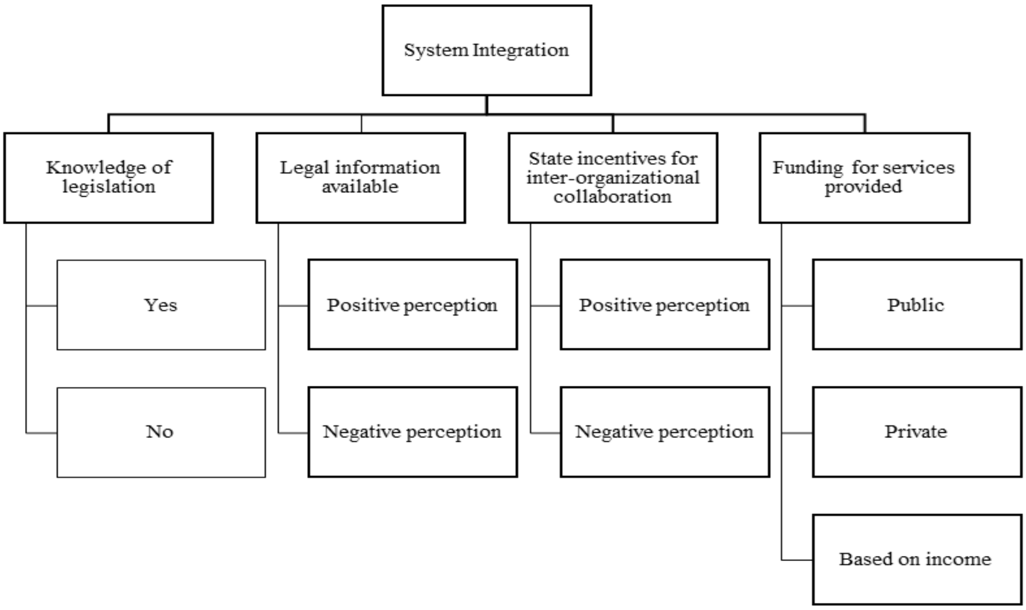


Figure 44. Macro Level and subsequent subcategories system design

System Integration was included in the Macro Level main theme. In the first part of the analysis, four generic categories were created to organize data that indicated the Macro Level collaboration relationship, in particular related to legal and legislation information about collaboration between organizations, the State incentives and funding for collaborative-related provided services. Table 106 provides an illustration of examples applied within the coding pattern in the Macro Level with adequate citations from interviews with the care providers.

Table 106. An example of the data coding of the categorization matrix template – Macro Level

Macro Level
System Integration
Knowledge of legislation **No** *"No"* **Yes** *"The law that is on the basis of long-term care since 2006."*
State incentives for interorganizational collaboration **Based on income** *"(...) Turn out to be the users, there is a reimbursement, there is a percentage and users pay that percentage."* *"(...) Depends on the income of the user…"* **Private** *"(...) the user himself"* *"(...) no State-funded"* **Public** *"The level of public funds. By the National Health Service* *"National Civil Protection Authority, the Regional Health Administration, the INEM"* *"The State"* *"(...) the central State"* *"The Ministry of Health"* *"(...) not state-funded, when patients are sent by the services of the State, or by patients themselves"* *"(...) proper City Council"*
Funding for services provided **Negative perception** *"(...) There are none, or at least I don't know."* *"(...) No, no."* *"(...) No, I didn't even know this existed."* **Positive perception** *"(...) exist for partnerships"* *"(...) the State has a very important role in financing"* *"(...) yes, if they are well sought after and well analyzed"*
Legal information available **Negative perception** *"(...) I don't know that there is this kind of specific information for people with stroke"*

“(...) is dispersed”
“(...) insufficient, very incomplete”
“No.”
Positive perception
“(...) I can access most of the information that I want too through this support system
“(...) Yes, yes, there is.”

7.2.2. Meso Level

The Meso Level theme was composed of two generic categories – Organizational Collaboration and Professional Collaboration. Each one was distributed into subsequent categories in order to expose their hidden internal assumptions and logical organizational patterns (presented in Figure 45 and Figure 46). Organizational Collaboration was further divided into Collaboration perception and Characteristics of collaboration categories and Professional collaboration was separated into Adaptability, Interpersonal relationships, Teamwork and Service quality of care providers subcategories. For analytical purposes, the above categories might be further split into more specific subcategories in order to express the full meaning of data.

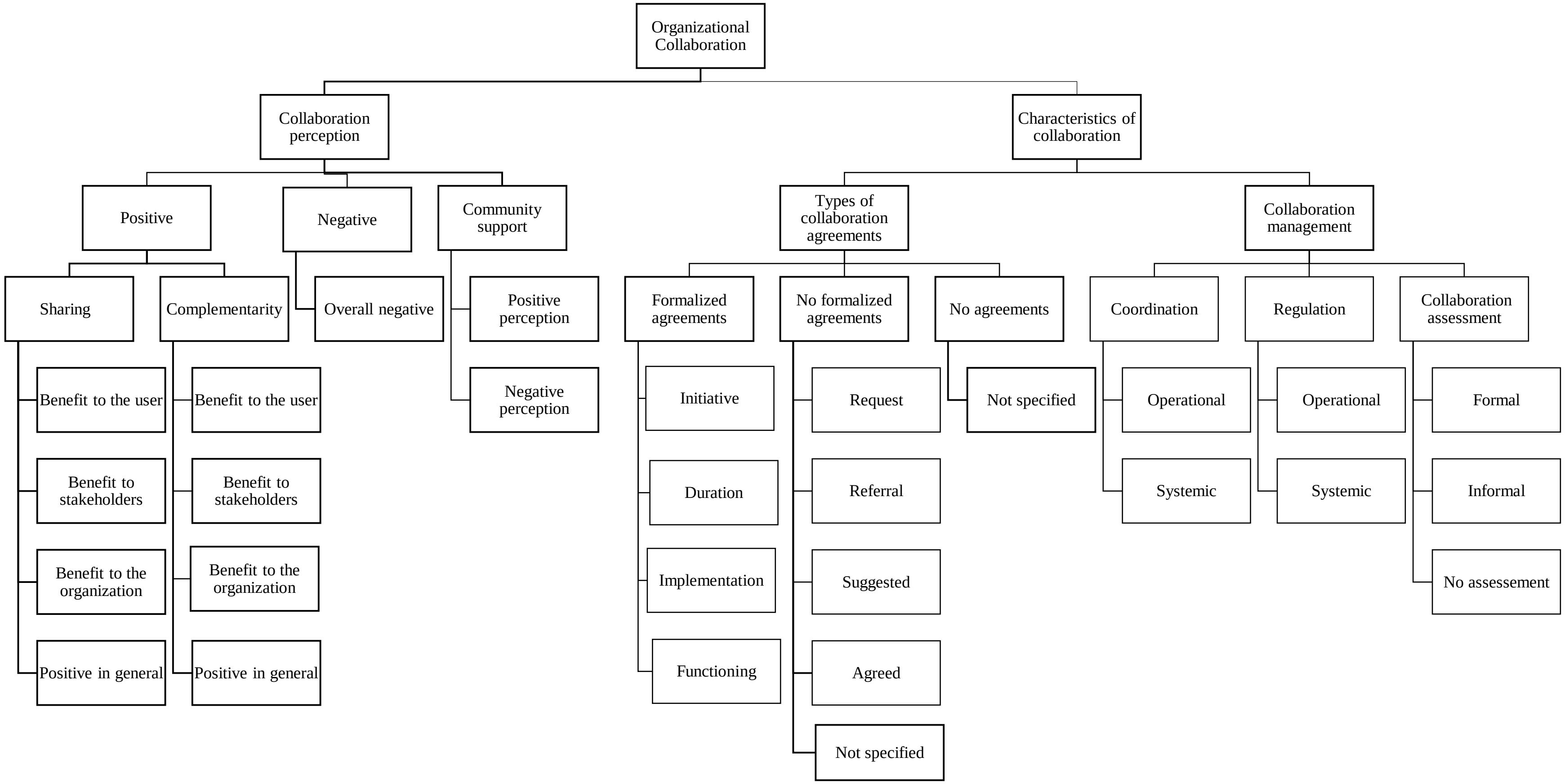


Figure 45. Meso Level and subsequent Organizational Collaboration subcategories system design

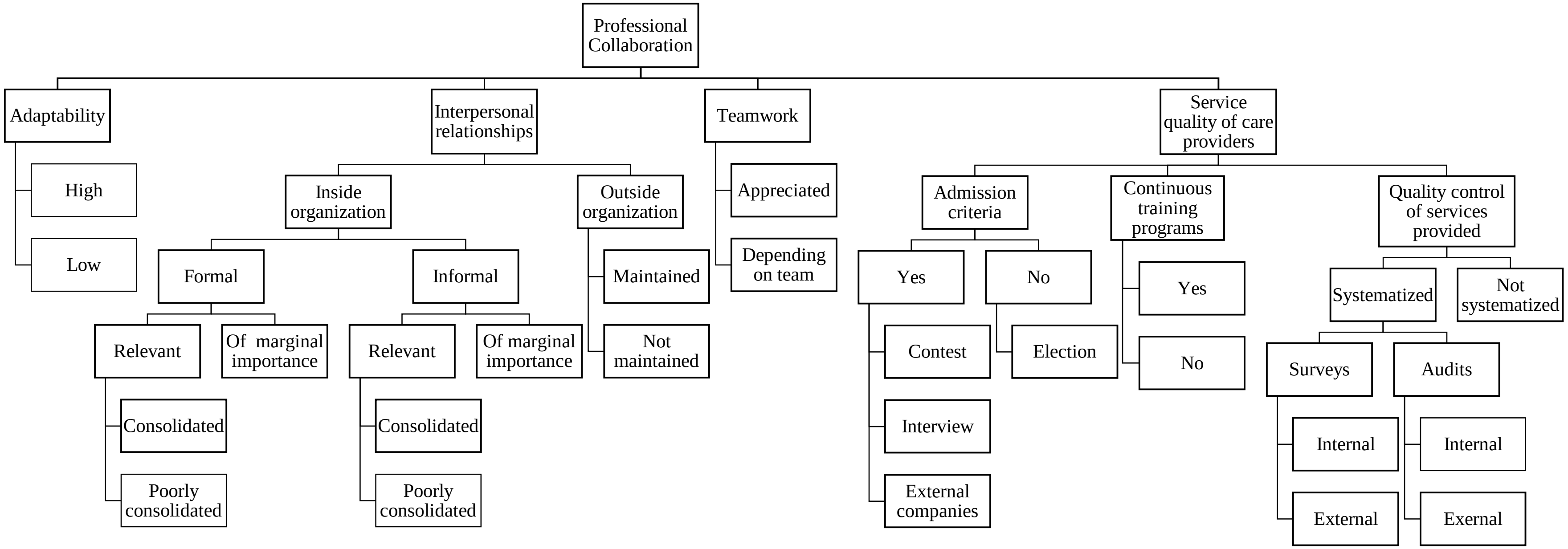


Figure 46. Meso Level and subsequent Professional Collaboration subcategories system design

Table 107 provides an illustration of examples applied within the coding pattern in the Meso Level with adequate citations from interviews with the care providers.

Table 107. An example of the data coding of the categorization matrix template – Meso Level

Meso Level

Organizational Collaboration

Characteristics of collaboration

Collaboration management

Collaboration assessment
Formal
"(...) Evaluation is made on basis of reports from the network; we have a partner-to-partner assessment."
"(...) We evaluated the other side with the filling in of questionnaires etc. and every month we do our statistical survey of what we are doing to know if what we're doing is justified or not."
Informal
"(...) so there's assessment but it is made informally through people's are going performance"
No assessment
"(...) There is no collaboration, no evaluation."

Coordination
Operational
"(...) that's why I advocate that it should be a family doctor because he's someone who receives [a patient] after the hospital for example, forwards to the appropriate services in light of the situation, it seems more logical..."
"(...) without doubt, who coordinates about the person, (...) the institution where you are, the doctor who takes care of (...), it has to be someone who knows you well"
Systemic
"I think that maybe someone from outside would not be bad, someone who would join all care services, would just make an individual plan of that patient and would have a greater perspective of a patient."

Regulation
Operational
"(...) but it will always be the Commander of relief operations who will take the final decision"
Systemic
"(...) some common rules, on the basis of organization"
"(...) There is a design to guide and direct the whole provision of all employees, leaving autonomy and power to each organization".

Types of collaboration agreements

Formalized agreements
"Various."
Functioning
"(...) There is a direct link between the operational part of the fire department and the operational part of the IPSS or an entity to the operationalization of the service."
Implementation
"3 years."
Initiative
"The organization."
External demand
"(...) I would say that the first step was ours; but it was definitely on our side."

No formalized agreements
"No, no, no, no formal.
"No, there are no formal agreements."
Agreed
"(...) Yes, we have agreed entities."
Referral
"There is a protocol to forward."

"There may be some referral." Request *"We provide support that a person requests within the possibilities of the city council."*
No agreements *"(...) contacts with IPSS but very limited to the operationalization"* *"(...) they are left, let's say, to take care of their health care by themselves"*
Collaboration perception
Community support
Negative perception *"It is bad, how the system is still lacking to provide them care they deserve."* *"(...) bad, because actually there is nothing…"* **Positive perception** *"It is good."* *"(...) that generally is good; people are always motivated to help a person with these conditions, because you can tell when people need help, they insist (...)"*
Complementarity Benefit to the user *"(...) is the total benefit to the user"* Benefit to stakeholders *"(...) when rehabilitated is not only to people we serve"* **Sharing** Benefit to the organization *"(...) Need to share some anxieties sometimes, isn't it? Some problems and get help until it is good so do not think that happens only here, but perhaps also happens in another organization, it is a general problem."* Benefit to the user *"The aim is always to improve patient care."* Benefit to stakeholders *"(...) A complementary relationship between what some institutions have and others don't."*

7.2.3. Micro Level

The Micro Level theme was divided into two generic categories – Access to diagnostic information and Integrated care information. As in Macro and Meso Levels, it was decomposed into ensuing categories and subcategories (Figure 47 provides a more comprehensible perspective). The category Access to diagnostic information was split into Access to patient clinical situation when arriving to the institution, Access to the integrated clinical diagnostic information and Position on clinical diagnostic sharing subcategories. The category Available integrated care information was further distributed into Informative, Referenced and Referral subcategories.

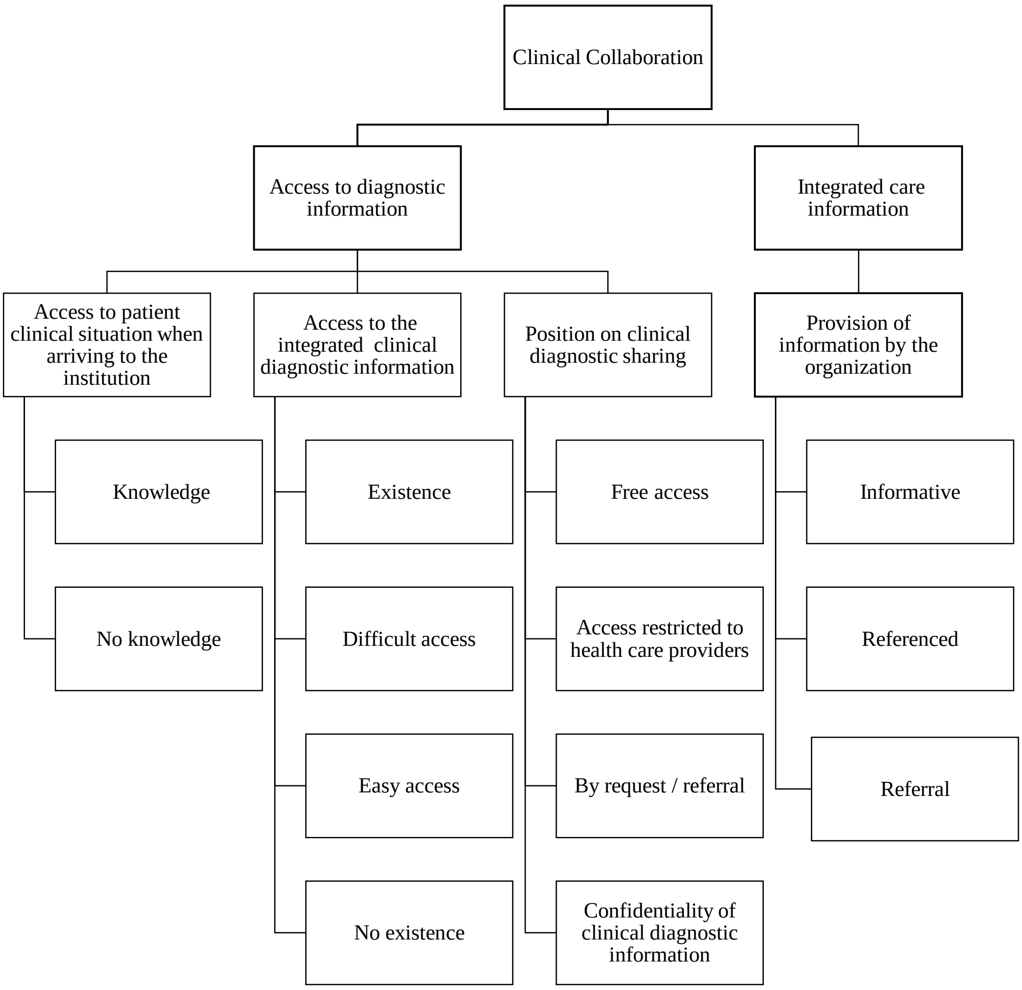


Figure 47. Micro Level and subsequent Clinical Collaboration subcategories system design

Table 108 provides an illustration of examples applied within the coding pattern in the Micro Level with adequate citations from interviews with the care providers.

Table 108. An example of the data coding of the categorization matrix template – Micro Level

Micro Level

Clinical Collaboration

Access to diagnostic information

Access to patient clinical situation when arriving to the institution

No knowledge

"No, when the patient arrives at my institution has the minimal information."

Knowledge

"(...) comes with tests and clinic information"

No existence

"(...) I don't have any information; (...) no, because things are not moving on yet"

Existence

Insufficient

"Yes and no, exists, but are not introduced."

Adequate

"I think that the essential basic information we have received…"

"(...) there is a system that doctors use that is mandatory"

Easy access

"(...) works in Coimbra that receives information, receives a call, the number of the patient, and always keeps in contact with the patient obtaining all necessary information and when the team arrives…"

Difficult access

"(...) this information remains hidden"

Position on clinical diagnostic sharing

Access restricted to health care providers

"(...) between technicians and multidisciplinary teams, sharing of medical information, information from nursing, physiotherapist, psychologist information, without reservations"

Free access

"(...) the patient has to share his life, show the needs; (...) everything what finds relevant, how is treated within the family or in other institutions, so that who is in front knew whether the patient is or not bad"

By request / referral

"No, I don't. Information about the process cannot be disclosed unless by necessity of the transfer from here to another entity, or because the patient will require physiotherapy then yes, then this is external information request".

Provision of information by the organization

Referral

"(...) Yes, we are gradually moving a lot of patients."

Informative

"(...) Yes, we help families to find other solutions if necessary"

"(...) all patients have information about all possibilities; in the middle of hospitalization period we make a point of situation regarding possibilities of remaining in the network and a technical indication, whether or not, to continue"

Referenced

"(...) we give a reference, we give a type of answer, but then we say 'look, just until that time you can make use of that, do it, this can be good for you'

"Yes, there's a list, for example 'If there is a person who needs care but has no transportation, the person goes there (...) and I help in this sense… there is a contact with firemen: "Listen, do you have any free place?", so I avoid the person lose this time. Sometimes we have a list and a contact'."

7.3. Care providers' perceptions of collaboration

The focus of interviews with representatives of the entities identified as providers of care and support for stroke patients was on understanding how care organizations perceive the system and the way they collaborate, and outlining the type of collaboration (if that existed) between them. For that purpose, two different types of matrices were developed in order to demonstrate:

1) Care and support service providers' perceptions on the relationships between organizations in different categories that were identified - collaboration patterns;

2) A comparison between health care service providers and “other” care service providers’ perceptions on collaboration existing between different organizations from different perspectives of assessment.

Information collected within nine interviews was firstly categorized and subsequently analyzed based on the theoretical framework proposed by Valentijn et al. (2013). This allowed to create descriptive summaries of different patterns and levels of collaborative relationships between the organizations and to understand perceptions of the interviewed care service providers about currently existing collaborative linkages in the care sector, their characteristics, advantages and disadvantages as seen by them.

The presentation of the results begins with the Macro Level - the system characteristics, followed by the presentation of the Meso attributes, related to collaboration between organizations and care professionals. Lastly, the position toward collaboration from the Micro Level perspective is provided, which focuses primarily on patient clinical diagnosis level of collaboration.

7.3.1. Macro Level

Table 109 presents results of the applied categorization system together with the frequencies of responses identified during interviews with representatives of the entities at the subcategory level. Perceptions of different service providers about System Integration with reference to organizational collaboration in the Macro Level approach are summarized. System Integration concerns legislation, incentives and funding regarding provided services and collaboration between organizations.

Table 109. Macro Level and System Integration – frequency table

Theme	Generic category	Category	Subcategory 1	Frequency
Macro Level	**System Integration**	Knowledge of legislation	Yes	3
			No	6
		Legal information available	Positive perception	2
			Negative perception	7
		State incentives for interorganizational collaboration	Positive perception	3
			Negative perception	6
		Funding for services provided	Public	7
			Private	2
			Based on income	2

Most of the interviewed care service providers did not have knowledge of legislation stipulating rules of collaboration between organizations and had a negative perception of the available legal information, e.g. *"insufficient, very incomplete"*. A greater part of service providers had a negative perception of the State incentives for organizations collaboration, e.g. *"no, no rewards"*, however, public sources were pointed out as funding for care services most times when multiple response options were allowed. Figure 48 presents the distribution of responses within the System Integration generic category.

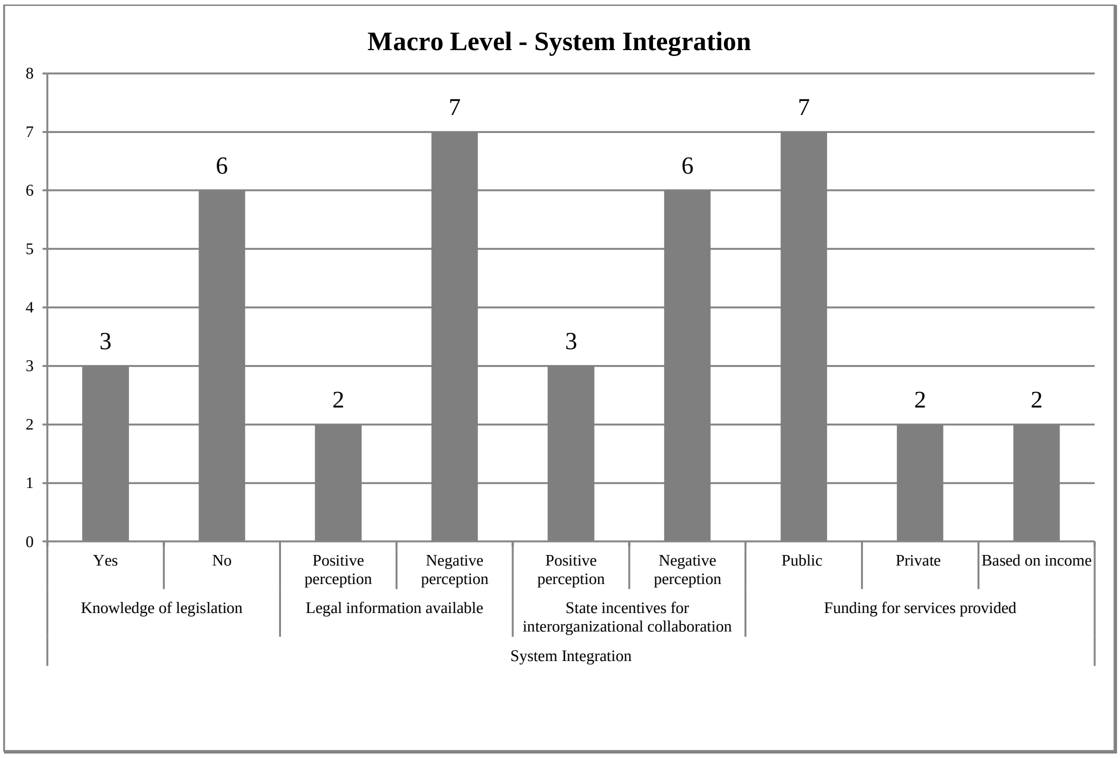


Figure 48. Macro Level and System Integration distribution of responses

7.3.2. Meso Level

Meso Level relates to perceptions of care entities concerning collaboration as a linked-up service provided approach. This main theme is divided into two generic categories – Organizational Collaboration and Professional Collaboration. The results of main categories are first presented separately and combined in the final phase in order to facilitate the understanding of overall outcome of content analysis.

7.3.2.1. Meso Level - Organizational Collaboration

A low number of interviewees had a negative perception of collaboration between organizations. Appointed reasons were related to a waste of time or different performance and commitment provided by different networked organizations, e.g. *"Our time and effort if the others don't have as much commitment and dedication as we do"*. Concerning support given by the community as an interconnection path between entities, a larger part of respondents considered it as positive, e.g. *"(...) the person in question is the user and not the client, he should always win; the goal is to give suitable responses so that he felt well-being; we all must move toward that"*. Table 110 presents perceptions of care service providers of collaboration as an incorporated service of care and Figure 49 provides the distribution of responses on collaboration perception.

Table 110. Meso Level and Organizational Collaboration – Collaboration perception – frequency table

Theme	Generic category	Category	Sub-category 1	Subcategory 2	Subcategory 3	Frequency
Meso Level	**Organizational Collaboration**	Collaboration perception	Positive	Sharing	Positive in general	1
					Benefit to the user	4
					Benefit to the organization	2
					Benefit to stakeholders	2
				Complementarity	Positive in general	0
					Benefit to the user	3
					Benefit to the organization	0
					Benefit to stakeholders	2
			Negative		Overall negative	2
			Community support	Positive perception		6
				Negative perception		3

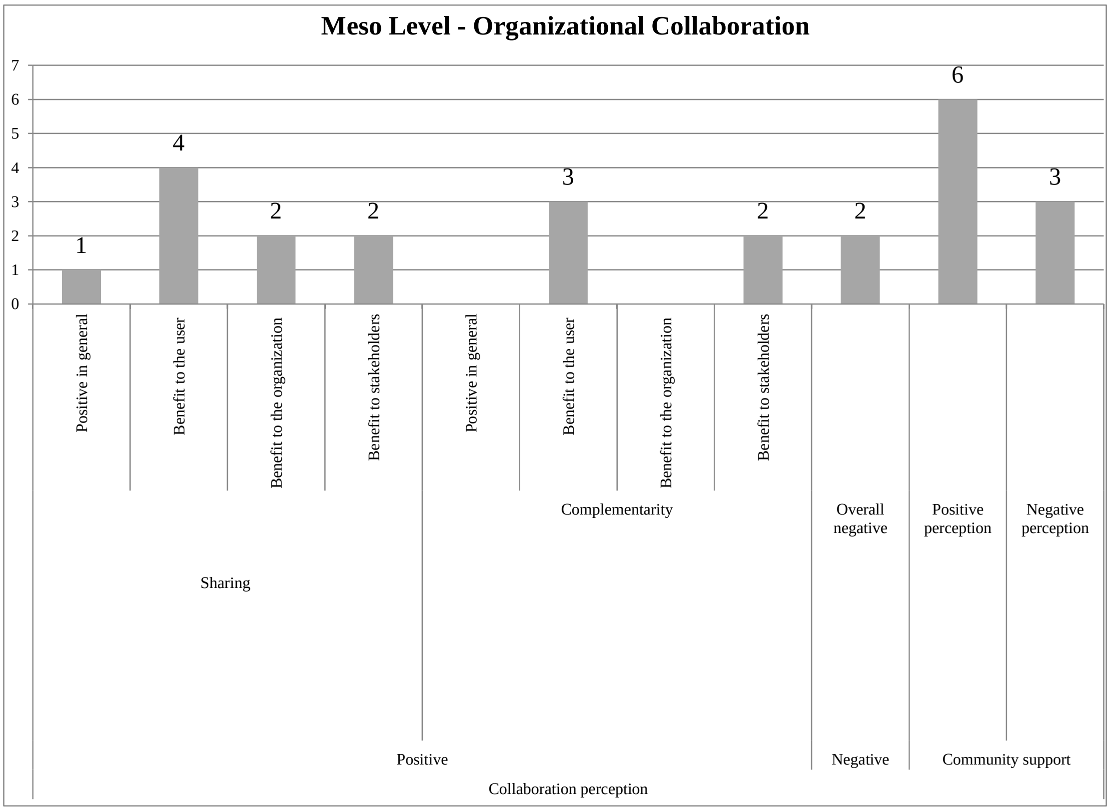


Figure 49. Meso Level and Organizational Collaboration - Collaboration perception

Table 111 refers to perceptions of care service providers about characteristics associated to collaboration. Majority of interviewees believed that collaboration between the organizations was established on informal basis and on such was functioning, e.g. *"No, no, we do not have formal partnership with (...), it is informal"*. Perhaps this is the reason for which most entities did not have a formal collaboration assessment system, e.g. *"so there's assessment but it is made informally through people's performance".* In respect to collaboration management process, most respondents did not have a systemic vision of services coordination between cooperating organizations. However, it is by services providers that the rules need to be commonly established, shared and respected in practice, e.g. *"some common rules, on the basis of organization"*. Figure 50 provides the distribution of the responses regarding characteristics of collaboration as perceived by the interviewees.

Table 111. Meso Level and Organizational Collaboration – Characteristics of collaboration - frequency table

Theme	Generic category	Category	Subcategory 1	Subcategory 2	Subcategory 3	Sub-category 4	Freq.
Meso Level	**Organizational Collaboration**	Characteristics of collaboration	Type of collaboration agreements	Formalized agreements	Initiative	From organization	1
						External demand	0
					Duration	3 years	1
					Implementation	Easy	1
						Hard	0
					Functioning		1
				No formalized agreements	Not specified		7
					Referral		4
					Request		1
					Suggested		0
					Agreed		1
				No agreements	Not specified		2
			Collaboration management	Coordination	Operational		5
					Systemic		4
				Regulation	Operational		1
					Systemic		6
				Collaboration assessment	Formal		3
					Informal		1
					No assessment		6

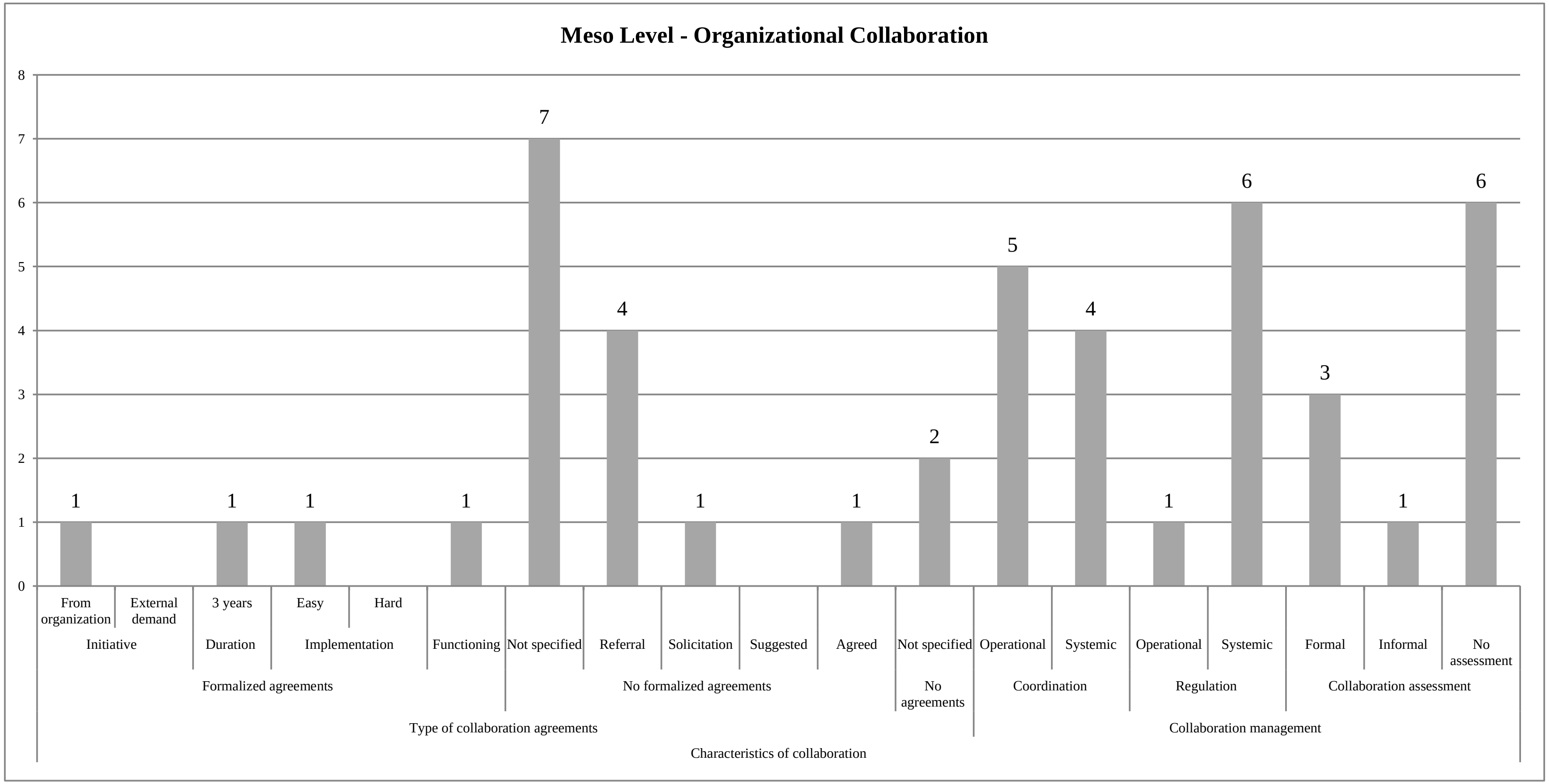


Figure 50. Meso Level and Organizational Collaboration - Characteristics of collaboration

7.3.2.2. Meso Level - Professional Collaboration

The distribution of responses in the Professional Collaboration generic category is presented within the Meso Level theme (Table 112). A disagreement in the perception of adaptability of service providers toward different functions was clearly visible. About half of the interviewees had opposite opinions in comparion to the other half, e.g. *“changes are always difficult, there's always resistance when there is a change”*; *“overall, it has to be, like I was saying I'm taking care of a baby of 6 months, later I'm dealing with sportsmen (...) they are completely flexible”*.

Respondents could evaluate relations within their organizations with multiple responses available. Formal relations appeared to be relevant and consolidated by almost half of them and informal were found pertinent by most care service providers taking part in the study. Figure 51 is a graphical demonstration of the responses concerning professional collaboration.

Table 112. Meso Level and Professional Collaboration - frequency table

Theme	Generic Category	Category	Subcategory 1	Subcategory 2	Subcategory 3	Frequency
Meso Level	**Professional Collaboration**	Adaptability	High			5
			Low			4
		Interpersonal relationships	Inside the organization	Formal	Poorly consolidated	0
					Relevant	4
					Of marginal importance	0
					Consolidated	4
				Informal	Poorly consolidated	0
					Relevant	8
					Of marginal importance	1
					Consolidated	1
			Outside the organization	Maintained		8
				Not maintained		1
		Teamwork	Appreciated			7
			Depending on team			1

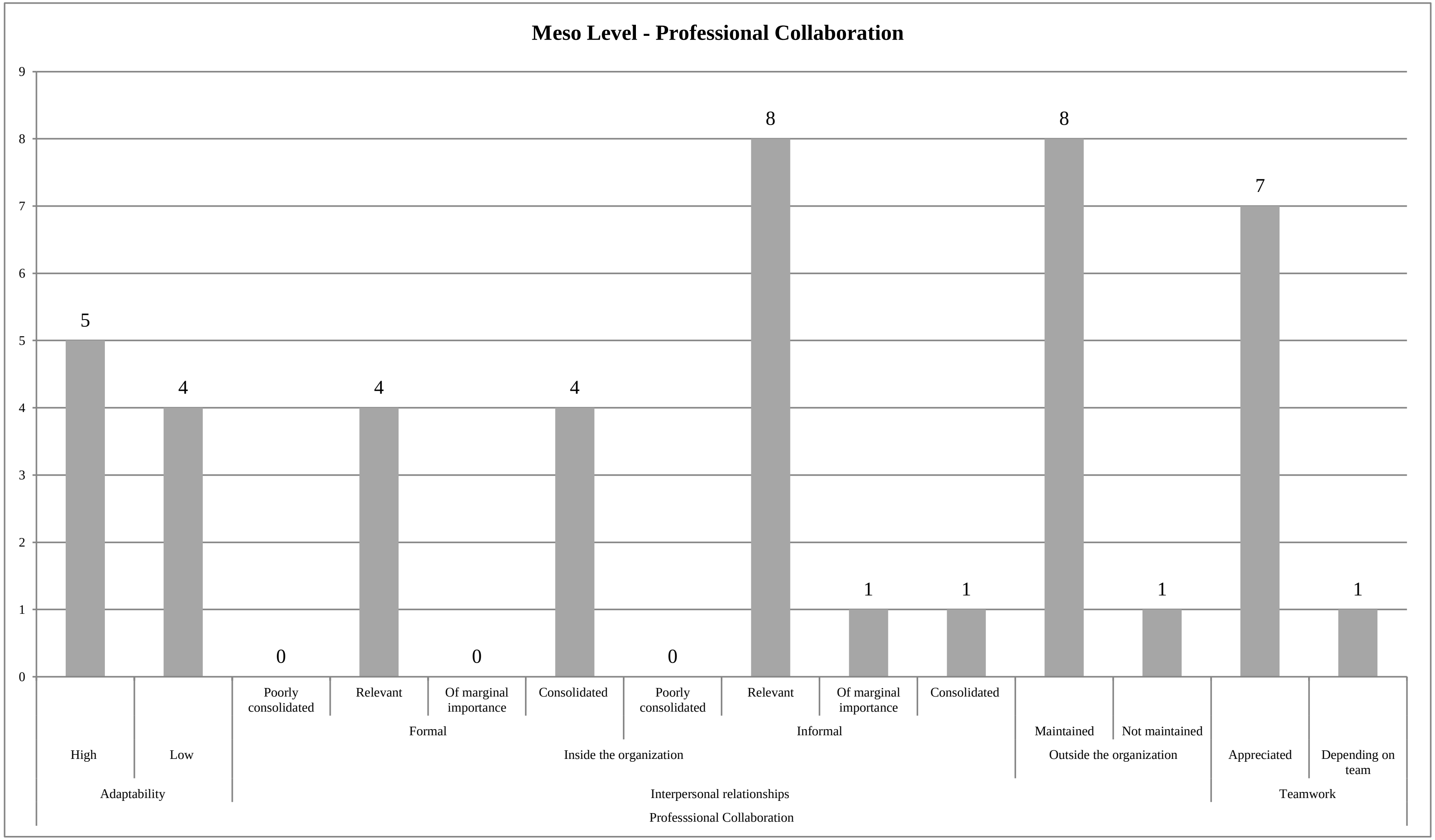


Figure 51. Meso Level and Professional Collaboration - Interpersonal relationships

The Service quality of care providers category was divided into Admission criteria, Continuous training programs and Quality control of services provided subcategories. The frequencies of responses are presented in Table 113. Responses gathered from interviews again do not sum up in some cases to nine as multiple options could have been poined out. Most of the organizations participating in this study admitted to practice admission criteria for the recruitment, e.g. *"responds to a given number of objectives"* and continuous training programs, e.g. *"continuing training is generalized to all"*. Quality control of delivered services was managed by different strategies. Some entities did not have a systematic quality control system, illustrated by a simple response by one of the interviewees: *"not systematized"*, while others had such a system by means of surveys or audits, whether internal or external, e.g. *"We do audits"*; *"No, our surveys are made to all patients who leave - they receive a satisfaction survey"*. Figure 52 portrays the distribution of responses gathered within the category Service quality of care providers.

Table 113. Meso Level and Professional Collaboration - Service quality of care providers – frequency table

Theme	**Generic category**	**Category**	**Sub-category 1**	**Subcategory 2**	**Sub-category 3**	**Sub-category 4**	**Frequency**
Meso Level	**Professional Collaboration**	Service quality of care providers	Admission criteria	Yes	Not specified		7
					Contest		3
					Interview		1
					External companies		1
				No	Not specified		2
					Election		1
			Continuous training programs	Yes			6
				No			2
			Quality control of services provided	Systematized	Surveys	Internal	2
						External	0
					Audits	Internal	3
						External	1
				Not systematized			3

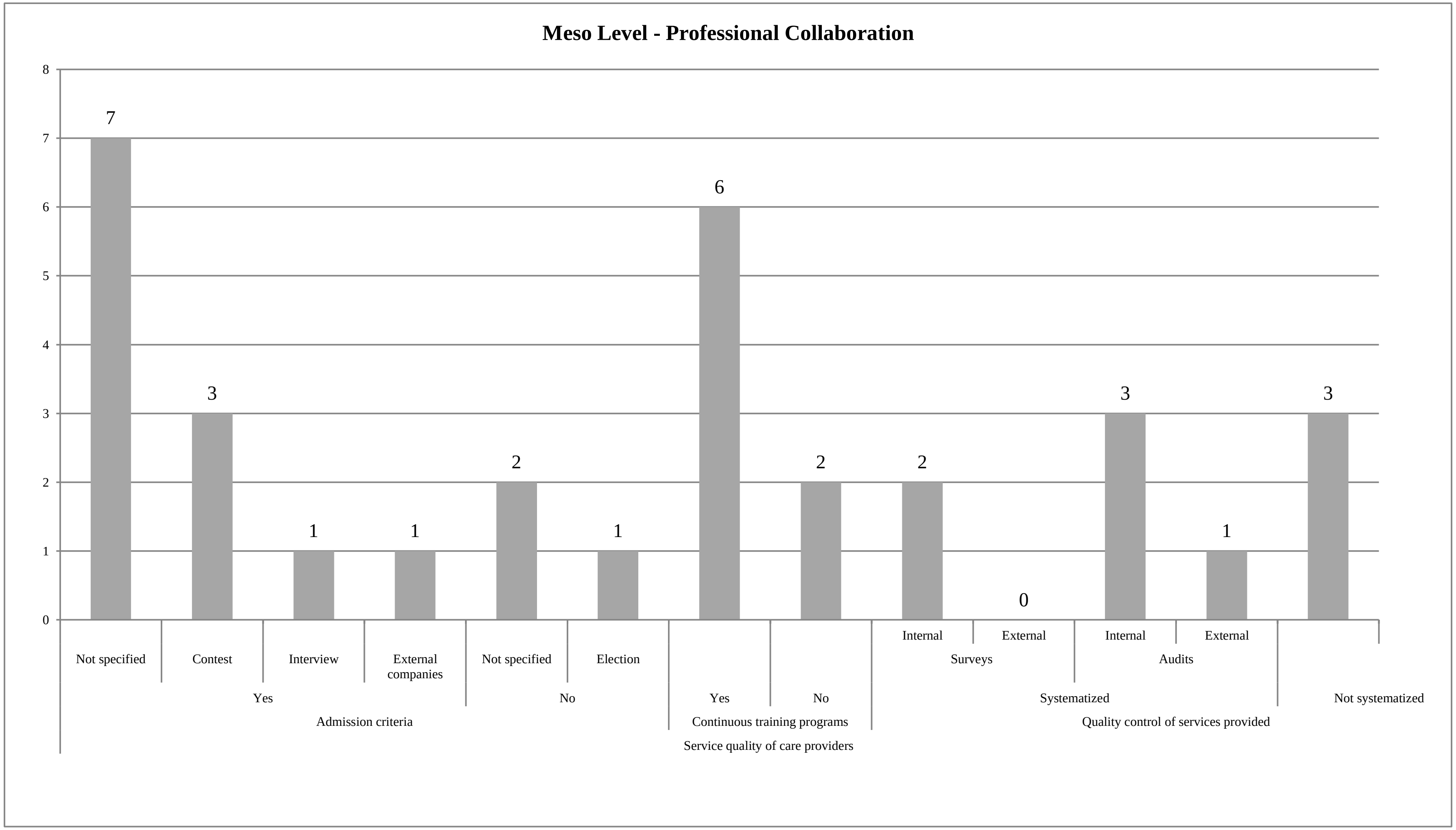


Figure 52. Meso Level and Professional Collaboration - Service quality of care providers

7.3.3. Micro Level

The Micro Level theme and the Clinical Collaboration generic category were divided into Access to diagnostic information and Integrated care information categories. A perception of an access to patient clinical situation when that arrives to an entity in question was positive in slightly more than a half of representatives of participating organizations, e.g. *“so all information is available to the team when you're moving to the location”*. More than a half of care service providers considered that access to patient clinical diagnostic should be restricted to health care professionals, e.g. *“between technicians and multidisciplinary teams, sharing of medical information, information from nursing, physiotherapist, psychologist information, without reservations”* and all of interviewees had the same vision about the importance of confidentiality of clinical diagnostic information when sharing it between organizations. Frequencies of responses gathered within the Clinical Collaboration categorical system are provided in Table 114, while Figure 53 presents the distribution of responses in a graphical format.

Table 114. Micro Level and Clinical Collaboration – frequency table

Theme	**Generic category**	**Category**	**Subcategory 1**	**Subcategory 2**	**Sub-category 3**	**Frequency**
Micro Level	**Clinical Collaboration**	Access to diagnostic information	Access to patient clinical situation when arriving to the institution	Knowledge		5
				No knowledge		4
			Access to integrated clinical diagnostic information	Existence	Adequate	3
					Insufficient	3
				No existence		3
				Easy access		1
				Difficult access		6
			Position on clinical diagnostic sharing	Free access		2
				Access restricted to health care providers		6
				By request / referral		1
				Confidentiality of clinical diagnostic information		9
		Integrated care information	Provision of information by the organization	Informative		4
				Referenced		1
				Referral		3

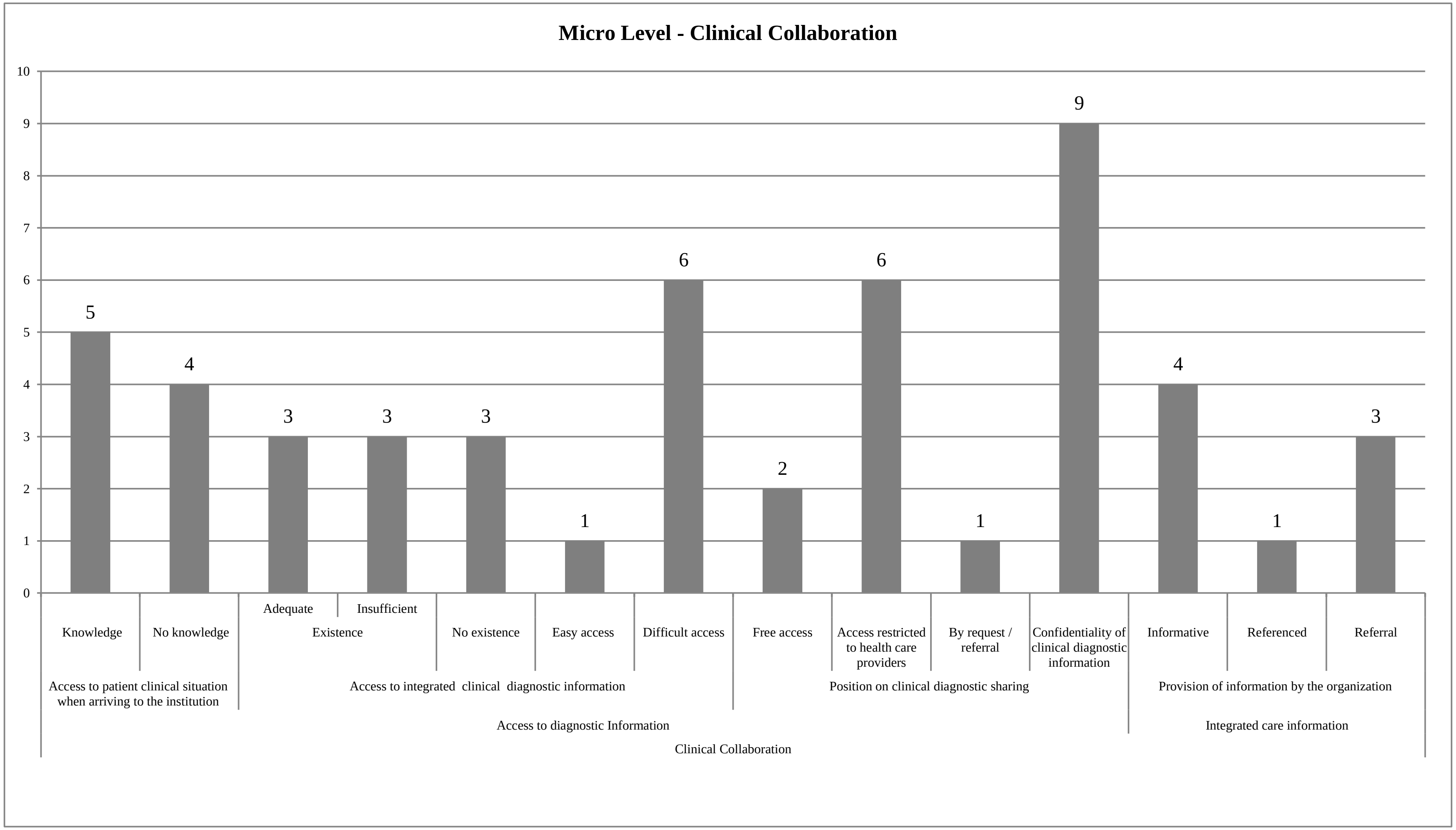


Figure 53. Micro Level and Clinical Collaboration

7.4. Appraisal of collaboration from health and not directly health care-related providers – a comparison study

This part of the work brings findings of the analysis of perceptions and opinions of health and not directly health-related service providers that sprang from interviews with their representatives.

A rehabilitation unit, a hospital, a health center and a physiotherapy clinic were considered as health care services organizations. A fire department, a charitable organization, a Private Institution of Social Solidarity, a city council and a parish council were considered as “other” care service providers. Since multiple responses were allowed for the analysis, it was performed comparing weights within a given group.

The first table summarizes an overview of the comparison between health care and “other” care service providers in a relation to the Macro Level, followed by a review of the Meso and the Micro Levels.

7.4.1. Macro Level

There were evident differences in some subcategories (Figure 54). All respondents constituting the “other” services providers group, which might provide possible care and assistance not directly related to health care to stroke patients, had no knowledge about legislation stipulating collaboration between organizations and had a negative perception of the legislation currently in force. Conversely, most of the health care service providers were aware of the legislation, and opinions were divided as to the subject of availability of legal information. In what concerned the State incentives for interorganizational collaboration, the health care providers had a better opinion than the “other” care service providers in this respect. However respondents of both groups considered that a greater investment for care services provision for the population was provided from public funds.

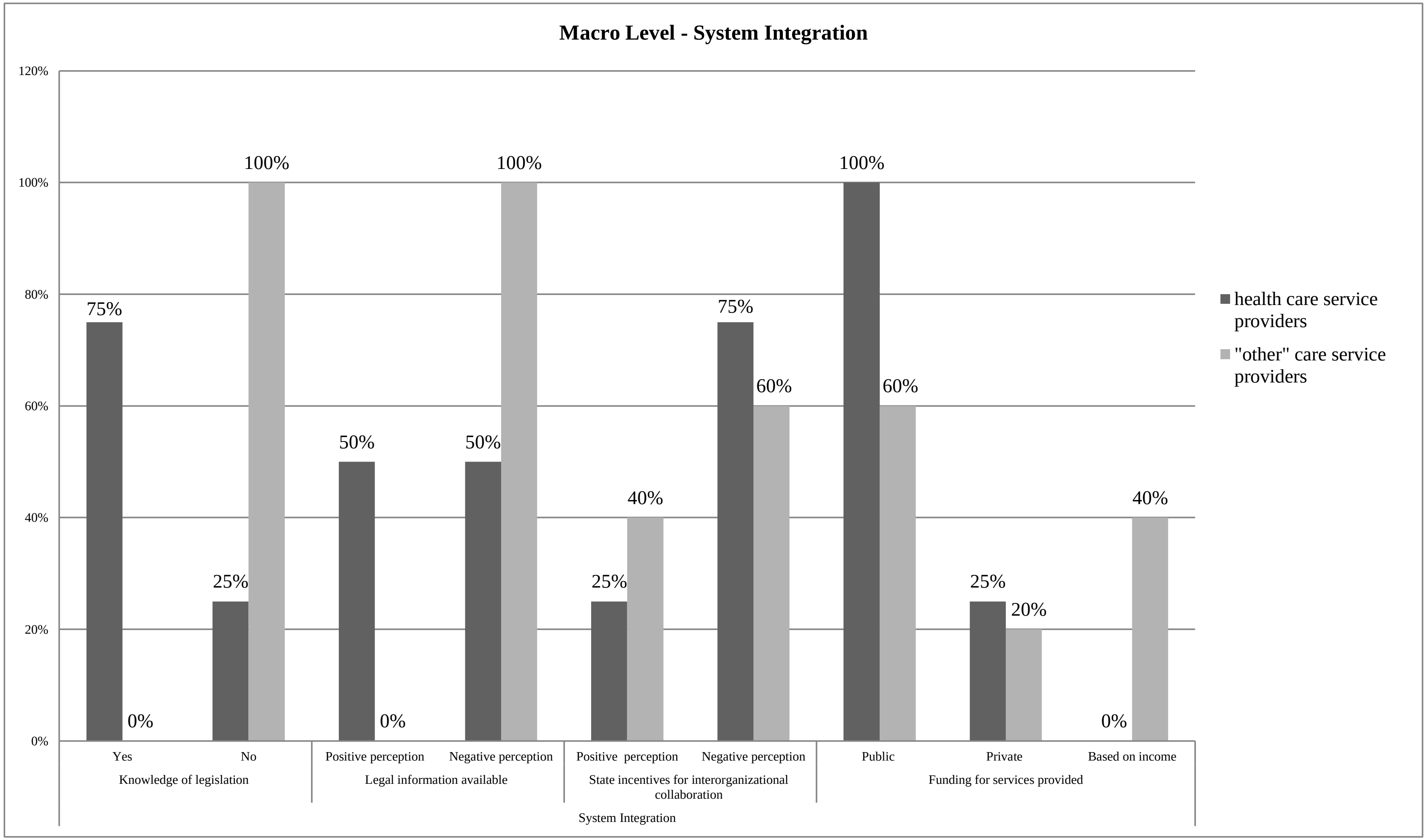


Figure 54. Macro Level and System Integration

7.4.2. Meso Level

Concerning perceptions on collaboration, it was found out that most respondents regarded the idea of collaboration between organizations as positive. There were no remarkable differences between the health care service providers and the “other” service providers. The main dissimilarity resided in the fact that the group of the health care service providers deemed the biggest benefit for users (whether it was a benefit by sharing or through complementarily) and in the opinion of the “other” service providers that benefit was distributed among users, the proper organization and stakeholders. The community as a support group had a more positive than negative opinion from both groups. Figure 55 presents the perceptions on collaboration identified during interviews.

Regarding characteristics of collaboration, in both groups the majority of respondents considered that when relationships between entities existed in practice, not formalized contract supported their bases (Figure 56). However, when considering existence or no existence of collaboration, about a half of interviewed key informants from the health care service providers believed that there were no collaborative agreements between their institution and other organizations.

Opinions gathered from the health care service providers and the “other” service providers regarding coordination of an eventual partnership agreeement. While the health care service providers assigned the responsibility of coordination to an operational level, the “other” care service providers considered that coordination of collaborations should be held through the systemic approach. Perceptions reversed entirely when it came to the Regulation subcategory where all health care service providers confirmed that this sphere should be managed at the systemic level. In the Evaluation subcategory, responses of the health care service providers were distributed likewise, between the Formal and No assessment subcategories, while the majority of the “other” care service providers considered that collaboration effort assessment simply did not exist in their institution.

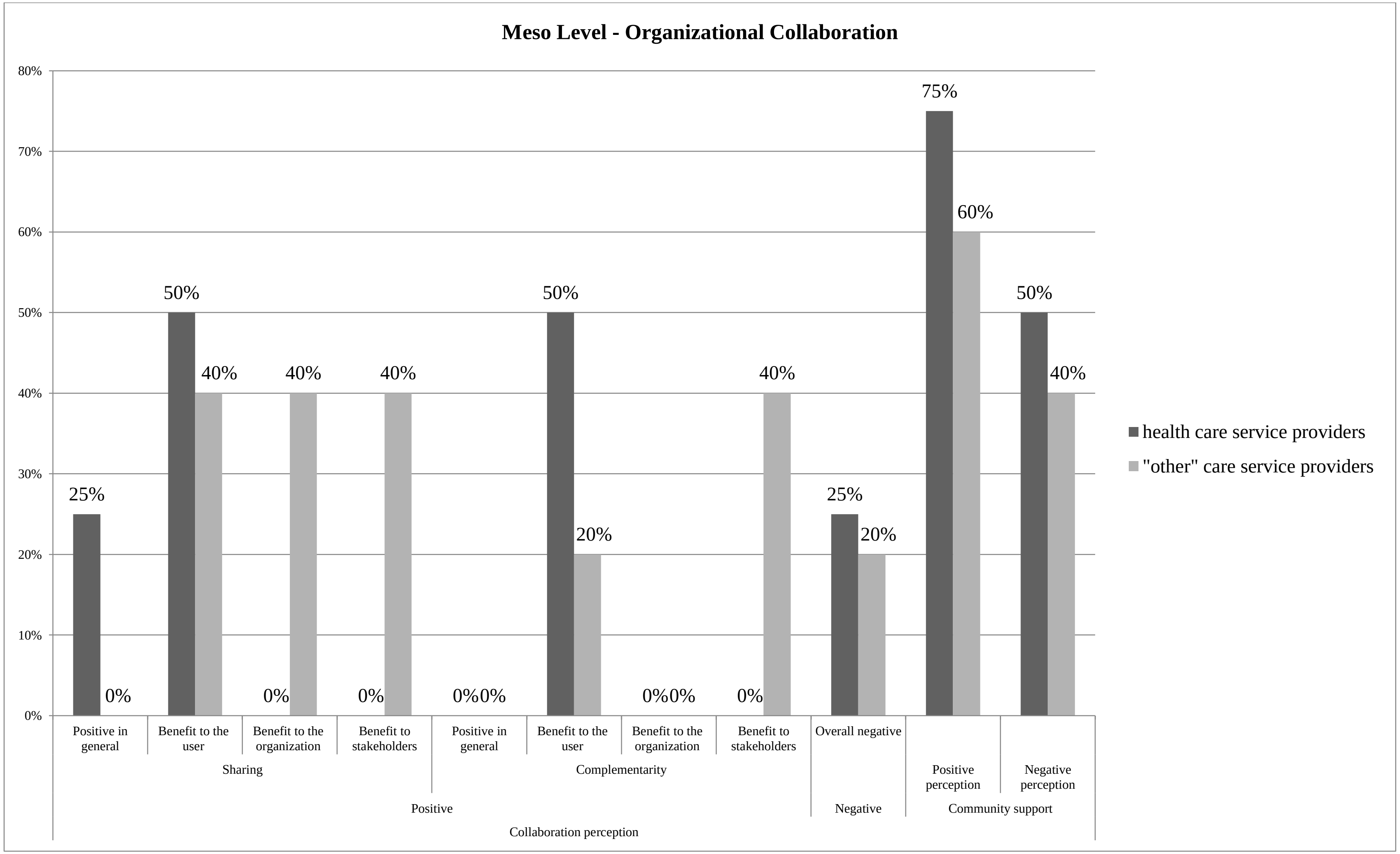


Figure 55. Meso Level and Organizational Collaboration - Collaboration perception

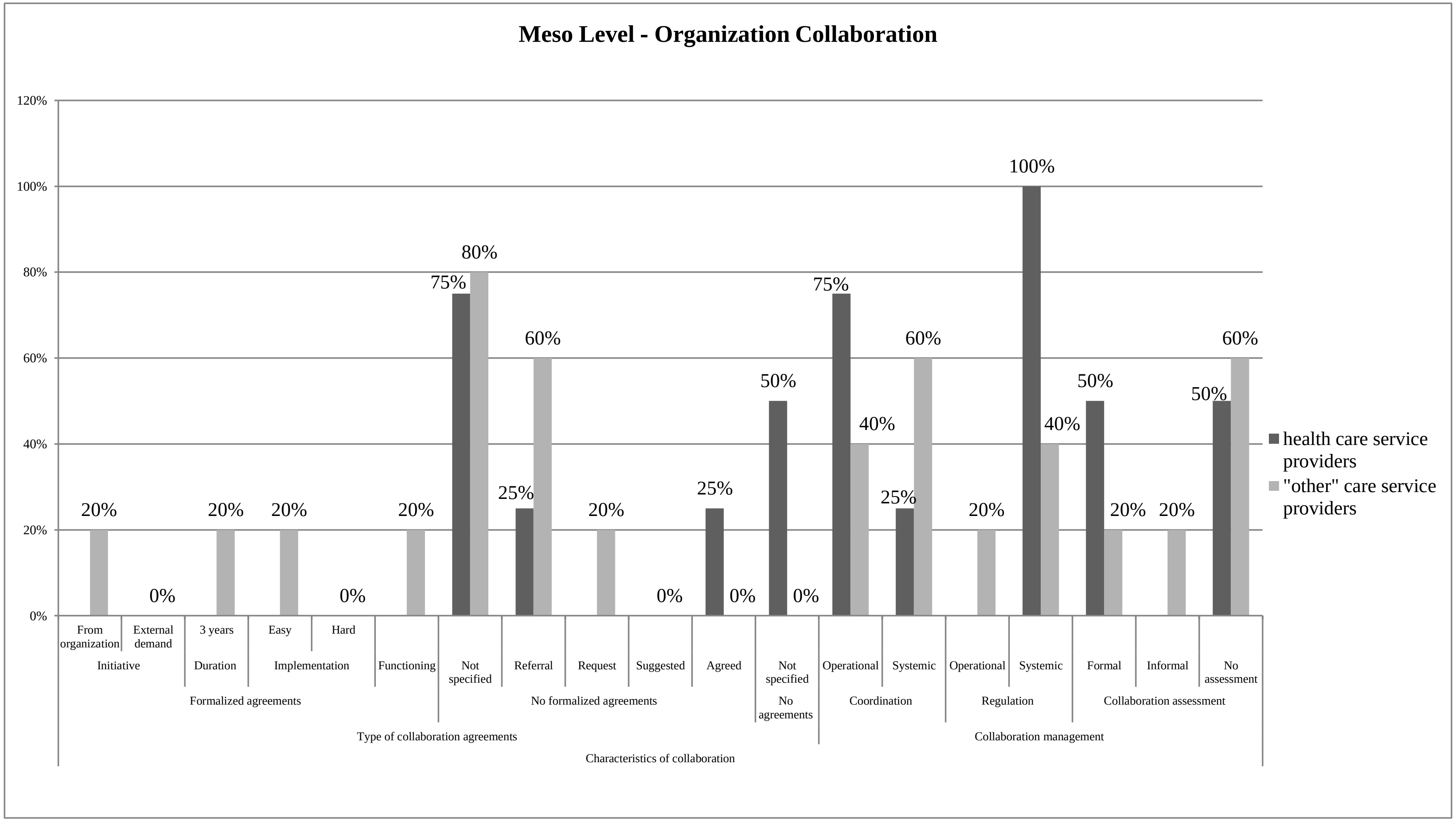


Figure 56. Meso Level and Organizational Collaboration - Characteristics of collaboration

In the interview, the “other” care service providers deemed themselves adaptable to different functions, slightly more than the representatives of the health sector. A half of the health care service providers considered their entity flexible while the other half considered there was a low level of adaptability between functions in their organization.

About interpersonal relationships within the Professional collaboration subcategory, it was found out that more than a half of the respondents from the group “other” care service providers attributed a greater relevance to formal relations in their organization. Informal contacts seemed to play somewhat more important role in health-related entities comparing to the “others”. In both groups, the interpersonal relationships were maintained outside the organization, with 100% health care service providers. Teamwork was definitely appreciated by both groups, however a slightly higher relevance was given to that factor by the “other” care service providers. Figure 57 presents the distribution of the answers in the category Interpersonal relationships.

Not much divergence was identified between the answers gathered from the health care service providers and the “other” services providers regarding the admission criteria in their organization. Both groups reported that the criterion or criteria in their entity existed, yet of different types. Continuous training programs were employed more in health than in not health-related service providing entity but the trend was positive as 75% of the first admitted having knowledge of their application by their organization. As for the quality control of provided services in the institutions, about a half of the organizations where the health care service providers were incorporated, a systematic control system existed, while in the organizations representing “other” care service providers, the assessment was not systematized. Figure 58 provides the distribution of responses in the category of Service quality of care providers.

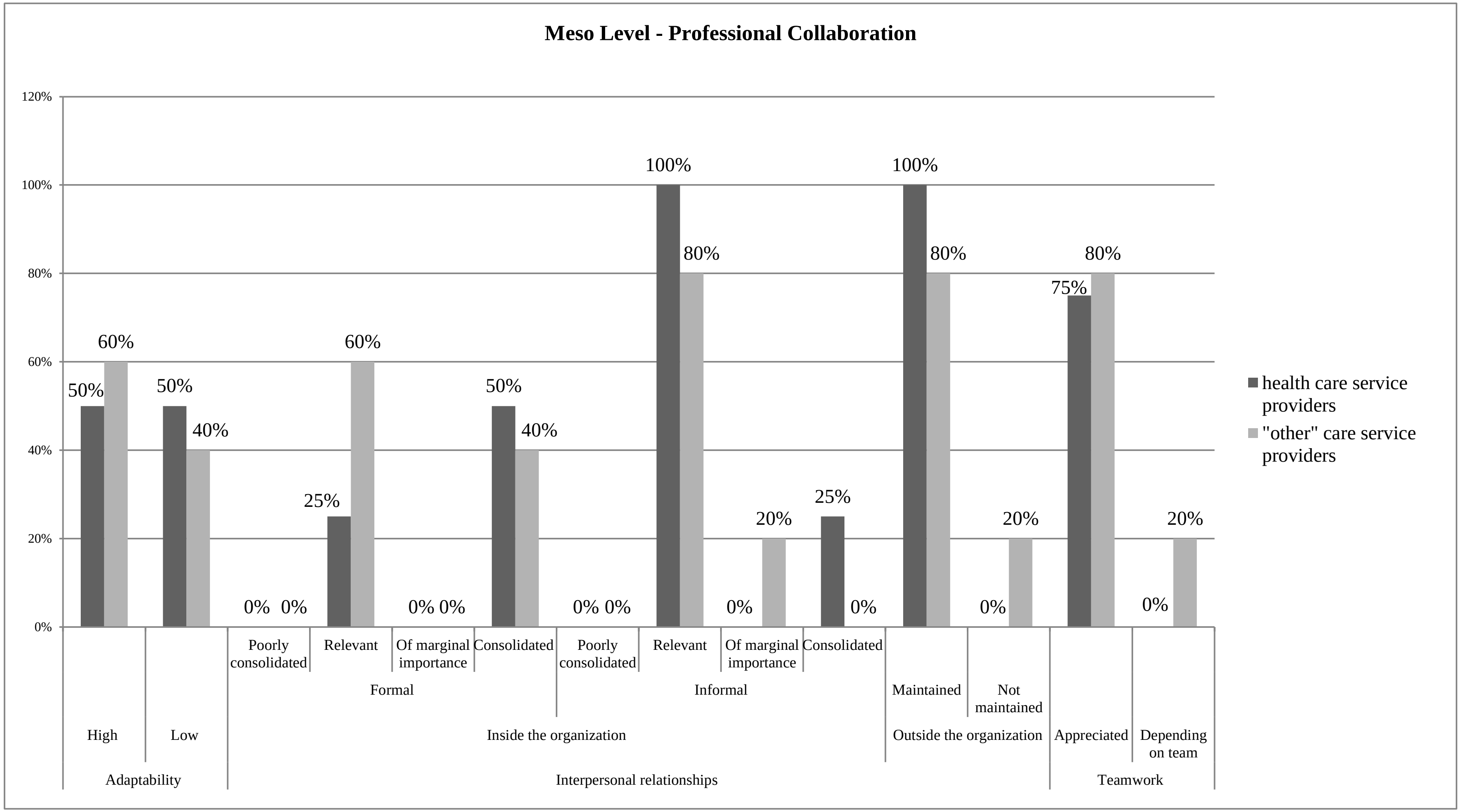


Figure 57. Meso Level and Professional Collaboration – Interpersonal relationships

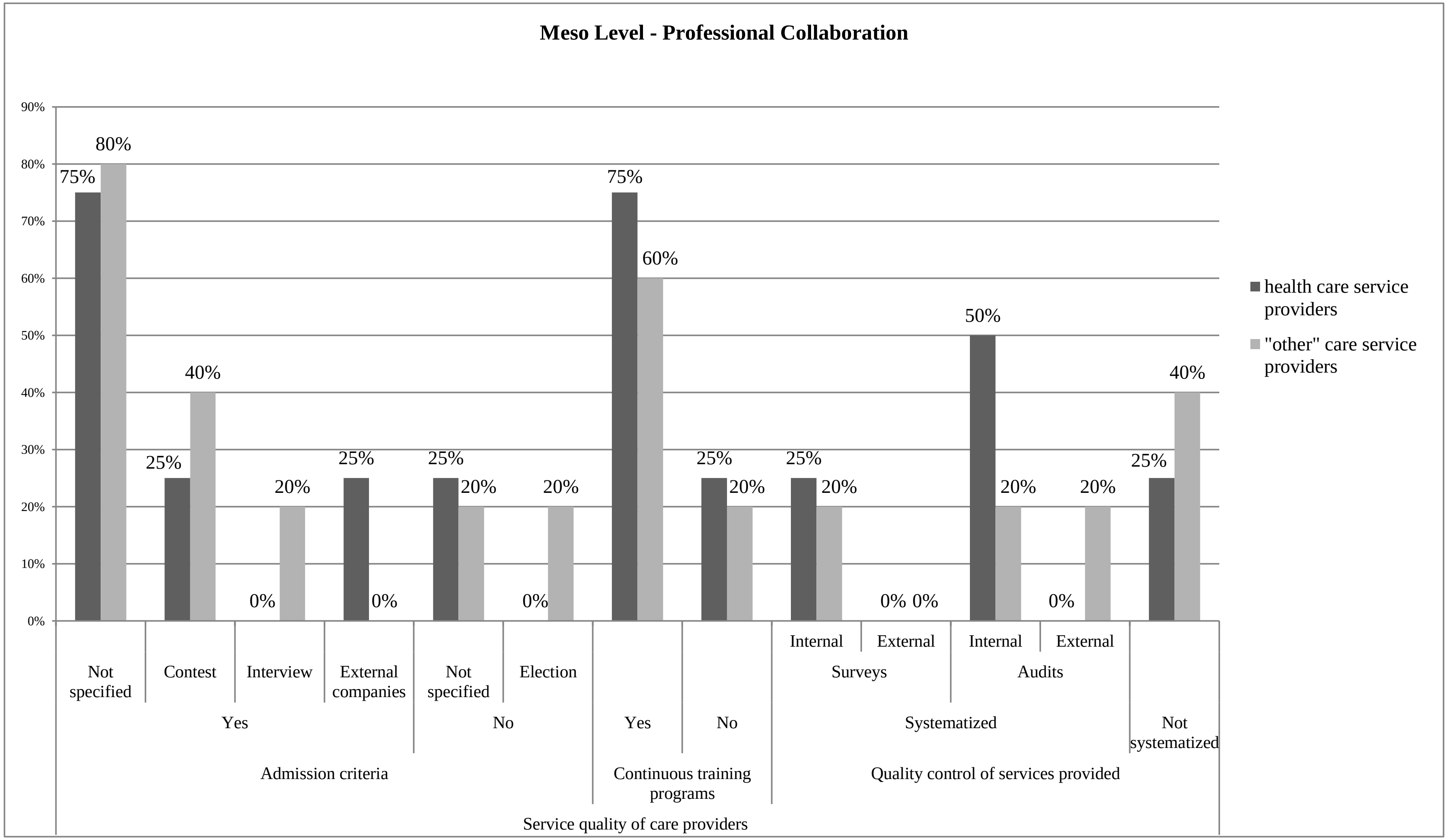


Figure 58. Meso Level and Professional Collaboration - Service quality of care providers

7.4.3. Micro Level

When compared with answers given by the “other” service providers, the health care service providers had better access to information relative to patient clinical situation when patients arrived to the institution in cause. While in case of the health care service providers some access to integrated information about the clinical diagnosis of a patient effectively existed, a half considered existing integrated care information insufficient, while 40% of the interviewed “other” care service providers claimed it was suitable for carrying out their functions. Yet, the same numer there was no access to integrated patient clinical diagnosis. Interestingly, all health care service providers found the access to integrated clinical diagnostic information difficult compared to 40% “other” care service providers.

Regarding the position on clinical diagnostic sharing, every health care service provider believed that clinical diagnosis of a patient should be restricted to health care providers, while the “other” care service providers said it should be either free, restricted to health care service providers or possible by request/referral. Both groups unanimously affirmed that confidentiality of patient clinical diagnosis information had to be ensured and shared with prudence between different institutions.

Considering provision of integrated care information by the organization, health care service providers claimed it was of informative type and as referrals, and “other” care service providers would rather provide referrals, information and reference to their users.

Figure 59 presents the distribution of the responses regarding this matter.

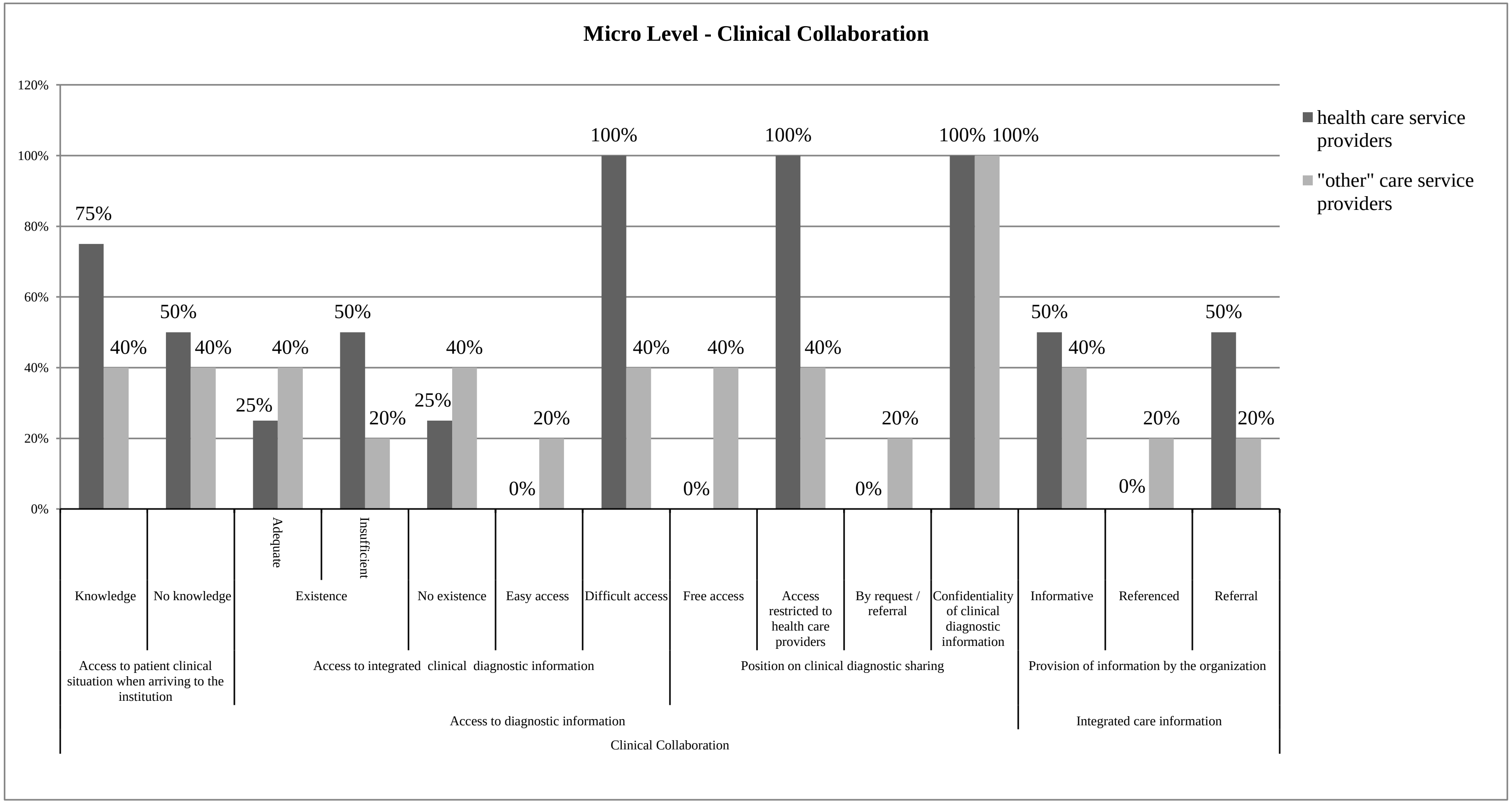


Figure 59. Micro Level and Clinical Collaboration

7.5. Collaboration intensity between care and support providers for stroke patients

The analysis was performed on the database consisting of 509 vertices (nodes) representing all entities effectively providing support and assistance to stroke patients in the district of Aveiro effectively contacted between March and July 2014. For all identified relationships, the analysis indicated 58 559 edges that connected the vertices.

Key graphmetrics, which represent all relationships of the strength from 1 to 5, are provided in Table 115.

Table 115. Graph metrics for the global structure of collaboration between providers of care and support for stroke patients

Graph Metric	Value
Graph Type	Directed
Vertices	509
Unique Edges	100949
Edges With Duplicates	0
Total Edges	100949
Self-Loops	0
Reciprocated Vertex Pair Ratio	0.235605875
Reciprocated Edge Ratio	0.381360885
Connected Components	1
Single-Vertex Connected Components	0
Maximum Vertices in a Connected Component	509
Maximum Edges in a Connected Component	100949
Maximum Geodesic Distance (Diameter)	3
Average Geodesic Distance	1.365388
Graph Density	0.390409634

Overall graph metrics are presented with the use of graphical means, typically employed in this case as they are a clear and simple form to demonstrate required graph characteristics (see Figures 60 to 65).

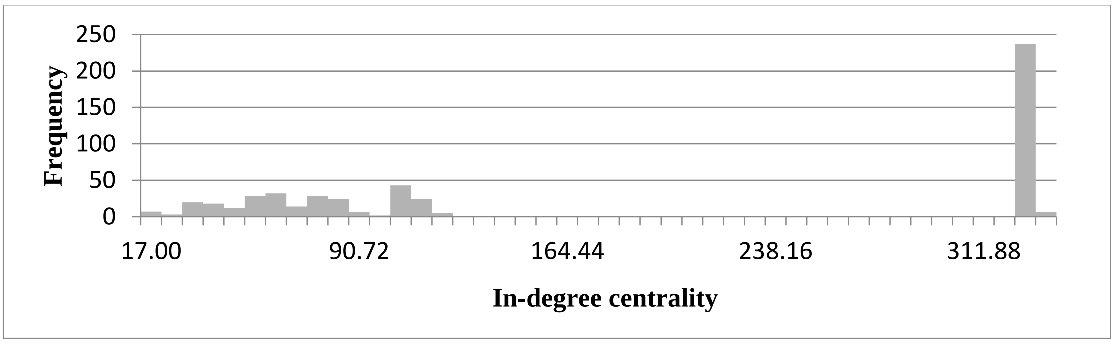


Figure 60. In-degree centrality of global collaboration between care providers for stroke patients

The minimum number of connections to a vertex was 17 and the maximum 334. The average in-degree centrality was 198.33 and median was 115.00.

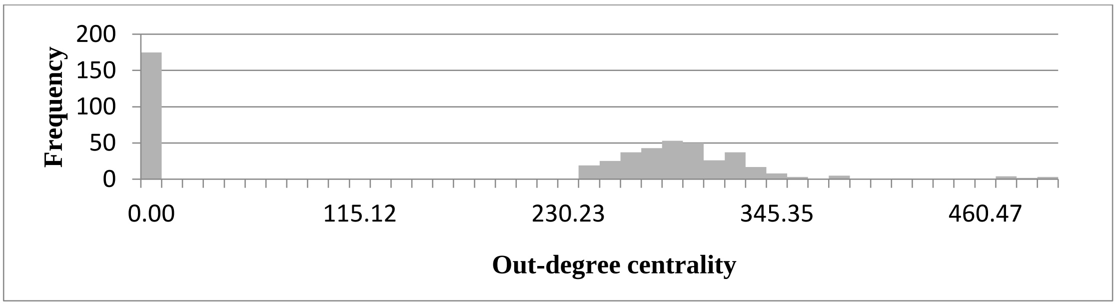


Figure 61. Out-degree centrality of global collaboration between care providers for stroke patients

The minimum observed number of ties directed to other vertices in the network was 0 (there were around 175 institutions, as it can be seen in Figure 61, which did not contact any other institution in the network) and the maximum was 495. The average out-degree was 198.33 and median out-degree was 275.00.

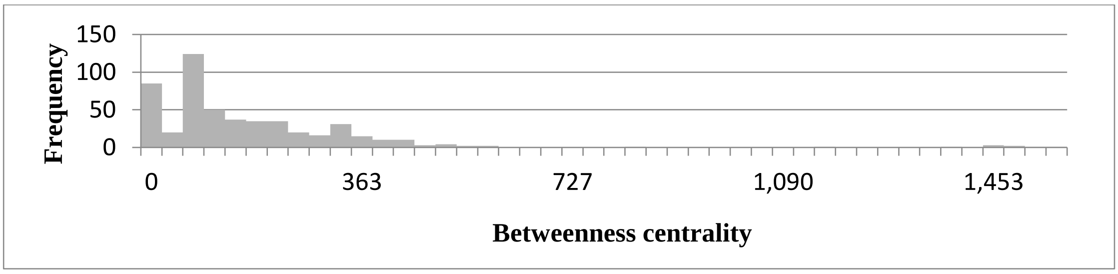


Figure 62. Betweenness centrality of global collaboration between care providers for stroke patients

Betweenness centrality is a metric illustrating the closeness of a node to all other nodes, in this case from the global network as the totality of collaborative relationships under consideration. The minimum betweenness centrality was in this case 0.08 and the maximum 1562.39, therefore with a substantial range. Mean of betweenness centrality was 186.99 and median was 126.03.

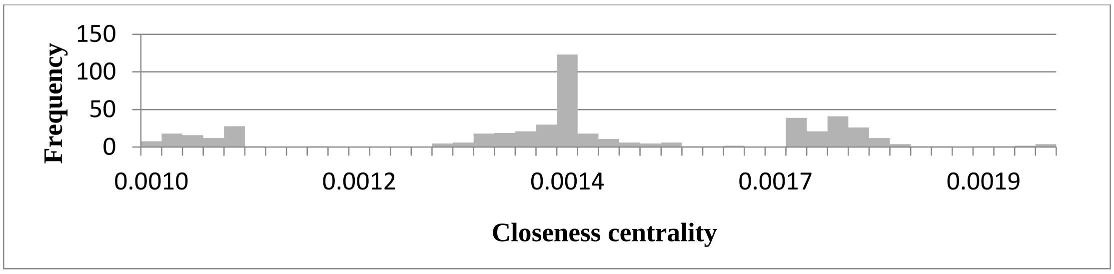


Figure 63. Closeness centrality of global collaboration between care providers for stroke patients

The minimum closeness centrality was 0.001 and the maximum 0.002. Mean and median were both 0.001. This metric illustrates how close vertices are located to the center of the group. The values indicate a high density with the members of the network focused around its center.

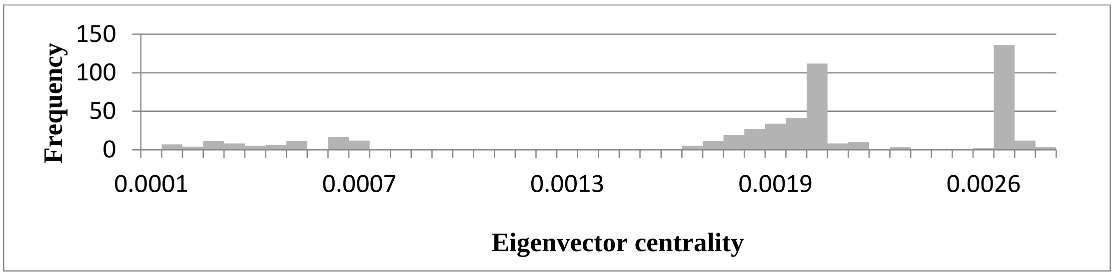


Figure 64. Eigenvector centrality of global collaboration between care providers for stroke patients

Eigenvector centrality constitutes a measure of a relative strenght of influence of a node within the network. In this case, the minimum eigenvector centrality was 0.00, with no influence, and the maximum was 0.003, indicating a very low influence. The average eigenvector centrality was 0.002, as well as median.

Testing with PageRank algorithm used by Google to create web hierarchy is another method of determining centrality within a researched population. Considering the global network, the minimum PageRank was 0.200 and the maximum was 1.588. The average value of PageRank observed within the network was 1.00 and median was 1.02.

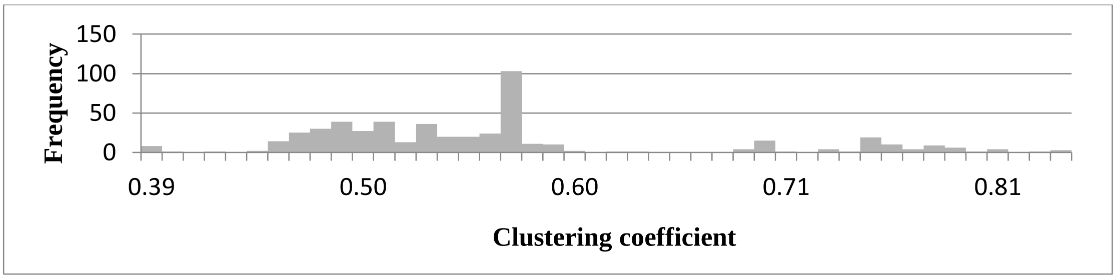


Figure 65. Clustering coefficient of global collaboration between care providers for stroke patients

Clustering coefficient measures how much vertices of the network tend to cluster together into distinct groups. The minimum clustering coefficient was 0.393 and the maximum 0.846. Mean of the metric was 0.567 and median 0.551. Clustering coefficient takes values from 0 to 1; Figure 65 proves existence of clustering tendencies, however, we must bear in mind all possible collaborative linkages are considered in this setting.

In the second step of the analysis, the weakest relationships, that is, those of the strength defined as 1, were eliminated from further calculations. The key graph metrics, which characterize all relationships of the strength from 2 to 5, are provided in Table 116. As it can be seen, the total number of 509 of initially considered institutions remained in the analysis.

Table 116. Graph metrics for the structure of collaboration of the intensity of 2-5 between providers of care and support for stroke patients

Graph Metric	Value
Graph Type	Directed
Vertices	509
Unique Edges	14325
Edges With Duplicates	0
Total Edges	14325
Self-Loops	0
Reciprocated Vertex Pair Ratio	0.178624321
Reciprocated Edge Ratio	0.303106457
Connected Components	1
Single-Vertex Connected Components	0
Maximum Vertices in a Connected Component	509
Maximum Edges in a Connected Component	14325
Maximum Geodesic Distance (Diameter)	4
Average Geodesic Distance	2.273166
Graph Density	0.05540043

Overall graph metrics are provided below (see Figures 66 to 71).

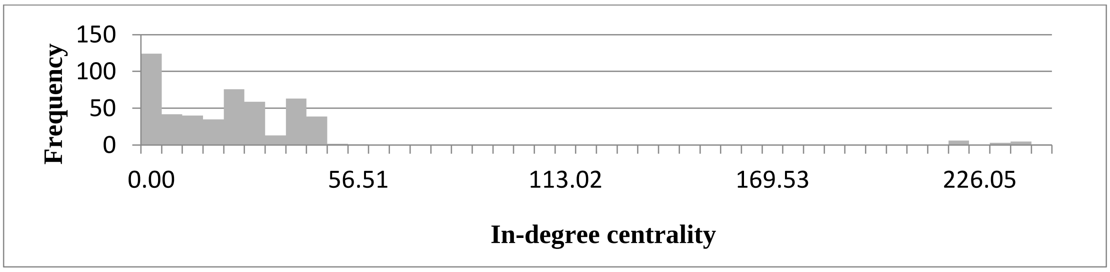


Figure 66. In-degree centrality of collaboration of the intensity of 2-5 between care providers for stroke patients

The minimum in-degree centrality was 0 and the maximum was 243. The average value of this metric in this configuration of the network was 28.14 and median was 24.00. Figure 66 demonstrates there were around 130 entities that did not receive any contact from other members of the network within this intensity.

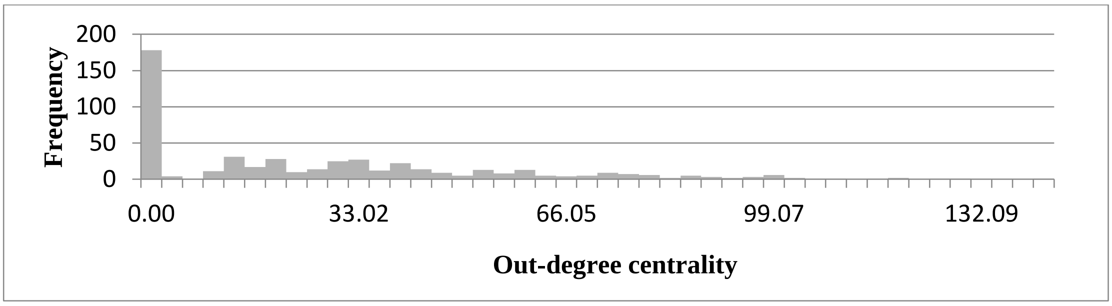


Figure 67. Out-degree centrality of collaboration of the intensity of 2-5 between care providers for stroke patients

Similarly, the minimum number of ties directing toward other vertices was 0 with about 180 entities demonstrating no relationship toward other elements of the network (Figure 67). The maximum out-degree was 142. Mean of out-degree centrality was 28.14 and median was 21.00.

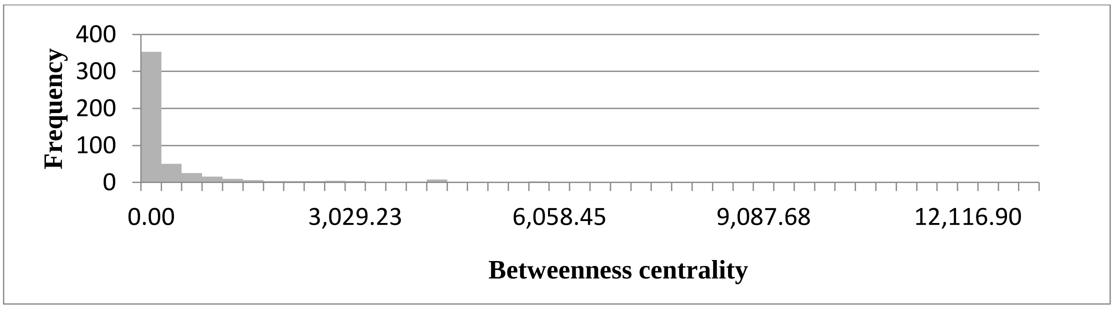


Figure 68. Betweenness centrality of collaboration of the intensity of 2-5 between care providers for stroke patients

The minimum betweenness centrality was 0.00 and the maximum was 13025.67, indicating the amount of the times (minimum/maximum) a vertex was used as a bridge along the shortest path between two other vertices in the network. Mean of betweenness centrality was 649.04 and median was 106.67.

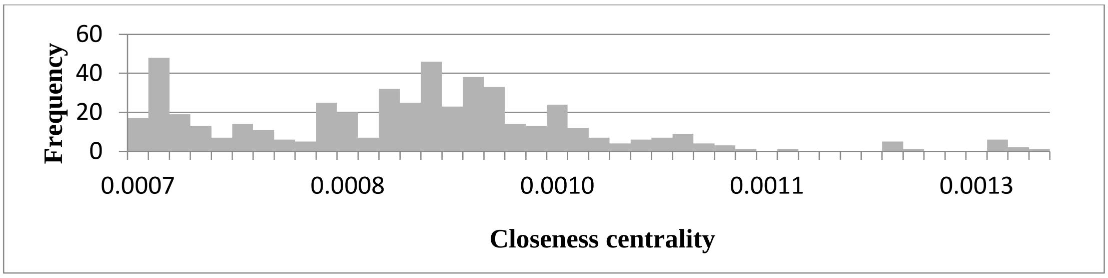


Figure 69. Closeness centrality of collaboration of the intensity of 2-5 between care providers for stroke patients

The minimum closeness centrality was 0.001 as well as the maximum. The same values were registered in case of mean and median of the metric. Comparing to the global collaboration setting, the distance between vertices remaned almost the same and very tight.

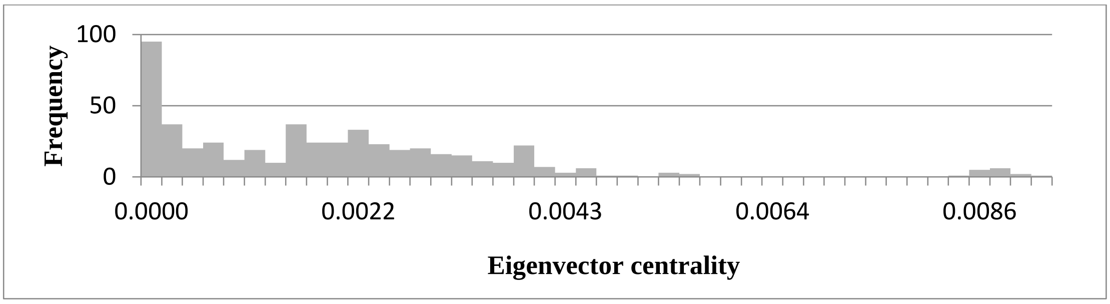


Figure 70. Eigenvector centrality of collaboration of the intensity of 2-5 between care providers for stroke patients

The minimum eigenvector centrality was 0.00 and the maximum was 0.009. Mean of eigenvector centrality was 0.002 and median in the considered setting was 0.002, as well. The relative strength of a node in the network remained very low.

PageRank, as another measure of centrality, demonstrated the minimum value 0.167 and the maximum 4.577. The average value of this metric was 1.00 and median was 0.857.

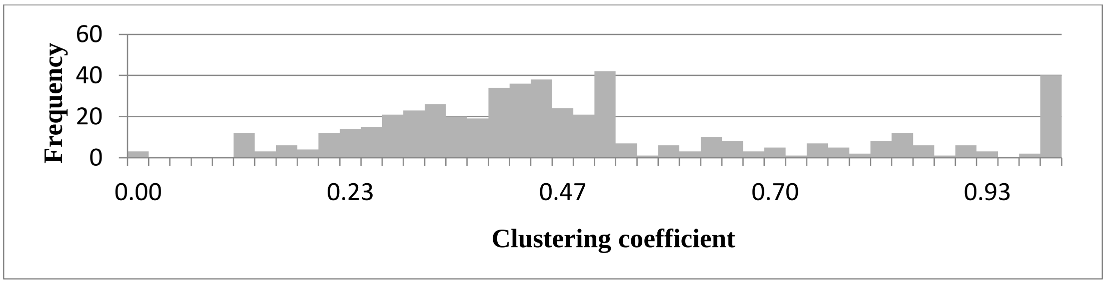


Figure 71. Clustering coefficient of collaboration of the intensity of 2-5 between care providers for stroke patients

The minimum clustering coefficient was 0.00 and the maximum 1.00. Mean of the metric was 0.50 and median was 0.44. With 509 entities remaining in the analysis even after eliminating the lowest level of collaboration intensity, clustering tendencies were mediocre, interestingly now with about 40 entities clustering very strongly (Figure 71).

In the next step, the subsequent weakest relationship according to the framework used as a basis of the strength of collaboration was eliminated. The principal graph metrics for relationships of the strength from 3 to 5 are provided in Table 117. 483 institutions remained in the analysis.

Table 117. Graph metrics for the structure of collaboration of the intensity of 3-5 between providers of care and support for stroke patients

Graph Metric	Value
Graph Type	Directed
Vertices	483
Unique Edges	3471
Edges With Duplicates	0
Total Edges	3471
Self-Loops	0
Reciprocated Vertex Pair Ratio	0.270497804
Reciprocated Edge Ratio	0.425813886
Connected Components	3
Single-Vertex Connected Components	0
Maximum Vertices in a Connected Component	450
Maximum Edges in a Connected Component	2831
Maximum Geodesic Distance (Diameter)	7
Average Geodesic Distance	2.998717
Graph Density	0.01490941

Overall graph metrics are provided below (see Figures 72 to 77).

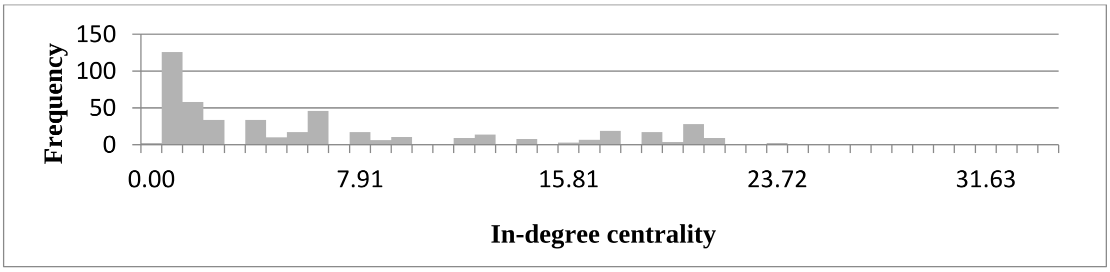


Figure 72. In-degree centrality of collaboration of the intensity of 3-5 between care providers for stroke patients

The minimum number of connections directed to one vertex in the considered configuration was 0 and the maximum was 34. The average in-degree centrality was 7.19 and median of in-degree centrality was 4.00. While the number of entities did not decrease much from the previous intensity level (509 to 483), there was a difference in the maximum number of connections directed to one institution (243 to 34) and therefore median of in-degree centrality suffered a change (24.00 to 4.00) (Figure 72).

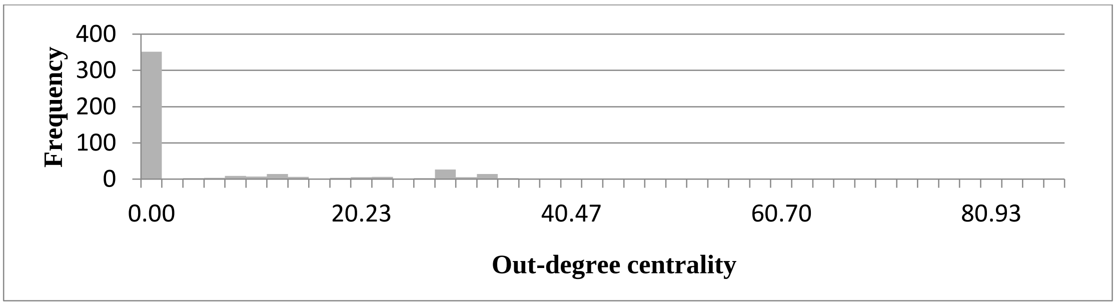


Figure 73. Out-degree centrality of collaboration of the intensity of 3-5 between care providers for stroke patients

The minimum number of connections directed to other vertices was 0 and the maximum was 87. Mean of out-degree centrality was 7.19 and median was 0.00. Similarly to the in-degree centrality, the maximum number of ties toward other nodes decreased comparing to the previous configuration (142 to 87) with around 340 having currently no outgoing relations (Figure 73).

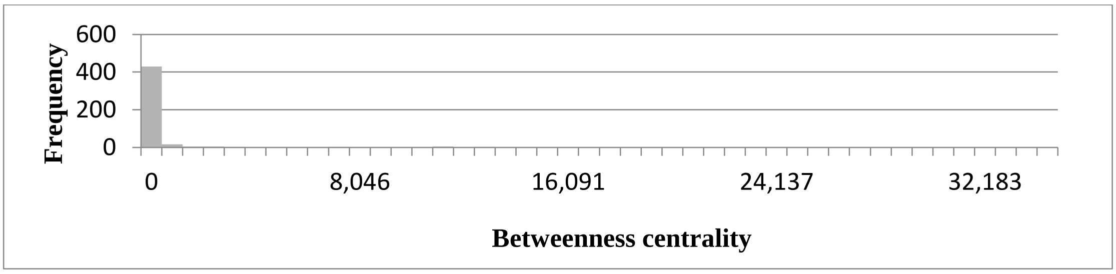


Figure 74. Betweenness centrality of collaboration of the intensity of 3-5 between care providers for stroke patients

The minimum number of times a node functioned as a bridge along the shortest path between two other nodes in the network was 0.00 and the maximum was 34596.66. The average betweenness centrality was 842.96 and median was 2.55.

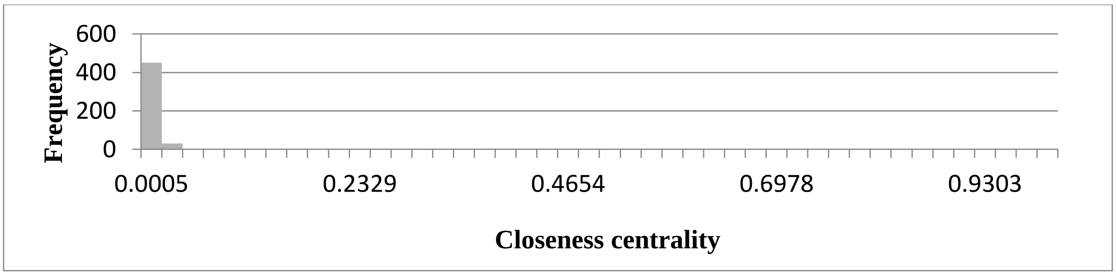


Figure 75. Closeness centrality of collaboration of the intensity of 3-5 between care providers for stroke patients

The minimum closeness centrality was 0.00 and the maximum was 1.00. The average value of this network metric was 0.007 and median was 0.001. There is in fact a significant change in the maximum value comparing to the configuration 2-5 (0.001 and 1) however the frequency of the latter is low. The current configuration indicates high density of the network with entities centrally located and closely related.

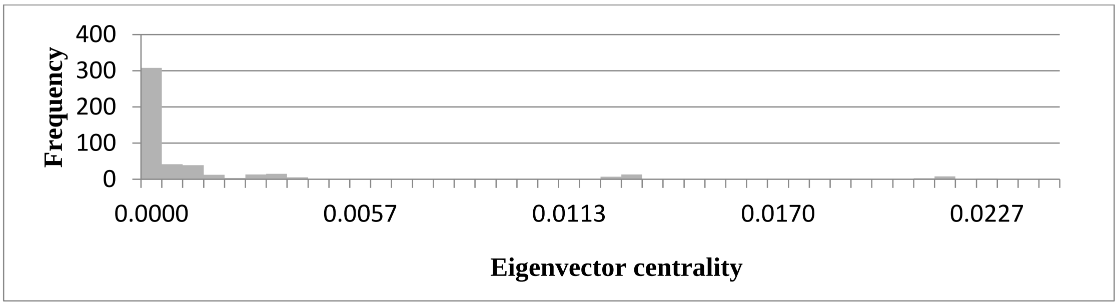


Figure 76. Eigenvector centrality of collaboration of the intensity of 3-5 between care providers for stroke patients

The minimum eigenvector centrality was 0.00 and the maximum 0.024. The mean was 0.002 and median was 0.00, therefore a relative strength of vertices in the configuration under consideration continued very weak.

PageRank, on the other hand, indicated the minimum 0.185 and the maximum 10.00. The average PageRank was 1.00 and its median was 0.642.

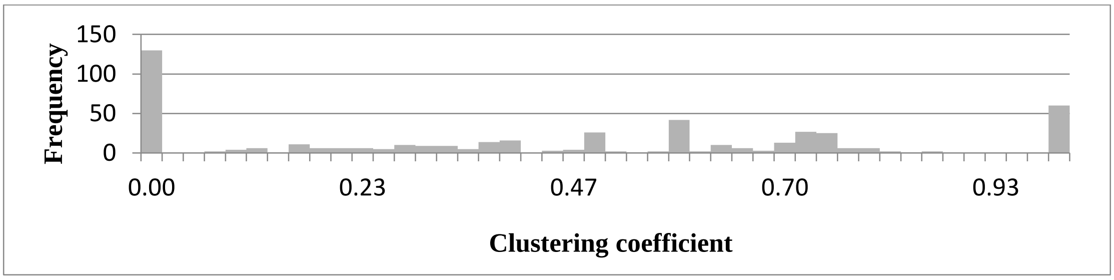


Figure 77. Clustering coefficient of collaboration of the intensity of 3-5 between care providers for stroke patients

Clustering coefficient showed the minimum value 0.00 and the maximum 1.00. Mean of this metric was 0.435 and median was 0.445. There were around 130 cases without clusters and a little above 50 clustering very strongly. Hence, cutting off intensity 1 and 2 we find something interesting, around 50 entities strongly cooperating (Figure 77). In the present analysis a high clustering coefficient is not recommendable as it limits the linking criteria and the ideal would be finding entities with linkages to each other rather than clustered around a few vertices.

Figure 78 presents betweenness centrality in the network configuration of the intensity of collaboration between 3 and 5. It allows to see that only a few nodes are in the direct center of the network.

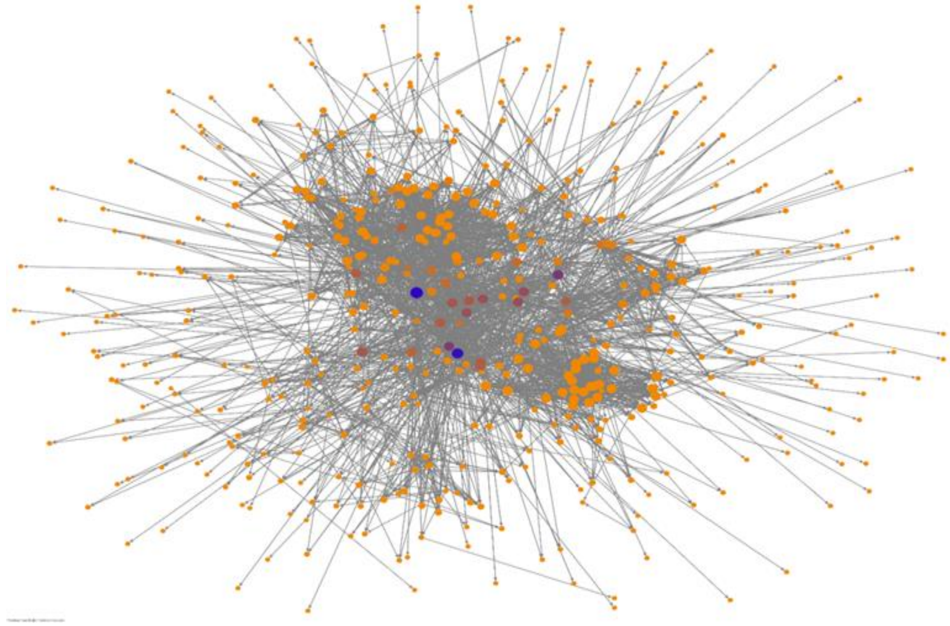


Figure 78. Betweenness centrality demonstration of collaboration with the intensity of 3 to 5 between care providers for stroke patients

Figure 79 presents clustering coefficient in the network configuration of the intensity of collaboration between 3 and 5. Clustering tendencies of the population under study show that most clusters at this level are distributed around the center of the population. This is an indication of strong relations among vertices.

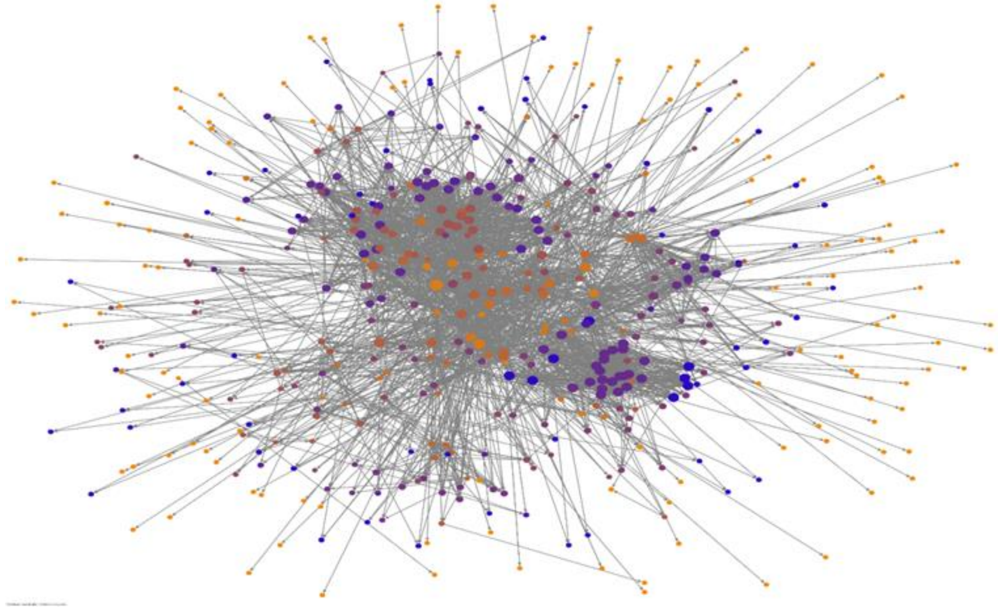


Figure 79. Clustering demonstration in collaboration with the intensity of 3 to 5 between care providers for stroke patients

Figure 80 presents reciprocated vertex pair ratio as a proportion of vertices with a connection returned to them in the network configuration of the intensity of collaboration between 3 and 5. Blue nodes visible on the scheme are the ones with the most connections within the network.

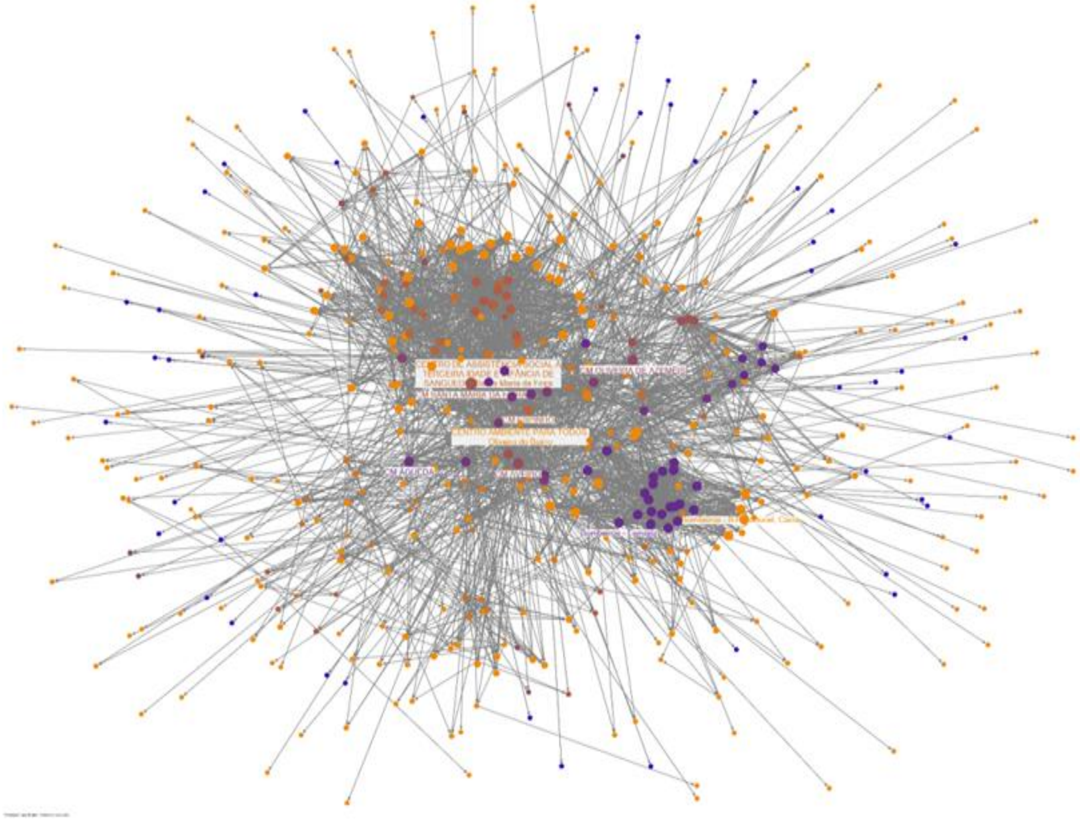


Figure 80. Reciprocated vertex pair ratio demonstration in collaboration with the intensity of 3 to 5 between care providers for stroke patients

Figure 81 demonstrates an overall perspective of regional collaboration between intensity levels 3 to 5 as those pointing a higher level of inter-connection between entities. This standpoint allows for eliminating an enormous quantity of connections indicating a very low or low level of relationship (1 and 2) which would make the outline impossible to visualize.

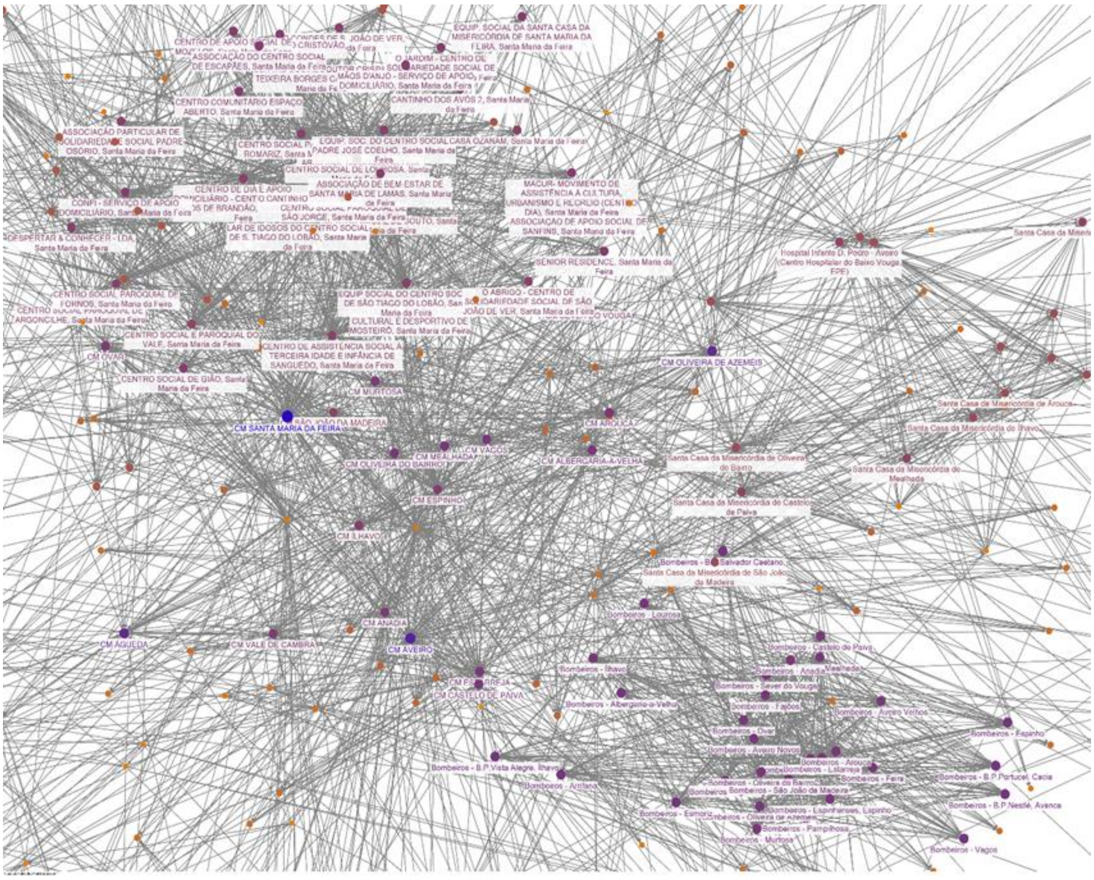


Figure 81. Regional collaboration with the intensity of 3 to 5 between care providers for stroke patients

Table 118 provides the list of municipalities and strength of connection between them in the network configuration of 3 to 5.

Table 118. Collaboration strength per most connected municipalities in the network configuration with collaboration of intensity 3 to 5

Santa Maria da Feira	798
Aveiro	332
Águeda	393
Oliveira de Azeméis	286
Albergaria-a-Velha	79
Espinho	89
Estarreja	115
Ílhavo	94
Ovar	209
Vagos	119
Anadia	190
Arouca	91
Castelo de Paiva	86

Mealhada	123
Murtosa	66
Oliveira do Bairro	123
São João da Madeira	94
Sever do Vouga	59
Vale de Cambra	108

Figure 82 presents regional collaboration between intensity levels 3 to 5 in the central part of the network. Labels describe a municipality.

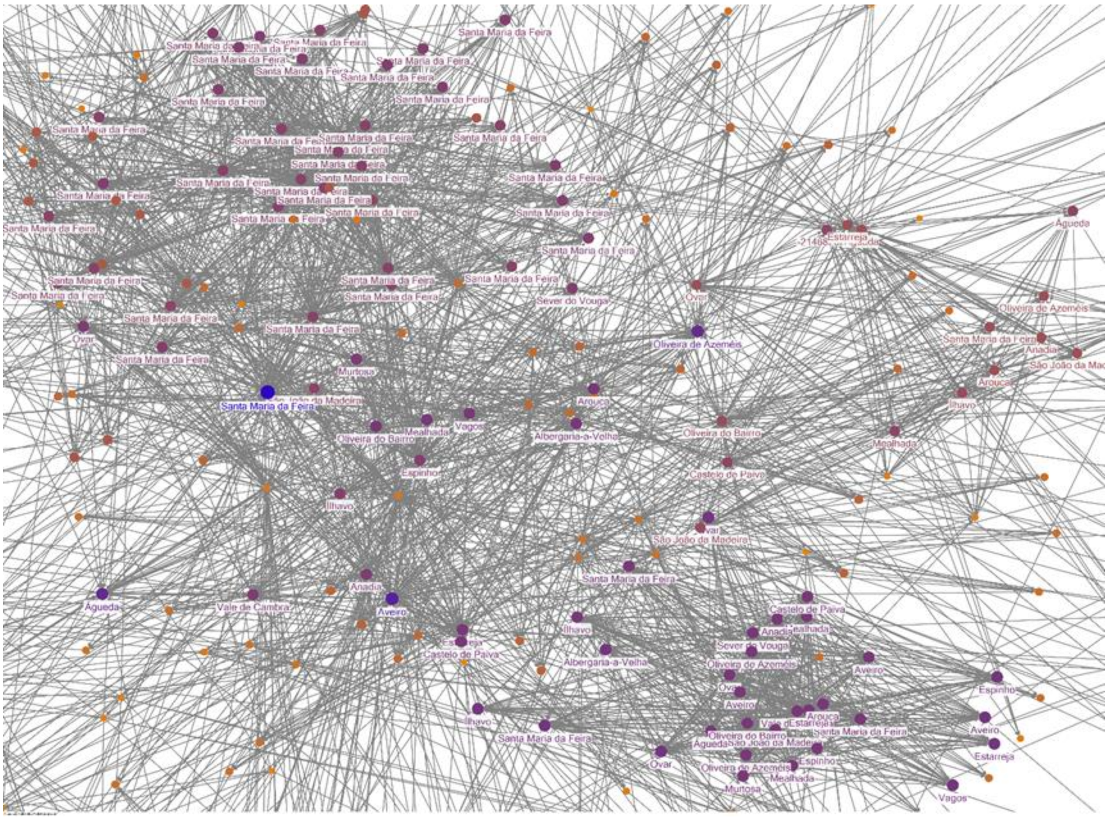


Figure 82. Regional collaboration with the intensity of 3 to 5 between care providers for stroke patients - the central part of the network

Figure 83 demonstrates a focused view onto regional collaboration between intensity levels 3 to 5 – the south-east part of the considered population. Grouping tendencies can be observed amongst around 20 nodes.

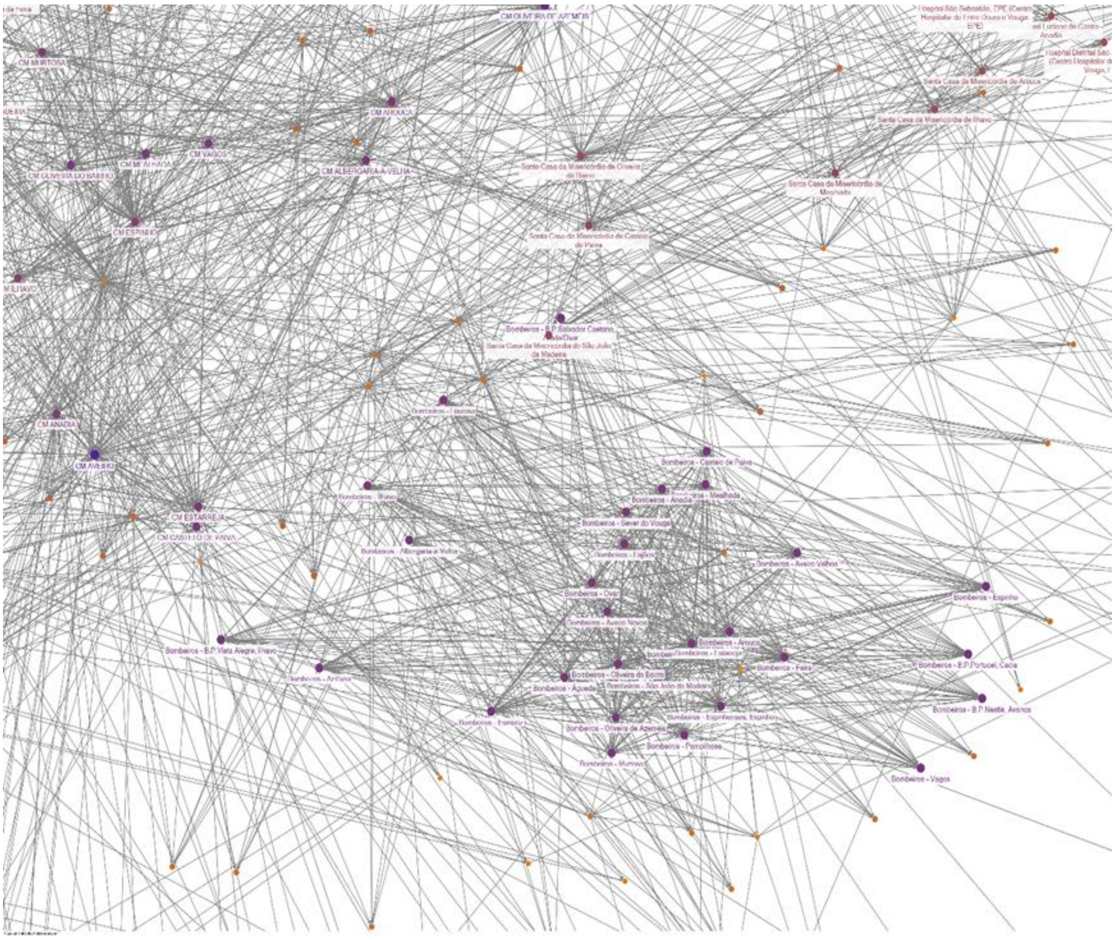


Figure 83. Regional collaboration with the intensity of 3 to 5 between care providers for stroke patients - the south-east part of the network

Figure 84 demonstrates a perspective on regional collaboration between intensity levels 3 to 5 – the north-west part of the considered population. In this part, one distinctive group is formed, with entities strongly collaborating within the group and with the entire network.

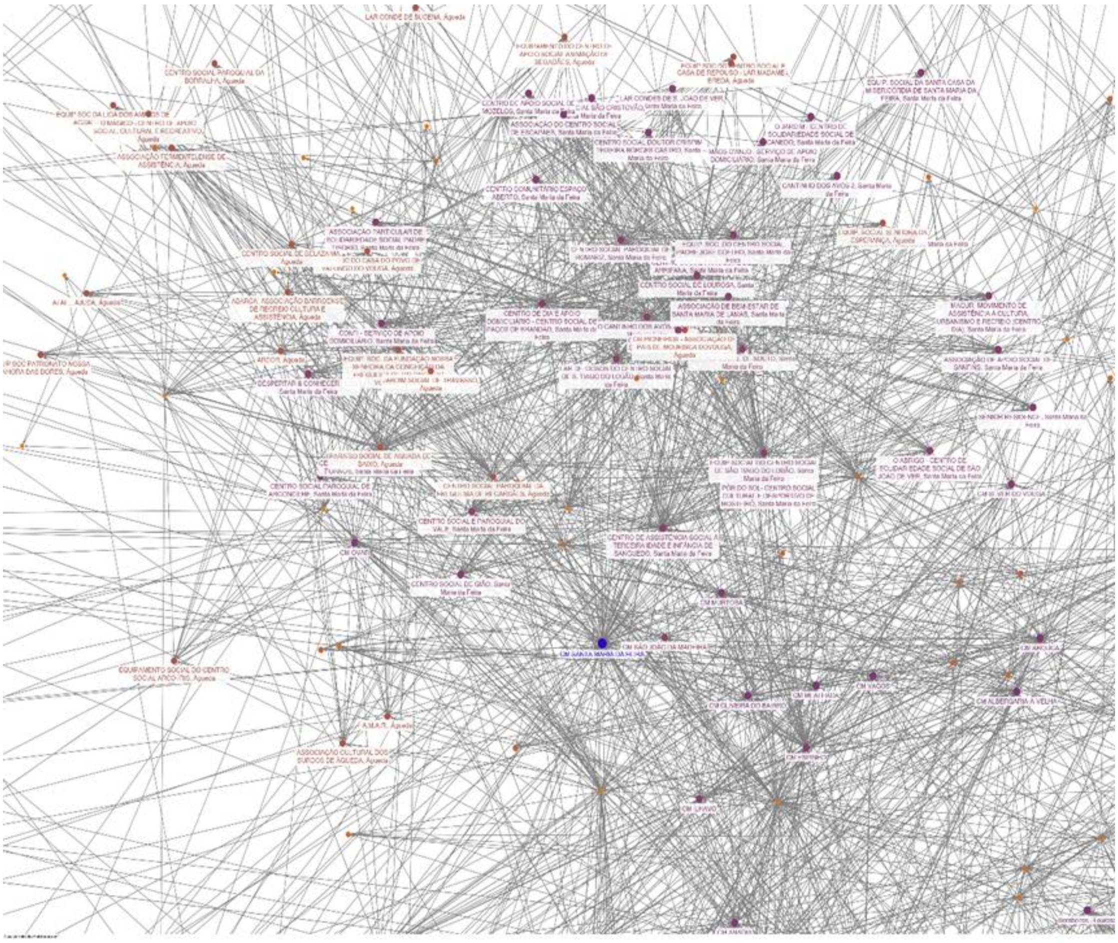


Figure 84. Regional collaboration with the intensity of 3 to 5 between care providers for stroke patients - the north-west part of the network

In the next step, the remaining weakest relationship was eliminated from further analysis having left 222 entities. The principal graph metrics, which represent all relationships of the strength from 4 to 5 are provided in Table 119.

Table 119. Graph metrics for the structure of collaboration of the intensity of 4-5 between providers of care and support for stroke patients

Graph Metric	Value
Graph Type	Directed
Vertices	222
Unique Edges	274
Edges With Duplicates	0
Total Edges	274
Self-Loops	0
Reciprocated Vertex Pair Ratio	0.376884422
Reciprocated Edge Ratio	0.547445255
Connected Components	29

Single-Vertex Connected Components	0
Maximum Vertices in a Connected Component	22
Maximum Edges in a Connected Component	36
Maximum Geodesic Distance (Diameter)	4
Average Geodesic Distance	1.938298
Graph Density	0.00558477

Figure 85 presents the overall view to the network with the intensity of relationship of 4 and 5. Nodes with the relation 5 are shown in color and relevant nodes are indicated by name. A color of the scale indicates betweenness centrality (yellow - lowest; blue - highest). The size represents degree. The vertex closest located with more connections with all others in this configuration is CM Santa Maria da Feira, with CM Aveiro, CM Águeda and CM Castelo de Paiva on a relevant position. Interestingly, they all represent one type of entity (city council).

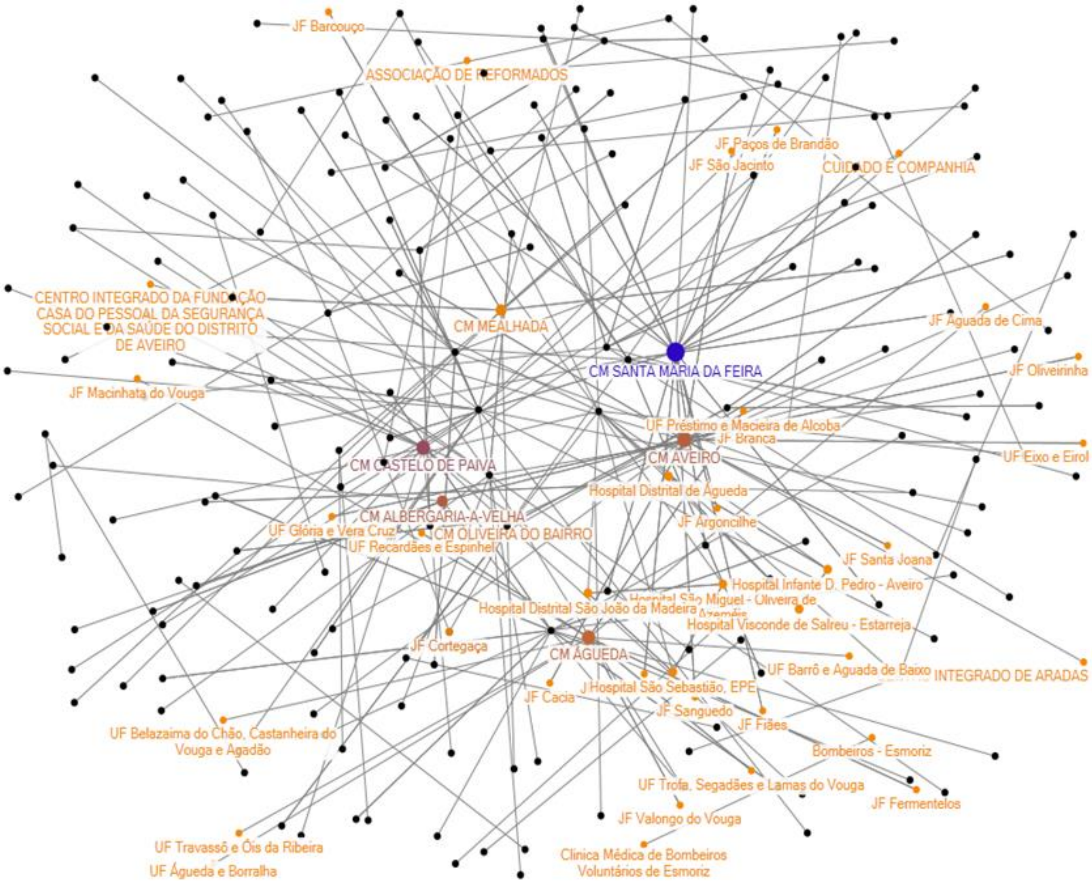


Figure 85. Nodes with the relationship intensity of 4 to 5

Overall graph metrics are provided below (see Figures 86 to 91).

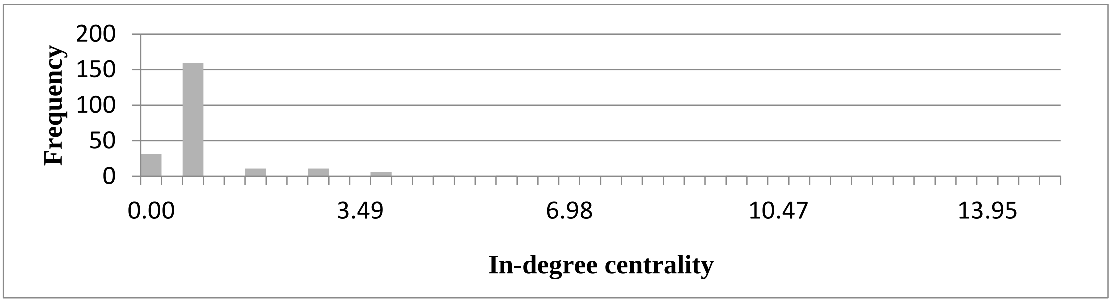


Figure 86. In-degree centrality of collaboration of the intensity of 4-5 between care providers for stroke patients

The minimum in-degree centrality indicating the number of connections directed to the vertex was 0 (there were still around 25 with no incoming ties) and the maximum was 15 Mean of in-degree centrality was 1.23 and median was 1.00.

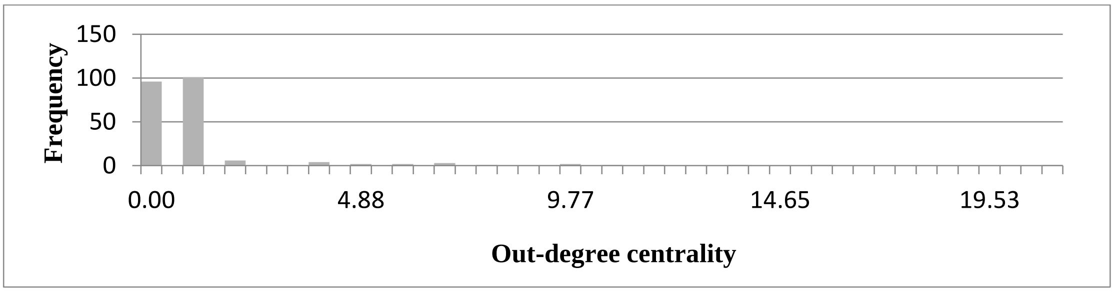


Figure 87. Out-degree centrality of collaboration of the intensity of 4-5 between care providers for stroke patients

About a half from considered entities did not have any outgoing connections toward other vertices of the network. The minimum out-degree centrality was 0 and at the maximum was 21. Mean was 1.23 and median was 1.00.

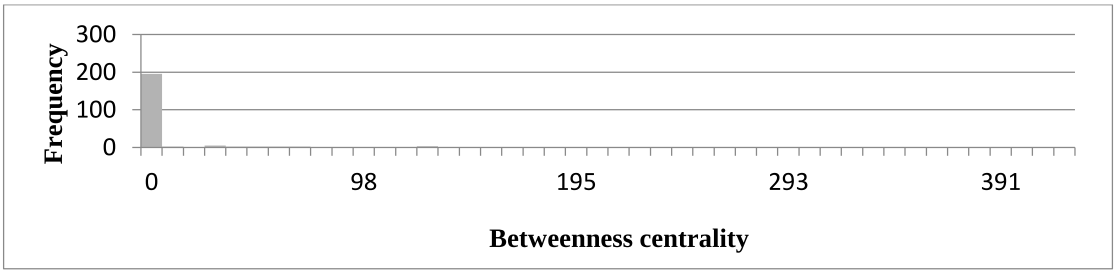


Figure 88. Betweenness centrality of collaboration of the intensity of 4-5 between care providers for stroke patients

The minimum betweenness centrality was 0.00 and the maximum 420.00, pointing out the number of times a node was used as a bridge along the shortest path between two other nodes in the network. Mean of betweenness centrality was 12.91 and median was 0.00. Median registered a substantial decrease from the configuration 2-5 (106.67) and 3-5 (2.55).

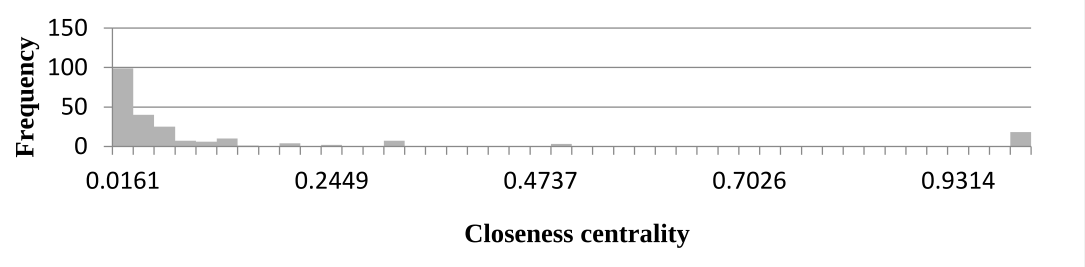


Figure 89. Closeness centrality of collaboration of the intensity of 4-5 between care providers for stroke patients

Closeness centrality is a measure of distance between vertices; the minimum value of the metric was 0.016 and the maximum 1.00. The average closeness centrality in the considered network was 0.145 and median was 0.043. Entities in the network remained very closely located and related.

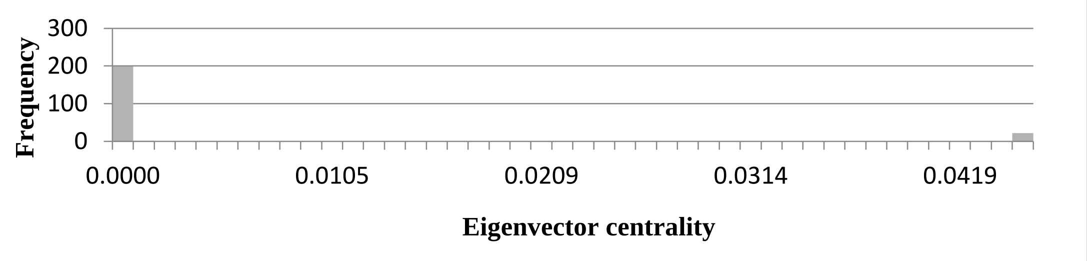


Figure 90. Eigenvector centrality of collaboration of the intensity of 4-5 between care providers for stroke patients

Eigenvector centrality designating the strength of the influence of the node within the network indicated its minimum at 0.00 and the maximum at 0.045. The average eigenvector centrality was 0.005 and median was 0.000. There were no high-degree agglomerations in the network and a relative strength of a vertex was very low.

PageRank showed the minimum value of 0.456 and the maximum 10.19. The average PageRank was 1.00 with median 0.593.

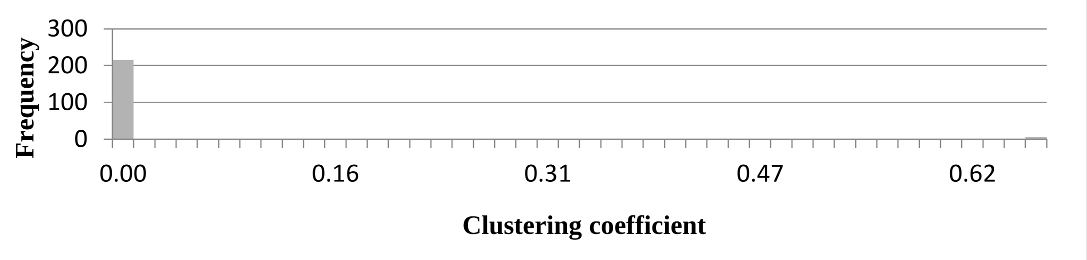


Figure 91. Clustering coefficient of collaboration of the intensity of 4-5 between care providers for stroke patients

At the level of collaboration intensity limited to 4-5, clustering tendencies decreased from those observed at the intensity 3-5. Over 200 entities did not cluster at all (almost all network in this configuration). The minimum clustering coefficient was 0.00 and the maximum 0.667. Mean of the metric was 0.018 and median was 0.00.

Figure 92 presents the strongest linked vertices within the network (marked in red). Just a few nodes had strong connections; these nodes (referred in Table 120) had the highest betweenness centrality metrics what made them 'closest' to all other nodes. Still, degree was low, with CM Santa Maria da Feira having only 21 connections with other nodes.

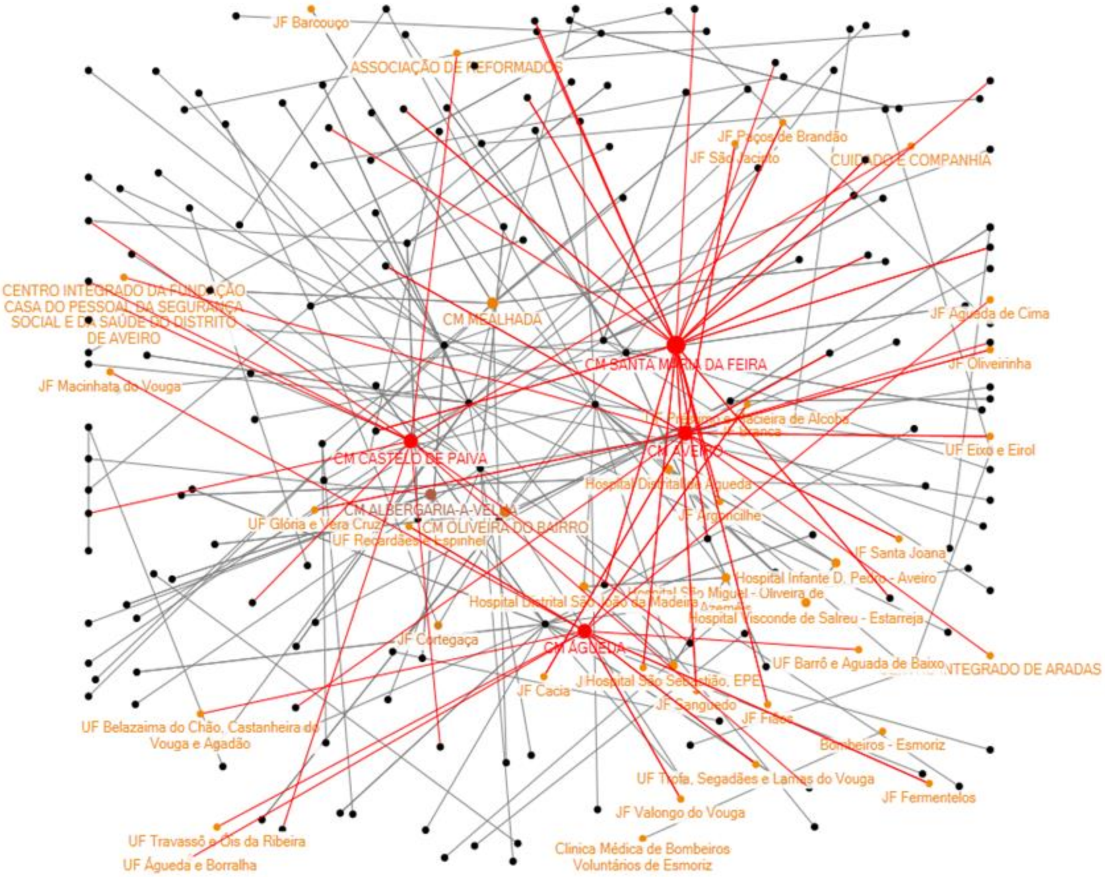


Figure 92. Four strongest connected nodes in the network of the relationship intensity 4-5

Table 120. Four highest degree nodes at the collaboration intensity level of 4 and 5

Node	Degree	Betweenness Centrality	Closeness Centrality	Eigenvector Centrality	PageRank
CM SANTA MARIA DA FEIRA	21	210.00	0.048	0.05	10.19
CM AVEIRO	12	66.00	0.083	0.00	6.06
CM ÁGUEDA	11	55.00	0.091	0.00	5.60
CM CASTELO DE PAIVA	11	95.00	0.045	0.00	5.41

Figure 93 presents the node with the highest degree in the considered network, CM Santa Maria da Feira. In this configuration, City Council of Santa Maria da Feira had the highest number of connections with other elements of the network, nevertheless, very restricted as demonstrated. In total, 222 institutions could possibly establish collaborative linkages at this stage.

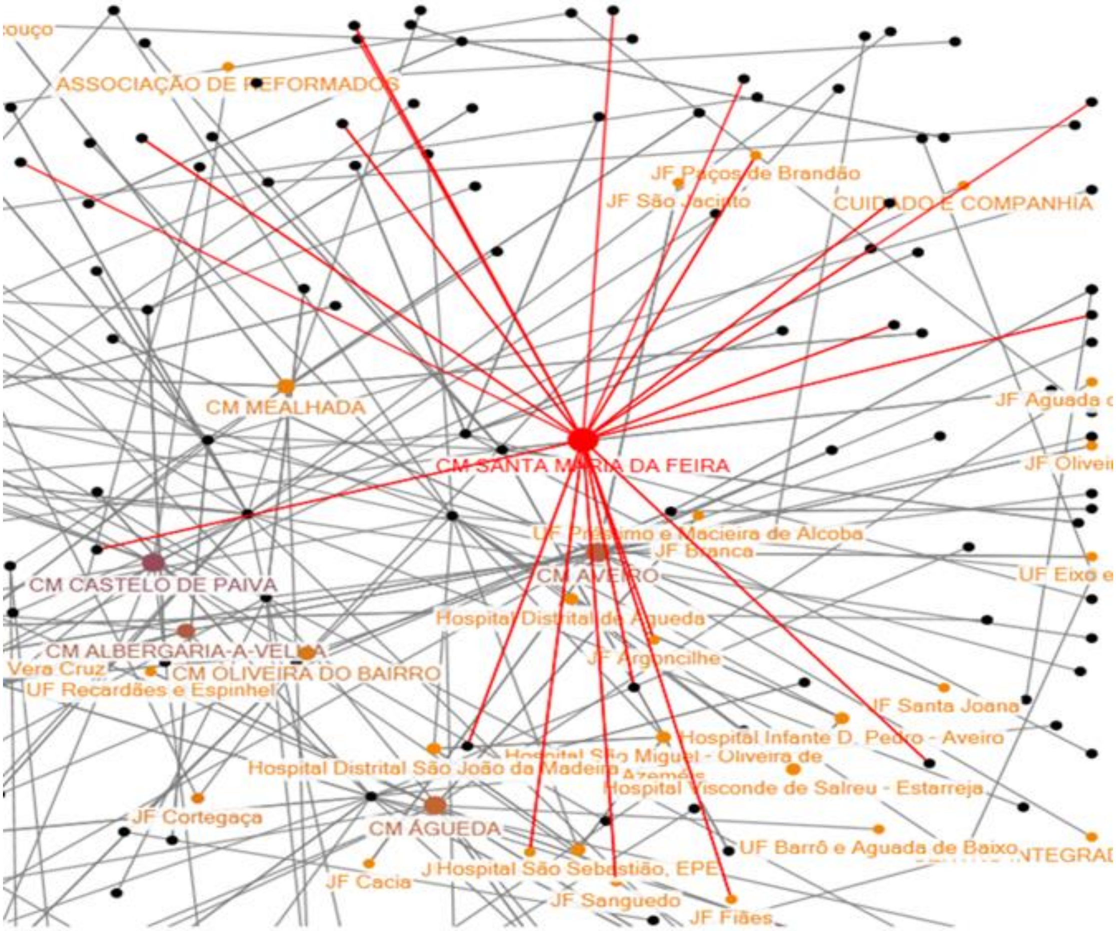


Figure 93. The node with the highest degree in the network of the relationship intensity 4-5

Figure 94 presents the node with the second highest degree in the network under consideration, which is CM Aveiro. City Council of Aveiro established linkages with 12 of the network members.

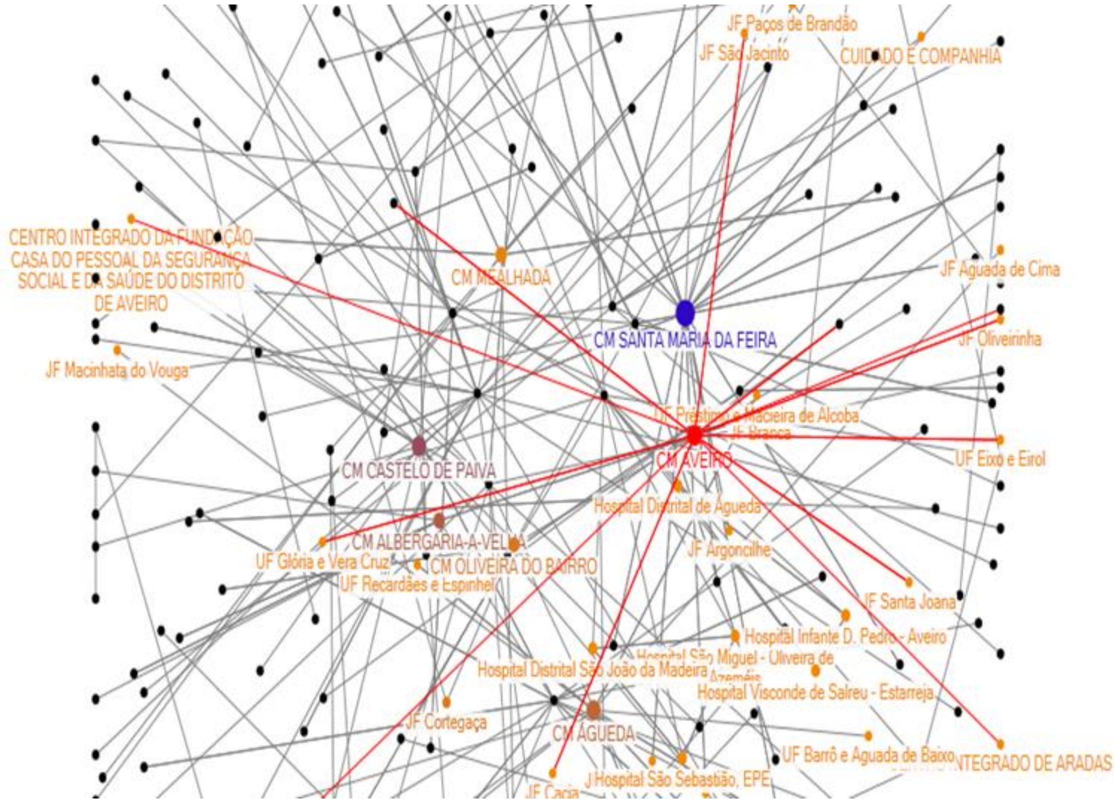


Figure 94. The node with the second highest degree in the network of the relationship intensity 4-5

Intensity of the collaborative linkages 5 indicated there were 44 institutions from the initial 509 which would remain under analysis. From these, around 35 had degree 1, that is, a number of connections with other members of the network. Figure 95 presents the overall view to the network with the intensity of relationship 5 with colors used to separate distinct groups and vertex size corresponding to degree.

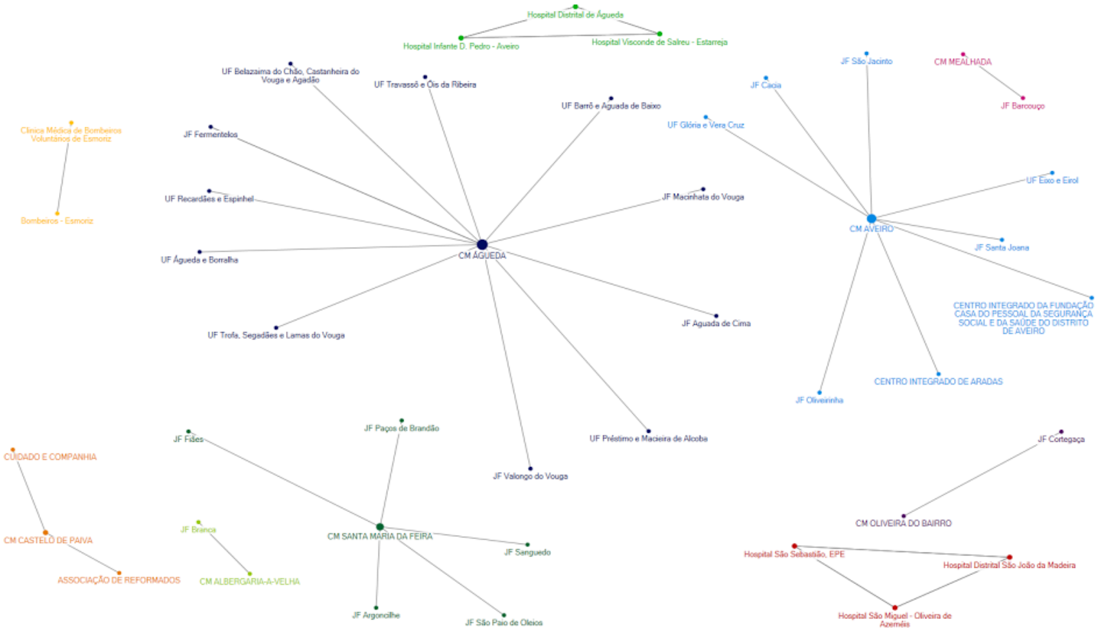


Figure 95. Collaboration configuration with the intensity 5

In the collaboration configuration with the intensity 5, there were two major entities of similar degree and centrality, CM Águeda and CM Aveiro, and one more well-connected institution, CM Santa Maria da Feira. These three vertices formed a group of a relatively high influence. The first had 11 and the second 8 connections with other members of the network. The last vertex was less ‘central’. In the group focused around CM Águeda, all collaborating entities represented either parish councils or parish council unions. In the group of CM Aveiro, these were parish councils or parish council unions and IPSS.

The quantity of involved entities and characteristics of relationships in configuration 5 was too scarce to proceed with further analysis of the network and take any conclusions on relationships existing between care and support providers. Therefore, collaboration intensity 4-5, with 222 entities in the network, was considered sufficient to provide evidence on the network of care for stroke patients in the district of Aveiro.

CHAPTER EIGHT:

DISCUSSION AND CONCLUSIONS

This thesis aimed to verify the status of the intersectoral collaborative action for stroke patients, evaluating perceived impact of existing partnerships on patients' quality of life, perceived service quality and satisfaction with care, support and assistance services they experienced. It analyzed ways the existing collaborative agreements function in the Portuguese context. This chapter discusses the results obtained throughout the study span by means of a number of methods with an objective to answer defined research questions. After major conclusions, limitations the study are presented. The final part of the chapter is dedicated to recommendations for researchers from this or alike fields for future research work that might use results of the present one.

8.1. Discussion of the results

Complexity of the present study, having its origins in a variety of reasons required a correct and accurate theoretical and methodological preparation for the field work.

Literature review was crucial for this phase as it built the theoretical base of concepts indispensable for conducting empirical study. Chapter 1 was an extensive and profound revision of existing theories and notions related to terminology referring to partnerships and intersectoral partnerships as a concept. As collaborative linkages were a core axis of this thesis, it was crucial to investigate what existed at the time being in the literature on this topic and could be used as a conceptual support for the partnership action in care services for stroke survivors in Portugal. The chapter presented results of the systematic review of Portuguese legislation concerning intersectoral approach to health and social care.

Chapter 2 provided the theoretical framework of networks and discussed the concept, development and relevance of network analysis, as health and social care organizations can be successfully approached through networks to pursue with their activities.

Chapter 3 examined constructs of service quality and satisfaction basing on extensive literature review. It presented models of service quality identified in literature and a well-known and yet still not resolved discussion on superiority between two most recognized service quality measurement instruments, the SERVQUAL and the SERVPERF, demonstrating their characteristics, advantages and disadvantages. Further, it provided evidence from lack of consensus between academics on a direction of relationship between service quality and customer satisfaction.

Chapter 4 allowed for understanding the concepts of quality of life and health-related quality of life. It was a result of literature review regarding measurement of quality of life, both in persons with general conditions and in patients after cerebrovascular accident. Generic and disease-specific measures of quality of life applied in stroke studies were depicted. The chapter discussed aspects particular and relevant to measuring quality of life in stroke survivors.

Methodology employed for the present study, albeit multi-level and multifaceted, was proven to be adequate for proposed objectives as the latter were fully accomplished.

8.1.1. Phase one

Cerebrovascular disorder is an acute health condition and, as such, requires, immediate medical intervention focused on stabilizing life functions. However, when that stage is achieved, following hospitalization, discharge from a stroke ward brings enormous anxiety for a patient and eventual relatives as it initiates a process of adaptation to the new reality (Ekstam, Uppgard, & von Koch, 2007). The adaptation is conditioned by a number of factors, starting from a level of impairment and limitations stroke resulted in to the particular situation awaiting when returning to the community, comprising social, physical and financial aspects in which available social support is of special importance.

A taxonomy of an expectation in literature differs, having an expectation understood as a personal judgment about an event to occur, hopes or desires expressed as wants or needs, concerning an event, a process or consequence of a treatment (Bowling et al., 2012) and is an important contributor to patients' decision-making process on both, care services and care providers to choose from. A divergence between care providers and patients may lead to inadequate care services offer and insufficiently fulfilled expectations regarding diverse aspects of care provision relevant from a point of view of a patient. Bowling el al. (2012) make a clear distinction between sufficient information leading to make informed judgment and subjective expectations.

Patient expectations for care they receive is an important element of further satisfaction (Bryan-Brown, & Dracup, 1996), however, few research has been conducted on issues concerning a possibility of expectations modification. Watt, Wertzel and Brannan (2005) make an interesting debate on expectations and satisfaction. Expectations refer to the concept of care provision a patient has before hospitalization. Satisfaction, on the other hand, may only be assessed during hospitalization or after discharge, with experience necessary for the assessment. However, fulfilling one aspect is not a guarantee for a fulfillment of another. That said, patients may express a high level of satisfaction with care while their expectations have not been completely met. Surely, patients with above average expectations are more challenging to be satisfied with care. Furthermore, patients with improperly high level of expectations will clearly express dissatisfaction even with finest care, while patients with low expectations will pronounce themselves satisfied with care insufficient at several aspects (McKinley et al., 2002).

There is a rich body of literature acknowledging a decision-making process centered on a patient while care delivery is shared by different care providers (Mellor & Green, 2002; Zandbelt et al., 2004). The importance of patient expectations in this process has been recognized and is nowadays broadly accepted as means to improve health outcomes in different treatments (Haanstra et al., 2012). As the care system is a sum of multiple care agents and interactions between them, a global perspective is required to comprehend the complexity of patient expectations in this environment. Floch's (1988, 2001) semiotic approach of consumption may constitute an interesting contribution to explain and categorize patients' global expectations, in this case, specifically focused on health care needs and the health care system as a whole. According to the framework proposed by Floch (1988), originally conducted in the retail industry, consumers associate two kinds of values with objects or services: utilitarian values and existential values. Utilitarian values are perceived to exist if a product fulfills functions it was designed for. Existential values may include elements such as emotional, social or epistemic values, going beyond functional aspects of a product. As such, any product will be considered either from a practical value it offers, its functionality and perceived quality, or from its potential existential value, feelings it creates, social recognition it brings with itself, and an interest it raises.

In order to better comprehend patients' expectations toward the health care system and health care services, Chalamon, Chouk and Heilbrunn (2014) have distinguished four types of values expressed by patients which have resulted in a typology of patients according to their attitudes toward care products and the health care system: 'hedonists', 'functional sceptics', 'functional optimizers', and 'critics'. 'Hedonists' treat purchasing health care products as shopping. Since taking care of themselves brings them a feeling of pleasure, a visit to a doctor and purchasing care products is part of the self-care process. 'Functional skeptics' use the health care system and services only when absolutely necessary, seeking quick and effective solutions. The more practical and functional system they meet, the higher level of satisfaction with the system the express. ‘Trustful (functional) optimizers’ express a high level of trust toward the system but are more price sensitive than two above groups, adopting possible strategies to lower health care product prices. Finally, ‘critics’ do not trust the system and seek advice in order to feel more confident about their choice. They are also price-sensitive.

A growing research on patients’ expectations reflects a shift from perceiving patient as a passive recipient of care into an active participant of their own care process (Afkhamebrahimi & Esfehani, 2012). Patients’ perceptions of relevance of aspects of care diverge from those of care providers and minimizing discrepancy between them constitutes an important factor on the way to patient satisfaction with care. Patient satisfaction is nowadays considered a key measure of quality of care constituting a focal point of major quality assessment studies and evidence shows that patients reporting higher satisfaction with care are more likely to experience higher quality of life (Afkhamebrahimi & Esfehani, 2012).

The challenge of providing a positive experience to a customer is undeniable and applies to any sector and the care sector is no exception in that. Most organizations nowadays pay a close attention to meet at least a basic level of service standards requested by their customers, further regulated by international and national-governmental regulations. However, in case of care organizations and particularity of services they deliver, capturing the meaning of patient experience is not easy as a difference between a correct and an excellent service can be vast and additionally deviated by perceptions.

The Health Leaders Media Patient Experience Leadership Survey conducted in the US context questioned over 200 health care CEOs, CFOs, COOs, directors, senior vice-presidents and other top officials to find out a general lack of consensus on what patient experience actually was. From the interviewees, 34.5% defined patient experience as ‘patient-centered care’, 28.6% said it was ‘an orchestrated set of activities that is meaningfully customized for each patient’, and 22.7% described it as ‘providing excellent customer service’. For the rest of participants, patient experience was ‘creating a healing environment’ or something else. Still, 33.5% of respondents found patient experience their top priority and 54.5% admitted to be among their top five priorities (Shaw, 2009).

The present study built on patients’ expectations toward the system of care expressed at discharge and confronted with their experiences six months later. The main outcome measures assessed patients’ expectations as the percentage of positive responses for each aspect of expectation, and included institutions of care and support expected to interact with, and other expectations toward the system of care. The quantity and type of interactions were tackled in the six-month follow-up.

The results suggest that the entities patients expected most to interact with in matters related with stroke they had suffered was hospital, health center and fire department, and a caregiver who was taken in consideration as a care provider. As it turned out, within the following six months, respondents established the most contacts with a fire department - for transportation services provision, with the hospital (HIP) and with a physiotherapy clinic. A confrontation between experiences and expectations allowed for understanding that, besides commonly recognized care providers, that is, a hospital, a health center and a fire department, expectations seemed limited, as limited were subjects' experiences. An exception in experiences constituted rehabilitation units functioning within the RNCCI, however, that interaction was eventually initiated thank to the existing systemic conditions. As for three predominant entities referred by patients, two represented health care system and one, a fire department, happened to be strongly inserted in the Portuguese community life. As it may be a voluntary organization, firemen play an important role in the voluntary sector in Portugal and are highly recognized as a community institution.

Interactions with care providers, more or less diversified, depending on each patient's case, result in service quality provided by a certain entity as perceived by a patient. Literature review and empirical findings suggest that service quality is a construct that should be approached and measured as an attitude (Cronin & Taylor, 1992) related to, but not the same as satisfaction, and is a product of comparison of expectations with perceptions of occurred performance (Rowley, 1996). Service quality is used by service providers as a differentiating tool for building competitive advantage and gaining distinctive leadership on the market (Lim & Tang, 2000).

Donabedian's (1980, 1988) understanding on quality focuses on structure, process and outcomes. Structural indicators of quality relate to somewhat established attributes of care providers, resources they dispose of and physical and organizational settings they work in. Process indicators refer to actions and relations between and within service providers and service receivers. Outcome indicators are related to results and effects of provided care activity, both, desired and undesired. Structural quality is associated with tangible aspects of care, facilities or equipment, hence easier to determine in case of health care than social care services due to difficulties in identification of such properties (Malley & Fernández, 2010). Process quality focal point is the delivered service and outcome quality focuses on the result. It is, however, argued by some scholars that the relationship between structural and process variables is inconsistent (Brook, Park, & Chassin, 1990). Steel et al. (2004) point out that from three under consideration, process quality indicators are those more frequently used for managerial service improvement decisions since they are the most sensitive to changes. Malley and Fernández (2010) indicate that outcome quality indicators should be preferable if quality across different types of settings is of main interest.

Evidence shows that in some cases even quality of care between care providers treating a group of similar or the same symptoms or diseases is different, referring an example of a study of six interventions carried out in six different hospitals that demonstrated a variation of the rank of hospitals performance in terms of both, process and outcome measures reached in each intervention (Cleary et al., 1991). Hence, it is difficult to generalize quality service results even in alike medical conditions.

The current study applied quantitative and qualitative methods to evaluate service quality of care service providers for stroke patients. The quantitative method was applied for entities thought at the study design phase to attain a higher amount of interactions with respondents, thus, hoped for a higher amount of acquired data. The qualitative method was chosen for entities for which a number of contacts was expected to be lower, making quantitative statistical manipulation unfeasible.

Service quality evaluated quantitatively was assessed by type of entity and not individually as in traditional studies bearing in mind a variery of care service providers that in some cases would result in a few or even one participant per each service provider. Therefore, the interest focused on the generic type of care and support service. The results indicate that for care entities evaluated by means of the quantitative method perceptions of service quality were positive and rated on average high on the provided 7-point Likert scale.

For hospital services, service quality was assessed predominantly in 6 at the 7-point Likert scale, what was the case of 74% of respondents, and so was median. Interestingly, responses ranged from 4 to 7 constituting important managerial information. In convalesce units, responses varied from 1 to 7, with median 7 and a highly skewed distribution of responses. In medium and long-term units, a number of cases was too low to allow for a more sophisticated data analysis; responses, however, varied from 1 to 7 with median 3.50. Health centers presented a more equal distribution from the above care entities, nevertheless, still asymmetric. Answers varied from 2 to 7, with median 5. Two highest options of response were provided by 39.6% of subjects. The overall service quality was also evaluated by respondents who recurred to services of a physiotherapy clinic. However, participants of the study could interact with more than one physiotherapy clinic and that was verified in a number of cases making impossible computation of descriptive statistics.

When assessed qualitatively, perceptions on service quality of care and support providers were not that linear. While still a positive opinion was found in participants' narratives, a fact of evaluating quality through a number of open-ended questions allowed for a deeper understanding and insights due to a multidimensional character that quality is characterized of (Santana, 2010).

In theory, quality measures origin organizational change. By their employment, care organizations may implement necessary improvements after understanding the process of patient's choice of care providers, the areas of care provision which lack patient appreciation and reflecting on ways to attract more users (Raleigh & Foot, 2010).

Literature provides a strong evidence on two measurement instruments in the area of service quality. The SERVQUAL has been proven to be a well-developed, multi-item instrument with a five-dimensional structure. The instrument places expectations and experiences as perceived by a customer in five dimensions: the tangibility aspects of the service; the reliability of the service provider; the assurance provided by the service provider; the responsiveness of the service provider and the service provider's empathy with customers. The SERVPERF, a result of Cronin and Taylor's (1992) work, arose as an ensuing measure of service quality, considered in a scientific environment an interesting alternative to the SERVQUAL with half of the SERVQUAL items and still, more efficient than the SERVQUAL (Cronin, Steven, & Taylor, 1994). Several posterior studies, applied, compared and confirmed superiority of the SERVPERF over the SERVQUAL (Brady, Cronin, & Brand, 2002; Zhou, 2004).

However, current understanding of care turns inevitably into a network setting in which articulation between individual network members is indispensable for patient best outcomes and places a patient in the center of that network. A problem of continuity of care is of particular importance nowadays and applies in regard to the frail elderly (Hebert et al., 2003), a group under a high risk of stroke.

Following this rationale, evaluation of the network member performance by means of a measure specifically developed to capture the individuality of the organization while forgetting aspects of the network and articulation between its members, becomes restraining. Measures of service quality will have to be developed across organizational boundaries and alongside patient pathways (Raleigh & Foot, 2010). A practical measure of quality of care should currently encompass procedures or functions provided by the same care provider and, ideally, join aspects of care with these of other care providers in the chain of care in order to construct a universal instrument capturing the network perspective. Assessing quality of the entire care network is and, perhaps will remain for now, hardly possible (Malley & Fernández, 2010).

Facing this challenge, a quality measure specifically developed to capture the particularity of current issues relevant in health and social care services from the view point of the network of care perspective was proposed. It laid on the SERVPERF measure, for the initial, exploratory analysis, as that was considered a gold standard for the service quality assessment, and suggested additional dimensions for the instrument, to verify their reliability and general usefulness for the construct throughout the analysis. Several authors and organizations have defined quality of care by describing a concept according to a set of dimensions. The most frequently used dimensions comprise effectiveness, efficiency, access, safety, equity, appropriateness, timeliness, acceptability, patient responsiveness or patient-centeredness, satisfaction, health improvement and continuity of care. Recurrently cited aspects of quality of care include accessibility, empathy and attitudes of staff, communication about changes in care process, privacy and dignity, responsiveness of staff, professional skills and capacities (Francis & Netten, 2004; Malley, Sandhu, & Netten, 2006). Beattie et al. (2014) call attention that what constitutes quality within existing instruments might not necessarily have been defined from patient's perspective and it does not put patient's needs at heart. The patient's perspective and patient-focused care become especially pertinent in social care, where some services, such as hygiene, require close interaction between service provider and receiver (Malley & Fernández, 2010), turning aspects of empathy and privacy of special relevance. Taking in consideration these aspects, dimensions of privacy (also bearing in mind privacy of personal data), and articulation between service providers and between service providers and patients in what clinical information and available options of care concerned were included in the initial measure.

The structure that emerged was subject of confirmatory factor analysis through structural equation modelling with the final structure of 21 items divided into seven dimensions, Tangibles, Responsiveness, Reliability, Assurance, Empathy, Communication and Privacy. According to existing recommendations for model fit, the model was considered suitable, fulfilling or approaching to a very close degree indicated fit parameters criteria with one from six considered criteria remaining clearly not satisfied. Positive significant coefficient results were found on all possible relations, with the highest magnitude identified in the Communication dimension. On the other hand, the lowest coefficients were found in the Tangibles dimension.

These findings contribute to existing evidence by proposing a reliable measure of service quality more specifically tailored to care services proven through principal component analysis and confirmatory factor analysis to be reliable. Moreover, the measure takes into consideration the existing need of the network approach and articulation between particular care service providers in contrary to out-of-date and inapplicable approach of an individual point-of-care. The results of the application of the Careperf to care provider organizations taking part in the study suggest that, in case of hospital services, the dimension that reached the highest percent of the maximum possible score was Assurance (86.50%) followed by Tangibles (84.06%), and the lowest was Communication (49.44%), with the score far distant from all other dimensions. In convalescence units services, the most appreciated by patients dimension was that of Tangibles (85.85%), however closely followed by the one of Assurance (84.69%). Two least scored dimensions were Empathy (35.29%) and Responsiveness (39.98%). For health centers, the Careperf dimensions of the highest maximum attainained score were Tangibles (81.90%) and Assurance (78.03%), and the lowest were Empathy (44.47%) and Responsiveness (51.75%). Finally, the application of the measure in physiotherapy clinics allowed for a conclusion that the dimension with the highest rate of appreciation was Assurance (84.30%) with two next of almost identical scores, Reliability and Tangibles (82.77% and 82.14% respectively), and the dimensions with lowest ratings were Responsiveness (37.48%) and Empathy (40.87%). What emerges from the analysis is a clear pattern of better scored dimensions of service quality, apparently independently of the type of provided service. A discrepancy between ratings achieved by dimensions of Tangibles and Assurance, which scored the best in all measured organizations, and dimensions of Empathy and Responsiveness, which reached the lowest possible scores in convalescence unit, health centres and physiotherapy clinics services varied around 40 percentage points from the lowest to the highest scores. Furthermore, in hospital services, Responsiveness and Empathy dimensions were rated very well, and the weakest dimension was that of Communication, distinguishing this care provider in that respect from the others. Providing clear and accessible information to patients and their eventual caregiver regarding possible options of care, support to be found and ways to proceed raises awareness of the care system and available alternatives open to them (Pfeffer & Coote, 1991). That aspect requires perhaps a special attention, as a team of social services workers in HIP offers patients, also stroke patients, necessary information about accessible care and support services focused on each patient's medical and social conditions. Thus, patients of the hospital have in their disposal medical care and social care information in place and 49.44% of the maximum possible score of the Communication dimension can be considered a weak result, especially that the same was not verified in case of the other care providers of which perceived service quality was assessed by the Careperf. These results are, however, not completely in line on what patients said later in this respect, in the 6th-month follow-up interviews regarding information about support and rehabilitation services, when HIP was pointed out as the principal source of information about rehabilitation units. Possible reasons for that might have been twofold: (a) the hospital constitutes the first organization a stroke patient meets right after cerebrovascular accident on the care pathway; and (b) information given to patients used to be unclear. While it is difficult to generalize and pronounce on behalf of participants on the idea they had on the system, what it known is that at discharge 34.1% of respondents were sure they knew how to proceed if specialized equipment became necessary in their case, and the next 64.3% admitted to may know or eventually find out that information. The remaining 1.6% gives quite an optimistic idea that a few patients would definitely not know how to proceed to seek specialized equipment, especially considering a profile of participants of the study, not necessarily an ‘empowered’ type of patient, with their age, education level or the fact some could not write or read. The situation may be due the fact that the hospital was the first institution patients met on their pathway, and their ideas about the reality could be different to be later verified in a real context of care setting after discharge, confirming therefore the theory of Oliver (1980). Oliver’s (1980) disconfirmation paradigm assumes that predictions that customers make in advance of consumption act as a standard against which customers measure an organization’s performance. In the context of the hospital, patients’ expectations in the specific dimension of Communication could have been higher than effective experience of communication with services of care, support and assistance they actually found. Another question that arises is whether and until which extent patients actually understood information that was provided to them by, in that case, social care professionals. Findings from interviews conducted in the 6th month follow-up revealed that several patients felt difficulties in following rationale of conversation with care professionals regarding their case, but felt too embarrassed and ashamed to ask for explanation. In some situations, the wording used by professionals was found too complicated for patients, and, again, they did not feel on place to request a clarification.

A common misinterpretation between terms ‘perception’, ‘experience’ and ‘satisfaction’ has been widely acknowledged in literature (Byrne et al., 2011; Coulter, 2006), however, they continue to be used interchangeably (Beattie et al., 2014). Satisfaction is defined as a response from a consumer. In other words, it is a judgment about whether a particular good or service conveys a satisfactory level of realization related to consumption including upper and lower levels of achievement (Oliver, 1980). Interestingly, Crow et al. (2002) see satisfaction as a gap between patient’s expectations and the actually received care. On the other hand, Beattie et al.

(2014) call for caution in use of instruments measuring patient experience and instruments measuring patient satisfaction so that each purpose was properly discerned.

An interest in measurement patient satisfaction with health care experiences has been increasing over time, resulting in reports and testimonies that patient satisfaction is associated with better health outcomes (Groene, 2011), currently accepted albeit nor prevailing conviction. Recent works have demonstrated that higher patient satisfaction has been related with reduced readmission rates (Boulding et al., 2011) or reduced inpatient mortality (Glickman et al., 2010).

Fenton et al. (2012) have recently published controversial results of their study that has initiated a hot dispute on a relation between patient satisfaction and health outcomes. Results indicate that from over 50 000 participants, those most satisfied had higher health care expenditure (both for health care services and medication), they were 12% more likely to be admitted to the hospital and 26% more likely to die. Not surprisingly, the matter of health outcomes and patient satisfaction remains under debate. As the present study verified overall satisfaction with the care system as a whole, its relation between perceived health status was ascertained. No statistically significant correlation was, however, found (*rho*= .110, p=0.274), to add to the discussion of Fenton et al.

The results of the study concerning satisfaction with care services in entities with number of responses sufficiently high for statistical inferences, that is, the hospital, fire departments, convalescence units and health centers, demonstrated that patients found themselves highly satisfied with care services. In case of the hospital, the minimum response was 4 and the maximum was 7, with median 6. In convalesce units, the minimum was 1, and the maximum was 7, median 6. In health centers, scores ranged from 2 to 7 with median 5. Transportations services provided by fire departments registered the minimum response 2 and the maximum 7, with median 6. In all above entities, means were above 5 revealing high satisfaction of patients. From other considered care and assistance providers in which number of responses was relatively low, the lowest response pointed out by subjects was 4 in four of the entities under consideration, indicating lack of dissatisfied respondents. In case of two others, the Social Security and IPSS, the minimum was 2.

From conducted logistic regressions with multiple and multivariate models of Overall quality and Overall satisfaction as dependent variables, one model tested, following the perspective from literature, the impact of Overall quality (as independent variable) on Overall satisfaction. The model results suggested the impossibility of estimating the odds ratio, however, when tested on contrary, and Overall satisfaction was a predictor of Overall quality. The model was feasible, with OR 24.69 ($p<0.001$), therefore for each unit of Overall satisfaction the odds ratio of reaching higher levels of Overall quality increased 24.69 more, indicating a very strong relation between satisfaction and perception of overall service quality.

Discussion over the relation between service quality and satisfaction has been long-lasting and has resulted in rich evidence supporting either one side or another. An opinion that these are two distinct constructs is indisputable. Already in the 1980s, Parasuraman, Berry and Zeithaml (1988) argued that service quality is “related but not equivalent to satisfaction” (pp. 15-16). Following this classic standpoint, Zeithaml (1988) has contributed to that with a perspective when the term ‘service quality’ is used to refer to a global, long-term approach toward a service provider, customer satisfaction is generally acknowledged as an antecedent of quality. In situations where the expression is used to refer to something more concrete, such as quality of delivered service, then there seems to exist a stronger inclination for seeing quality as an antecedent of satisfaction. Cronin and Taylor (1992) support the position that satisfaction ensues service quality and provide evidence that service quality contributes to overall satisfaction. Bloemer and Ruyter (1995) deem that quality can be viewed as one of factors that determine customer satisfaction. On the other hand, Bolton and Drew (1991) represent the group which considers satisfaction as an antecedent of service quality. Our results indicating that satisfaction is a predictor of overall quality go in line with that last group of academics.

Several scholars have stressed out the importance of supplementing pure survival data and functional measures by patients’ subjective perceptions on their well-being and quality of life (Fallowfield, 1990; Hobart et al., 2002; Wyller et al., 1998). Wyller et al. (1998) emphasize that a precondition to such research is a determination of factors having impact on life satisfaction. Undoubtedly, in the last years, there has been an increased interest in use of quality of life as an outcome measure of treatment of diverse medical conditions and quality of received care (Hobart et al., 2002), and stroke, as a major public health issue nowadays has received its attention as well (Carod-Artal et al., 2000). Measurement of quality of life, in this case, more focused on health-related quality of life, can, potentially, provide health care professionals valuable information on diverse aspects of medical interventions, including complete information on patient recovery process, intervention effects and its evaluation (Li et al., 2004; Pickard et al., 1999). On the other hand, sceptical voices have been questioning which aspects of life quality to focus on in its assessment and which to deem less relevant, and thus have been criticizing a high degree of subjectivism measurement of quality of life is subject of (Fletcher et al., 1992; Gill & Feinstein, 1994).

Quality of life has been so far defined in many different ways, especially between different disciplines. Some academics see it as perceived global satisfaction and satisfaction within a number of key domains, including physical and psycho-social (Hörnquist, 1982, 1990). Michalos (2007), among other scholars, uses the term ‘quality of life’ as equivalent to happiness and well-being. Following the results of their empirical study, McKevitt et al. (2003) find happiness to be the main component of quality of life, although not its synonym. Wyller et al. (1998), however, challenges this understanding of quality of life considering it too broad as it may, in consequence, extend beyond other existing concepts, such as activities of daily living. As such, in their study they propose happiness and satisfaction to be more appropriate to the term ‘subjective well-being’, while quality of life is deemed to comprise more aspects. While it is common to see the use of the term ‘well-being’ as a synonym of quality of life, it is a narrower viewpoint into quality of life and constitutes an important albeit not the only one aspect of quality of life (Bech et al., 2003).

There were some attempts to simplify the problem be defining a concept by one question: ‘How would you rate your present quality of life?’ (Ahlsiö et al., 1984; Gough et al., 1983). Yet, over time, the approach of a multidimensional character of quality of life has been gaining a wider recognition in the scientific environment (Aaronson, 1988; Buck et al., 2000; King, 1996). While the term ‘quality of life’ is increasingly used in clinical medicine and medical research, it remains rarely defined, what has led to confusion when measurement of the construct has been attempted. Quality of life is believed to be a difficult construct to define and, consequently, to measure because cultural, ethical, religious and other personal values influence connotation of its perceptions.

Overall quality of life may encompass health-related and non-health-related elements. Since overall quality of life includes non-health-related factors, such as social relationships, spirituality and other life-related circumstances, but also those strongly related with health, namely emotional, mental, physical or functional, in the theoretical discussion on quality of life overall quality of life should be distinguished from health-related quality of life. In this logic, patients asked to evaluate their quality of life might be invited to evaluate relative contributions of health-related versus non-medical phenomena (Gill & Feinstein, 1994).

Health-related quality of life refers to functioning and well-being in physical, mental and social dimensions of life. More specifically, it refers to physical, psychological and social domains of health seen as distinct areas that are influenced by person’s experiences, beliefs, expectations, and perceptions (Testa & Simonson, 1996). Health-related quality of life aims therefore to tackle those aspects of quality of life affected by disease. It reflects the way patients perceive and react to their health status (Gill & Feinstein, 1994). A specific definition of health-related quality of life has also been proposed as “the value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment, or policy” (Patrick & Erickson, 1993, p. 22). The concept of health-related life quality is hence a multidimensional approach to quantify patients’ burden of disease (Haacke et al., 2006).

Measuring quality of life, as it is understood from an individual perspective, is usually carried out by identifying what specific aspects have come to be valued by an individual and by matching these to individual’s perceptions of personal satisfaction. Concepts such as quality of life are not easily measurable. In fact, Wyller et al. (1998, p. 363) claim quality of life is not actually measured but “estimated” since it is considered as a latent variable.

The present study measured quality of life by means of a disease-specific instrument in order to capture effects of cerebrovascular disorder on different areas of patients’ lives. The results measured by the Stroke-Specific Quality of Life Scale aimed to efficiently assess various domains relevant in determining stroke-specific quality of life across a spectrum of stroke symptoms and severity. Twelve domains (Self-care, Vision, Language, Mobility, Work/Productivity, Upper Extremity Function, Thinking, Personality, Mood, Family Roles, Social Roles and Energy) and an overall estimate provided the score of health-related quality of life of patients participating in the study in the 2nd and the 6th months allowing for computing the difference between those periods, with an objective to evaluate an eventual improvement in the domains of the instrument and in the overall quality of life.

The results show that in the 2nd month, in average, participants reached the highest scores in the dimensions of Language, Vision and Thinking what indicates the best quality of life is these dimensions. The lowest scores were registered in the dimensions of Work/Productivity, Energy, Mobility and Upper Extremity Function. In the 6th month, respondents were questioned again about their quality of life, and the dimensions of the highest mean scores were Vision, Language and Thinking, and the lowest were Energy, Work/Productivity, Mobility and Upper Extremity Function. Interestingly, the most problematic dimensions of life quality and those in which patients felt the strongest remained the same.

The results demonstrating that among dimensions the most affected by stroke were those related to physical function go in line with studies using other measures evaluating quality of life in stroke patients such as these of Hackett et al. (2000), Carod-Artal el al. (2000) and Viitanen et al. (1988). In patients with symptoms affirming a lower or higher degree of physical impairment in the 2nd and 6th month, that would keep influencing their daily life activities and quality of life in further stages of life, however, would still be subject of an eventual improvement between the two periods of measurement thank to the rehabilitation effort. In the present study, differences between respondents' quality of life after stroke in the 2nd and 6th month after discharge revealed an improvement of quality of life of participants in all dimensions of the SS-QoL except of Personality (a decline from 3.88 to 3.83). Statistically significant differences were identified in the dimensions of Self-care, Mobility and Work/Productivity. Furthermore, considering standard levels, the dimensions of Vision (0.057), Upper Extremity Function (0.061) and Social Roles (0.065) approached the statistical significance. Overall quality of life between the 2nd and the 6th month in subjects improved and this, importantly, was a highly statistically significant result (t= -2.755, p=0.007). Evidence demonstrates a tendency for prevalence of some cerebrovascular accident consequences over time, despite of the treatment efforts, to which belong mood disorders and depression (Clarke et al., 2002; McEwen, Mayo, & Wood-Dauphinee, 2000; Niemi et al., 1988), and repeatedly in literature, physical impairment (Clarke et al., 2002; de Haan et al., 1995; King, 1996), leading to long-term disability (Clarke et al., 2002; McEwen et al., 2000). Patel et al. (2006), in a large, population-based longitudinal study showed how substantial an impact of cerebrovascular disorder may be. Their research revealed that three years after stroke, slightly over a half of patients became handicapped, 26% of subjects were moderately or severely disabled, still, their mental health-related quality of life remained reasonable. Much more optimistic seemed evidence coming from Suenkeler et al. (2002) who investigated quality of life in patients with stroke, making measurements 3, 6 and 12 months after the event. Their data shows that not only participants remained at high level of mobility, with the capacity to perform their daily life activities (79% were able to dress themselves with no help and 87% to use the toilet with no need of support at 3 months), but also their progress did not change significantly over the study span. However, when assessing quality of life at the end of one year, it was found out that overall quality of life of patients declined. Nevertheless, reports on quality of life are far from linear and often confounded by "disability paradox" (Carr & Higginson, 2001, p. 1358). Patients with poorer health are found to have lower expectations for treatments, and, correspondingly, do not expect their quality of life to improve significantly. In opposition, a person experiencing good health may feel a considerable negative impact of relatively minor health condition, and, if evaluated at moment, feel a worsening in their quality of life (Carr, Gibson, & Robinson, 2001). Skevington (1999) gives an example of patients who, despite being diagnosed with neoplasms, rated their quality of life in the top 25% of scores of the WHOQOL-100, moreover – in all life domains of the measure, and scored better than all other groups assessed in the study. Albrecht and Devlieger (1999) focus on patients with serious and permanent disabilities and speculate why their reported perceived quality of life is good or even excellent, when, for an external observer, it should be the opposite. This might explain why, even with lowest scores in the dimensions of Energy, Work/Productivity, Mobility and Upper Extremity Function in the 6th month of the study, the mean score of Overall quality of life in the 6th month was high and the difference between the 6th and the 2nd month in Overall quality of life was statistically highly significant (p=0.007). The majority of elder people evaluate their quality of life on basis of their personality traits, social contacts, dependency level, health-related subjective experiences, material conditions and social comparisons (Guyatt & Jaeschke, 1990; Netuveli & Blane, 2008; Seshamani & Gray, 2002; Spiro & Bossé, 2000). This happens because quality of life is a dynamic concept. As dependent from expectations, it is highly particular and relative. Expectations of quality of life derive from people's background and environment they come from, from life experiences that have shaped their vision of life and coping strategies (Carr, Gibson, & Robinson, 2001). Moreover, expectations are not static and change over the lifespan according to life trajectories and experiences. In the elderly, at least less severe health problems are faced as a natural part of life and aging (Hunt et al., 1980).

In order to compare the results of quality of life between the 6th and the 2nd month, a One-WAY Repeated Measures ANOVA for each instrument dimension was conducted. In comparisons between genders, significant p-values for moment (6th-2nd) in dimensions of Self-care, Language, Mobility, Work/Productivity, Upper Extremity Function and Overall quality of life demonstrated that quality of life increased regardless the effect of gender, meaning that both, males and females registered an increase of quality of life in the second moment of evaluation. Significant p-values for gender in Mood and Energy dimensions indicate that males had higher Mood and Energy levels in both moments.

In comparisons of groups by age, significant p-values for moment (6th-2nd) and age were found in Self-care, Mobility, Work/Productivity, Upper Extremity Function dimensions and Overall quality of life, and showed that quality of life of participants of the study was better at the sixth month and higher for patients younger than 65 years, in both moments. Mastekaasa and Moum (1984) came to an interesting conclusions that the effect of age depends on whether quality of life is weighted toward happiness or satisfaction. Results of their research demonstrated that with age happiness dropped off, however, satisfaction might have increased. A number of studies conducted at other time points after the primary measurement have indicated that age is one of the factors independently influencing quality of life after stroke (Ahlsiö et al., 1984; de Haan et al., 1995; Lai et al., 2002; McEwen et al., 2000).

A comparison of groups by current professional situation (dichotomized as professionally active and professionally inactive) demonstrated significant p-values for moment (6th-2nd) in Self-care, Language, Mobility, Work/Productivity and in Overall quality of life. All these dimensions scored better in quality of life results in respondents in the 6th month.

A comparison by civil status (dichotomized as in a relationship and not in a relationship) demonstrated significant p-values for moment (6th-2nd) in Self-care, Mobility, Work/Productivity, Upper Extremity Function and in Overall quality of life. In all these dimensions subjects scored better in the 6th month. A significant p-value for civil status was found in Personality; in that domain patients who were not in a relationship presented higher average results in both moments of evaluation than patients in a relationship..

In comparison of groups by housing situation, significant p-value for moment (6th-2nd) was found in Self-care indicating an improvement in quality of life. A significant p-value for interaction (housing situation*moment) was identified in Vision, with a positive progress in quality of life in patients who lived with someone, and a negative progress in patients who lived alone. Interestingly, no significant p-value for moment was found hence no significant improvement in Vision was identified regardless the effect of housing situation.

Two last groups under consideration have, until some extent, some shared points since at later stages of life people are characterized by some common housing patterns related to their civil status, perhaps more traditional ones. Moreover, what has been recurrently found in other studies, and observed in the present one, patients shared household with other family members. That tendency at elder age cannot be considered without advantages. An important component of quality of life of a person, especially the one with any level of dependency, is support received from those of trust, and a subjective feeling to be able to count on that support. In case of stroke survivors, dependency is one of the consequences that, at a lower or higher degree, may worsen quality of life. Given an average age of a stroke patient, we can presume that quality of life, at least in its physical domains may be deteriorating gradually, due to decreasing mobility capacities and in spite of efforts to maintain them on the past levels. Some of post-stroke limitations included in the SS-QoL measure employed in the study were comprised within dimensions of Self-care, Language, Upper-Extremity Function or Mobility. These abilities may have a negative impact on other spheres of a person’s life, affecting Mood and Family Roles, followed by Social Roles or reducing Energy. Overall quality of life without appropriate support may worsen meaningfully over time.

In Portugal, policy makers seem to still rely on social bonds as those typically providing social support due to tradition, and accept them as natural caring attitudes toward elder family members. However, inevitable changes have been leading into redefinition of the traditional family model and dynamically contribute to shifting a structure of social support sources. A high number of women on the labor market decreases their vailability as potential caregivers (Costa-Font, Gori, & Santana, 2011). Economic crisis has triggered a wave of migration with an average age below 29 of a half of leaving the country (OECD, 2012a). Another migration is that from the inland to large cities on the coast line offering more employment opportunities. Social isolation has turned to be a very likely scenario for some and constitutes a realistic threat to a person’s well-being (MacDonald & Leary, 2005; Santana, 2000), hence the importance of having social bonds and support from individuals and groups considered the closest and most significant. A post-stroke burden can be intensified by difficulties in maintaining satisfactory social relationships, a difficulty which can be alleviated by ties with kins and non-kins important to the person (Lynch et al., 2008; Tsouna-Hadjis et al., 2000).

Despite unceasing changes in family traditional roles driven highly by economic and cultural changes, by the time of the study a family remains the prime source of social support. From the point of view of a patient, a family is perceived as a preferred caregiver for an elder family member (Carvalhais & Sousa, 2013; Quaresma, 1996). According to Eurobarometer (2007), only 20% of the surveyed Portuguese respondents would give preference to a professional home care service comparing to an average 27% of the other EU-member states. Our study complements to this knowledge, reinforcing a stronger perceived social support available from the family than from other groups in the study. This preference needs to be, however, carefully deliberated with a notion of actual physical and emotional burden of providing care and support to a familiar in state of continuous readiness (Opara & Jaracz, 2010; Rigby, Gubitz, & Phillips, 2009; Rigby et al., 2009) affecting a caregiver and other potential members of the family (Lutz & Young, 2010; van Heugten et al., 2006).

An image of a typical stroke patient emerging from this study indicates a subject in a relationship, mostly married, sharing residence with relatives. The analysis demonstrates that respondents in a relationship had, in average, stronger social support from family, neighbors and friends, however, evidence confirming statistical significance was found only in case of family (p=0.005). These findings are in accordance with other studies; for instance, Mota-Pinto et al. (2011) indicated marital status as a key predictor of social isolation in in-depth analysis of social network in the Portuguese context. Until some extent, civil status could be related with the fact of sharing a household with another person (or persons), what in the present study was associated with a higher level of social support from family and neighbors. In interventions such as the one implemented by the HOMECARE project, requiring presence of a number of new persons in participant's life during the study period, it is plausible to believe that the patient's family network size may change. The network can either increase or decrease, depending on personal traits and characteristics of its members, and a variety of other, external, factors. From one hand, the project team's regular presence and sessions with professionals might result in reestablishing damaged foundations in relationships and breaking the stigma associated with contacts with a family member affected by stroke, an issue reported by several authors (Hare et al., 2006; Kitzmuller, Asplund, & Haggstrom, 2012). Moreover, awareness of the intervention could make extended family members become more involved and interested in the recovery progress. On the other hand, a presence of 'strangers' (because that the team of professionals was for those of patients' relatives who did not share the same household) could constitute a limitation for contacts between respondents and their further family members. Also, independently on the level of affinity, for more introverted and timid relatives, rehabilitation sessions could be incommoding to the point they could limit contacts with the patient during the study span.

The results of the present study suggest that the difference in perceived available social support, as measured by the Lubben Social Network Scale-18, existed between genders in favor of men (in overall support: t= 2.089, p=0.039), what is interesting as literature frequently assumes that women have a larger social network and social support than men (Haines & Hurlbert, 1992; Presidência do Conselho de Ministros, 2004; Saraceno & Naldini, 2003), nevertheless, studies in this matter are in general inconclusive. Vinokur, Price and Caplan (1996), for instance, do not give reasons to believe there are any differences in gender. Believing or not in a direct relation between the size of a network and support it provides, the fact is that women tend to be emotionally more involved in their network, of whatever size it is (Lim, Yi, & Zebrack, 2008), inevitably exposing themselves to stressors emerging from that network (Bracke, Christiaens, & Wauterickx, 2008; van de Velde, Bracke, & Levecque, 2010). A network, as an open and dynamic system, is a subject of changes, that is, conflicts, departures, deaths of its members, and women are more affected by these events, while supporting other members experiencing difficult moments at the same time (Belle, 1983). This tendency is nowadays probably enhanced by increasing longevity of populations and a discrepancy between genders in life expectancy.

The LSNS-18 applied to measure respondents' social support allowed for assessing social relationships and a couple of participants noticed, as a comment to the interviewer, that perhaps the size of their network was not extensive, but they had few, close, unquestionably reliable peers with whom they maintained a regular contact of which they were absolutely satisfied. Nonetheless, there is no evidence in literature that members of smaller networks provide better social support to compensate the size of their group (Wellman et al., 1987) and a body of literature demonstrates that larger networks tend to provide more social support and a higher proportion of members in the network is usually more reassuring (Burt, 1987; Durkheim, 1951; Lim, Yi, & Zebrack, 2008; Seeman & Berkman, 1988). Participants of the study who, after discharge and within the following six months did not use services of a Private Institution of Social Solidarity were identified to have received more social support from their family, neighbors and friends, as they perceived, and social support in overall, comparing to the group who used services of IPSS. The difference was statistically significant for support of family (p=0.011) and overall support (p=0.042). A network, with its subgroups providing social support may not, however, necessarily be a source of constant fulfillment and happiness to a person. In its assumption, social support intends to be satisfactory, but, with the enlargement of the network, the probability of interpersonal conflicts and complications between its members increases. Riley and Eckenrode (1986) found that larger networks provide, indeed, more social support, but are, at the same time, a source of more interpersonal problems.

Events happening across the lifespan affect, at several stages of life, due to numerous reasons, a person’s well-being. Changes that tend to occur with age and increase in the elderly affect health and lead to reducing social bonds. Aging then is likely to be associated with shrinkage of social support and network, as well as a change in its composition (Walen & Lachman, 2000). Over time, importance of neighbors or friends may increase, as a result of death of a spouse and other family members or their distance. Interestingly, value associated to support received from a neighbor or a friend may be viewed as more appreciated as that from a relative, which is often unconsciously seen as an obligation (Fan, 2007; Stuifbergen & van Delden, 2011; Theixos, 2013). While findings of this study clearly point out family as a pillar of social support for stroke patients, the importance of neighbors and friends is also substantially valued by respondents, not deriving from their belief of attainability of that support they had presented at discharge. Perceived quality of family support was esteemed the highest, with 45.3% respondents attributing it the maximum rate. Globally, family support was rated as ‘very good’ or ‘good’ by 80.2% participants, followed by 77.7% given to friends and 72.3% to neighbors who were attributed such score. These findings were confirmed by interviews and provided richer evidence and personal insights on social interactions of stroke patients. Apparently, therefore, consideration of social support by stroke survivors in Portugal does not represent substantial variation among measured groups. These results contradict some evidence suggesting that most relationships with non-kins, even if living in the neighborhood, are of weak and not close character. American data indicate that, in average, a person knows zero or one neighbor who can be considered intimate, and one other who can be considered active but not intimate (Hunter & Riger, 1986) having direct effect on intensity of willingness to provide eventual support (Wenger et al., 2007). Some scholars debate whether patterns of social relationships between kins and non-kins are characterized by complementarity or substitution (Hank & Stuck, 2008; Kohli, Hank, & Kunemund, 2009). Such differences can also suggest we might be dealing with a more complex phenomenon than one could at first think, which can be driven by context-specific factors such as culture or tradition (Attias-Donfut, Ogg, & Wolff, 2008; Kohli, Hank, & Kunemund, 2009).

Results indicate also that considering a difference of quality of life between the 6th and the 2nd month, in patients with a very high support from family in the dimensions of Vision, Language, Thinking, Personality, Mood and Energy, quality of life substantially improved. Among respondents with a very low level of social support from family, a fairly resilient drop of quality of life in the dimension of Energy was registered. Interestingly, subjects with a very low level of family support made considerable achievements in quality of life in Mobility, Work/Productivity, Upper Extremity Function and Social Roles. Was that case somehow driven because they knew they were left on their own?

Respondents who could count on very strong support from neighbors, progressed much in terms of quality of life in the dimensions of Mobility, Work/Productivity, Thinking, Personality, Mood, Social Roles, Family Roles and Energy, that is seven from twelve of the dimensions of the instrument. More specifically, while the results of patients receiving very high perceived social support from neighbors made a significant improvement in the domains of Personality, Mood and Family Roles, in case of patients with the lowest support from neighbors’ results in these domains worsened. The fact of such strong support from neighbors may be derived from a number of factors. First, because after years of living focused on own family, driven partially by cultural values and principles, a person is obliged to start living the life ‘again’, when children get adult and establish their own families. Over time, the importance of neighbors or friends may increase, as a result of death of a spouse and other family members or their distance. Generally, it is assumed that changes occurring with age increase their intensity in the elderly and lead to reducing social bonds. Aging then, is likely to be associated with shrinkage of social support and network, as well as with changing its composition (Walen & Lachman, 2000). The second reason explaining a strong impact of neighbors support on person’s quality of life may be explained by the structure of the proper questionnaire. The questions of the LSNS-18 regarding neighbors come before friends and, as frequently happened during interviews, respondents had difficulties in distinguishing who was considered a neighbor and who was a friend if, as they felt, both belonged to the same category. After a more accurate explanation given by the interviewer, also provided jointly with the original questionnaire by the authors, this ambiguity could have been eventually elucidated. Still, the risk of uncertainty remained due to specificity and characteristics of participants of the study, with possible cognitive impairments additionally influenced by their advanced age.

Analysis of the LSNS-18 Friends subscale led to the conclusion that patients with the strongest support from friends had, in average, much higher improvement in the dimensions of Thinking, Personality, Mood, Family Roles and Social Roles. On the other hand, among subjects with the lowest support from friends, considerably higher scores were achieved in the dimensions of Mobility and Upper Extremity Function. Remarkably, a soundly strong decrease in the dimensions of Personality, Social Roles and Family Roles of quality of life was registered among respondents with a very low level of social support.

Respondents receiving very high overall social support improved their quality of life in a much higher degree in the dimensions of Mobility, Work/Productivity, Thinking, Personality, Family Roles, Mood and Social Roles. Conversely, in case of patients with very low overall support, reasonably strong decrease of quality of life was registered in the dimensions of Mood, Thinking, Personality and Family Roles. A slight increase of overall quality of life was detected in participants with a very strong social background and a minor decrease of overall quality of life was observed along with very low overall social support.

Lubben Social Network Scale-18 tested for the number of factors associated with its original structure in the sample of the Portuguese stroke patients participating in the study revealed a three-factor structure, however, with 15 items. The KMO measure of sampling adequacy was 0.855 and the Bartlett’s test was 1077.489 ($p<0.001$). The lowest observed communalities now registered were from 0.4 (three variables) to 0.8 (one variable). Three factors of the solution accounted for 62.38% of the total variation. Factors presented very good levels of item-total correlation coefficients (from 0.56 to 0.86) and were characterized by excellent internal consistency with Cronbach’s alpha between 0.83 and 0.92. The factor associated to social support of family demonstrated the highest mean, 4.06, followed by the factor relative to social support of friends with mean 2.8, and the factor combining items relative to social support of neighbors which had mean 2.6.

All these results do not surprise as social relationships are an important aspect of person’s life and constitute a factor influencing well-being. Literature clearly demonstrates destructive consequences of poor social support and, on the other hand, provides evidence on protective effects of availability of social networks, both in their quantitative and qualitative dimension, on maintaining physical and mental health (Astrom, Asplund, & Astrom, 1992). Older adults, a predominant target of cerebrovascular accident, among a number of other health conditions of which risk increases with age, experience an unceasing process of shrinkage of social bonds. It reaches its peak with a death of a spouse and/or other close family members, leading, inevitably to, larger or lesser scope of loneliness. Societies aging in a global dimension will only be escalating during next decades, hence the urgency of policy initiatives to prevent social isolation and promote social support. Social isolation relates to integration of individuals into their wider social environment with the size of their social network constituting a measure of that concept (Wenger, et al, 1996). Loneliness is a perception of availability of the level of social contacts measured often by social support they can count on (Andersson, 1998). As a subjective feeling, loneliness is a pessimistic result of an evaluation of availability of kins and non-kins to make part of a person’s life and is revealed in a situation of the actual need of help or support by kins or non-kins. Loneliness can determine into a high extent person’s quality of life, especially that it is able to influence its other aspects, such as mood or energy, and effectively limit a person’s mobility within a proper household affecting their motivation to recovery effort (Theeke et al., 2012). Relations between quality of life and other domains of life demonstrate how complex phenomenon we are dealing with (Borge et al., 1999), and that, indeed, quality of life is a multidimensional concept and as such should be approached (Bowling et al., 2002; Wismeijer, Vingerhoets, & de Vries, 2010).

Social support constitutes therefore a current social issue of high relevance and social isolation represents a very realistic threat to well-being. In older adults, the most subjected to stroke incidents, social support through social linkages becomes a challenge as aging is likely to be associated with decline of a person’s social network (Population Reference Bureau, 2009). In case of stroke patients, struggling frequently with motor limitations and cognitive impairments, and suffering from related emotional burden, sustaining satisfactory social relations seems therefore to be even more challenging.

8.1.2. Phase two

The review of national and international literature on the intersectoral action surprises with the amount of empirical documentation and, on the other hand, scarcity of theoretical approaches. This tendency has been, however, changing over time, with few conceptual approaches appearing last years. Visibly, there is interest into accommodating intersectoriality into scientific theorems. Taking into account a scope of the appraisal, it allows for a comparison of an international and national dimension of visibility of cross-sector collaboration in legislation and general documentation. In general, Portugal lags behind in what intersectoriality in health and social care concerns when compared to international standards. Interestingly, though, a use of the term and a call for intersectoral action appears in abundance in regular activity, project or study reports, working papers, white papers, notes and personal communications. Official documents from national bodies concerning health and social care exist in abundance and are easily available from several sources. The quantity of accessible documents is substantial, including official reports, official publications and presentations, among others. The range of use of expressions seems vast and there are a few concerns in conceptualization of the partnership concept and its intensity. Definitions of a term used to describe a collaborative linkage vary from one document to another; however, what makes it even more challenging is leaving the interpretation of the classification to the reader. In fact, little emphasis is put to conceptualization of terminology employed in a document. Moreover, expressions are frequently used interchangeably within one document.

The tendency for the use of intersectoral-related phrases is contrary to that observed in the Portuguese legislation. A systematic review of the Portuguese legislation reveals an extremely cautious usage of the expression-related terminology.

Literature search led into two conclusions. While evidence exists on the practice of intersectoral action, little has been made in order to explain this phenomenon as a theoretical concept. Most of evidence exists in form of grey literature, and the share of peer-reviewed literature is scarce. Generally, empirical documents were identified, with a little contribution of theoretical knowledge and a few of them regarding the methodological approaches to intersectoral action. In case of legislation, the situation was somehow similar. Evidently, the use of intersectoral-related expressions in laws and legal acts needs to be acknowledged. An in-depth analysis indicates, more importantly, that the practice has become more meaningful over time. If analyzing regulatory acts, the level of concreteness and specification of the scope for which the term is used (with an indication of a concrete entity, in some cases), has increased. The average notion of intersectorial partnering is present in the Portuguese legislation, perhaps, more than it seems from the results here indicated. While the proper term seems not frequently used, especially in what health and social care areas concern, a collection of other terms may be an indication of some type of collaborative indication. Nonetheless, bearing in mind the time limits of the performed analysis, the amount of legislation on intersectoral action in health and social care in Portugal remains scarce. A number of key laws and regulatory acts have been identified, yet, the major part of legislation constitute that of the 2nd Series of *Diário da República* thus of the local scope.

Collaborations and partnerships have been seen to increase significantly over last years and can be perceived as an opportunity to create competitive advantages in general (Lim & Tang, 2000). Christensen and Larson (1993) consider collaborative relations between health care professionals a key factor in any process of improvement. This viewpoint was clearly shared by representatives of interviewed institutions providing a broad kind of care and assistance to stroke patients. Collaborative action need between organizations in light of current complexity of care demand was acknowledged and emphasized.

Content analysis was the method employed to analyze the interviews. Content analysis cannot be seen as a linear approach. It is considered more complex and difficult than the quantitative analysis because it is less standardized (Polit & Beck, 2004). There are no simple and objective guidelines to conduct qualitative data analysis, each research is distinctive and results depend on knowledge, analytical skills and style of the researcher (Hoskins & Mariano, 2004). In fact one of challenges of content analysis is that there is no simple and exact manner to conduct it, in a way that no unique defined standard or pattern has been established according to which content analysis should be carried on.

Despite a relatively limited number of conducted interviews, some evident patterns were identified about perceptions of care service providers regarding system insights, collaboration characteristics, advantages and disadvantages between institutions within different collaboration levels. Three main themes - Macro, Meso and Micro Levels were based on the previous study of Valentijn et al. (2013) and subsequent categories followed that the logic, however, adapted it to the rationale of the present study as this strategy was more adequate to capture the idea of organizational partnership linkages this thesis aimed to investigate. As such, the study based on categories related to collaborative patterns rather than focusing fully on integration concepts. This resulted on creating the categories of System Integration, Organizational Collaboration, Professional Collaboration and Clinical Collaboration. As can be noticed, the first category remained its original classification, as proposed by Valentijn et al. (2013), since it was considered that on the systemic, Macro Level, that approach was more appropriate than collaboration.

The process of coding the Macro and the Micro Level was naturally accomplished with the process of summarizing information, likewise the elaboration of the relations between concepts or categories was straightforward and objective. Macro Level was clearly related to system integration, and the information was evidently related to the perception of legislation, knowledge of legislation and regulations of collaboration between organizations: *"The law that is on the basis of long-term care since 2006"* (a hospital); *"No, with the Social Security we have partnerships, but only to have this form of knowledge"* (a Private Institution of Social Solidarity); *"Dependent on the income of the patient"* (about funding of provided services).

Systems are well-established and stable inter- and intra-sets of structures and configurations. Any attempt of intervention is understood as an attempt of a system change and creates an automatic negative system response (Shannon & Schmidt, 2002). Systems and organizations respond according to their internal procedures, rules and beliefs, which derive from their history and past experiences and on them are based. Therefore, in addressing new challenges identifying them and adjusting into them actions they should have capacity to come ahead partner's expectations.

The Micro Level was clearly associated with patient-focused collaboration. The information was directly related to the perception of clinical diagnosis collaboration: *"We've got no information, there is, but is not available and in most cases data is not introduced"* (a rehabilitation unit); *"The doctors have, I don't, because as I am not a doctor I don't have to evaluate it. I have to have access to social context, etc., other variants, the clinic, and all these tests, are forwarded to our doctors"* (a charitable organization).

The Meso Level coding process was more complex than the case of the other two themes. Organizational Collaboration and Professional Collaboration conceptualize this main theme. Organizational Collaboration refers to services that are delivered in a networked structure whereas Professional Collaboration is related to quality share and efficiency in organizational collaboration setting. Because of these characteristics, the allocation and coding process in the Meso Level theme was non-linear and less objective than in the other themes.

When analyzing perceptions of care providers in health care institutions (hospital, health center, physiotherapy clinic, rehabilitation unit) and care providers working in organizations not related directly to health-care provision (firemen, *Misericórdia*, IPSS, parish council, city council) some patterns turn evident. At the Macro Level, it was apparent that the health care service providers had enhanced knowledge and access to legislation governing collaboration between organizations. At the Meso Level, there were some common and divergent patterns between perceptions of the care providers in both analyzed groups. For instance, formal relationships were found relevant for 25% of health care service providers and for 60% of "other" care service providers, and informal relationships for 100% of health care service providers and 80% "other" care service providers. Collaboration between organizations and sectors has become a strategy for improving health and well-being, and a level of formality of relationships is much subjected to cultural conditions (Batt & Purchase, 2004; Mattessich, Murray-Close, & Monsey, 1994). The more informal relationships, the more difficult becomes capturing their genuine nature and their evaluation. Conversely, informality of relationships shall not be understood as less valuable and possibly profitable than formalized relations. Adaptive capacities of organizations are (into a higher or lower degree) limited even considering the systemic relationship and importance of structural connection.

WHO (1997) acknowledges that, specifically the health sector, is characterized by particular complexities associated with cross-sectoral activities, also reflected in the present study by factors such as: (a) first and foremost, the health sector (as a whole - as found out in the field work of this thesis - and individual elements of the health system) must be willing to collaborate with other sectors; (b) sectors and involved organizations need to have capacity to assume the suggested action; (c) intersectoral activity is built on already existing structures or, if not, is widely accepted and supported by the community; (d) some relations between involved entities are already established and robust, encouraging others to join; (e) the initiative is planned and well-conceived, with adequate control and evaluation measurements; (f) initial evaluation needs to result in sustainable and promising results.

Furthermore, it became evident that between the interviewed health care service providers there was a common idea about existence of admission criteria and continuous training programs in their organizations. Under the Micro Level theme, a universal perception of the relevance of confidentiality of patient clinical diagnosis information was noticeably manifested by all interviewees.

The most important divergent perceptions were related to knowledge about legislation and access to the patient clinical diagnosis with a clear advantage on the side of the health care entities on the subject of promoting factors of collaboration between organizations.

When thinking about patients’ insights provided during interviews on the topic of Assessment of Situation and Care Provision after Discharge, these in fact confirmed some opinions acquired during interviews with representatives with care providers. One of the conclusions of interviews with patients was that information about rehabilitation units was predominantly received in the Hospital Infante D. Pedro during the patient’s hospitalization (from a nurse, a social worker, a doctor), or through the Social Security. Most admitted not have been aware about the rehabilitation unit before the hospitalization for the recovery purpose after stroke. Patients reported that what concerned medical monitoring after stroke, including accompanying by the family doctor, that was taking place, facilitating their recovery process (n=49). Importantly, at that point, despite having emphasized to have resorted to the GP if necessary, subjects admitted their access to information about rehabilitation services, support and assistance existing in the community was perceived as hard and intricate (n=51). In light of current considerations the meaning of this information is clear. Not only did respondents consider blurry and less accessible information about care and support available for them in the community, neither did they find it easy to move through the system for the assistance if such was necessary.

Analysis of the intensity of relationship made on a basis of the Levels of Collaboration Scale of Frey et al. (2006) who based it on the model of Hogue (1993) allowed to verify relationships between stroke care and support of entities as perceived by them and gradually increase the relationship intensity, eliminating in the first place the weakest connections.

As betweenness centrality has no limits, a reasonable approach seemed to be comparing a distribution of values of the metric among considered configurations. It was found out that along the process of decreasing intensity of relationships between entities, median of betweenness centrality increased (in the configuration 3-5) to substantially drop (in the configuration 4-5). Vertices with high betweenness centrality are frequently located at the crossing of two or more high dense network groups. This is an indication that at the level 4-5, the structure of the network changed significantly in terms of connectivity between vertices.

Closeness centrality, if observed throughout configurations of relationship intensity, remained always very low, even considering its maximum values. One characteristics of this metric is attributing high scores to nodes located near the center of local constellations of nodes, that is, local communities, within the overall network. The results clearly point out continuous high density of the network and a close localization of vertices from the center of the group.

Eigenvector centrality allowed for confirming a clear absence of vertices linked with parts of the network of the greatest connectivity throughout different configurations of collaboration intensity. A relative strength of a node remained very low.

Clustering coefficient analysis across the network evolution suggested that, in average, the metric value was around 0.5 for the global network and did not change when the first collaboration intensity level (‘networking’) was eliminated, either with the elimination of ‘cooperation’ or ‘coordination’, having, however, variations in other indicators of the measure.

With a limitation of the relationships into intensity 4-5 a significant change was identified indicating a movement toward decline of clustering tendencies within the network.

Frey et al.’s (2006) model was found the most suitable to the present study to approach measuring intensity of collaborative linkages between care and support providers in the Portuguese context from existing theoretical contributions after an extensive literature review. The five-level model was found appropriate, with an adequate number of levels to express the collaborative action, neither too high, nor too low. Other available models of collaboration intensity were either considered too extensive, hence too complicated for the population under study, or intensity levels they proposed were hardly applied to the Portuguese reality of the health and social care systems. Still, the chosen instrument was not without disadvantages. First, Frey et al. (2006) following originally Hogue (1993), consider collaboration the highest level of the intensity of relationship. That, at first sight seems a positive aspect since studies frequently tend to focus on integration of care, and in a multiple-setting and networked multi-agent context toward which current care systems are tending this approach is infeasible and unmanageable as all systems, organizations and services cannot be integrated. However, when looking at the description provided jointly with the classification of the intensity, one may argue that it has much in common with integration, despite its designation. Frey et al. (2006, p. 387) deem collaboration as a level on which “consensus is reached on all decisions” and “members belong to one system”. One challenge with the application of the instrument in the empirical part of the study was an apparent little acquaintance with a term ‘coalition’ as it is not a common word among several others in use to describe collaborative action. It was overcome, as the classification comes with the attributed numeric values and a short description in order to facilitate the understanding.

However, neither the proposal of Frey el al.’s (2006) nor any other existing model seem to comprise aspects of collaborative stages adequately to the complexity of care services needs due to the amount of long-term and chronic health conditions and requirements of current health and social care systems demand. Several academics consider as an end-point of a collaboration continuum merged organizations with an objective to create a new joint identity. The present study proposes therefore, a framework for evaluating the intensity of collaborative relationships between organizations, yet, with no objective of their integration as the highest degree of involvement. While integration has been proven to function within one system-setting (professional integration) or even specific groups from different settings and vast evidence exists on examples of such implementation, when considering more complex settings, such as intersectoral environments, integration does not seem to be a reasonable solution to a problem.

A proposed model results from both, literature review and the empirical application of the instrument of Frey et al. (2006), and encompasses elements deemed vital for evaluating the intensity of relationship between organizations with a likelihood they may derive from different sectors. The proposed model is presented in Figure 96.

Relationship characteristics	**Intensity Levels of Collaborative Linkages**
	No interaction at all *0*
	Networking **1**
	Aware of entity Independent decision-making
	Cooperation **2**
	Separate entities Typically informal relation Independent decision-making Provide information to each other Loose communication process
	Coordination **3**
	Separate entities Informal relation or formal agreement Some shared decision-making Established communication process Communication means tailored to the context Regular articulation
	Collaboration **4**
	Separate entities Formal agreement Shared decision-making for common purpose Shared vision, values, objectives Trust Joint contribution of resources (financial, human, etc.) Established communication process Communication means tailored to the context Regular articulation
	Partnership **5**
	Common entity (may be temporary) Formal agreement Joint decision-making Shared vision, values, objectives Trust Mutual accountability Joint contribution of resources (financial, human, etc.) Not a goal in itself but means to achieve objectives Established communication process Communication means tailored to the context Regular articulation

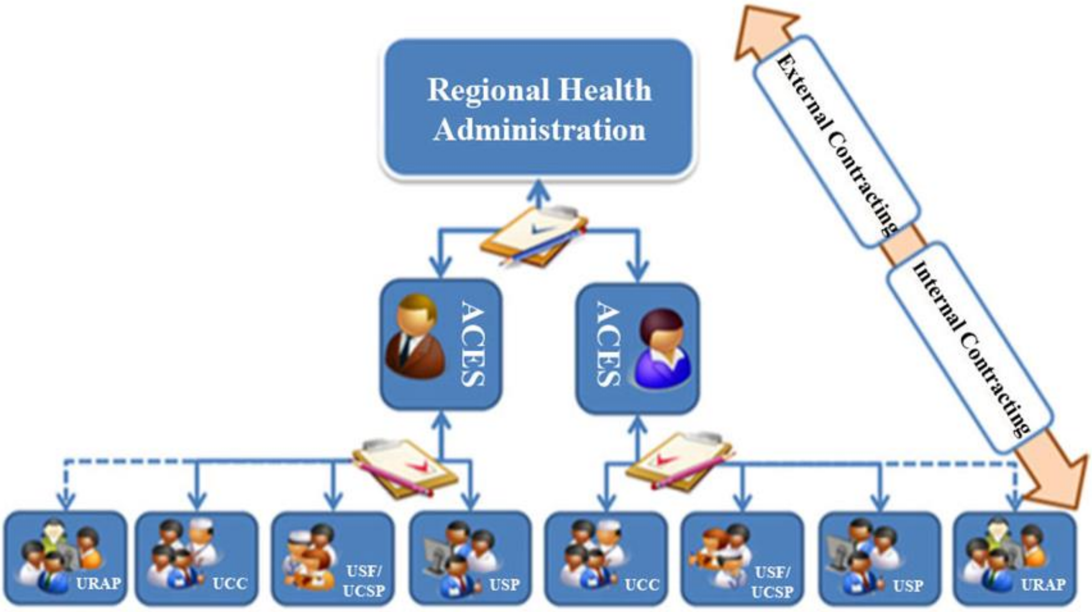
Figure 96. Model of Intensity Levels for Collaborative Linkages

The model provides five levels of intensity for collaborative linkages, building on Frey et al. (2006) includes also level 0 (‘no interaction at all’) as it was found relevant to make a distinction between no awareness about the organization and acquaintance with it. On level 1 (‘networking’), entities are aware of each other but continue independent at the organizational and functional level, with self-governing structures and separate decision-making processes. On level 2 (‘cooperation’), formally distinct entities are aware about each other and establish relationships, typically on the informal level. There is communication between them, albeit unstructured and conducted on a low degree of formalization, and exchange of information. On level 3 (‘coordination’), entities remain formally separated, however, the process of decision making moves toward a division between involved organizations. The relationship remains on informal level or moves toward a formal agreement. Communication and articulation between entities is set up and frequent. On level 4 (‘collaboration’), independent a legal and organizational way entities work together in order to achieve common objectives. The relation is based on a formal agreement, and shared vision and values with a contribution of resources from all partners. Regular communication and articulation constitutes a basis for decision-making process in which all participate. On level 5 (‘partnership’), a formal agreement based on common vision and objectives leads to launching a new entity, sometimes temporary, with the involvement of all partners. The entity is characterized by joint decision making and joint contribution of resources with mutual accountability. In practice, partnership agreements are often established for achieving a specified objective and then they split up, nevertheless, cases of partnerships which evolved over time, adapting into new challenges and goals, and the changing reality, also exist.

Finally, attention shall be put on organizational changes within care system, here more specifically within primary health care system since the present study has been designed. The primary care reform has aimed at restructuring the primary health care system and promoting decentralized care facilities to increase accessibility to primary care units. The progressing transformation of the primary health care is considered unique in history of the Portuguese health care. ACES may contain a range of Family Health Units, Community Care Units, Personalized Health Care Units, Shared Assistance Resources Units and traditional health centers together with the Public Health Unit, the Management Support Unit and the Clinical Council respective for every ACES. The crucial role in the system plays USF, a nuclear group of health professionals who accompany a certain person; typically a family doctor, family nurse and an officer who deals with administrative part of the process, although they may use common resources of the ACES, depending on their availability. USF are considered, until some extent, an expansion of competencies and responsibilities of health centers; nonetheless, a crucial distinction between their concerns of service quality needs to be emphasized at this point. Community Care Units (*UCC - Unidades de Cuidados na Comunidade*) are strategic units, with a plan preceded by health and social diagnosis of a given community and consisting of programs to be implemented continuously in order to solve identified problems. They provide health and social services within a domiciliary and community scope. These entities were considered essential to be incorporated into the new model since traditionally health centers in Portugal used to be involved in some community activities, as well. The vital difference between USF and UCC is the emphasis: while for USF it is a patient and a family, the aim of UCC services provision is the community as a whole. Personalized Health Care Units (*UCSP - Unidades de Cuidados de Saúde Personalizados*) are transition models between health centers and USF. Offering the same type of services and requested to reach at least minimum acceptable service quality level in order to guarantee an equal standard of services for citizens, they are not entitled to financial incentives as USF are. Shared Assistance Resources Units (*URAP - Unidades de Recursos Assistenciais Partilhados*) are entities composed of a number of different categories of health professionals and responsible for common resources allocation depending on request. Public Health Units (*USP - Unidades de Saúde Pública*) are transversal bodies, with precise tasks comprising prevention and dealing with problems affecting considerable groups of population. While in case of every other entity, their focus limits into a restricted area, a zone of activity of USP is a whole region of the respective ACES. Management Support Units (*UAG - Unidades de Apoio à Gestão*) connect administrative professionals who solve bureaucratic and operational issues with the Clinical Council (*Direcção Clínica*) - a technical organ of clinical governance, composed by professionals with a background in health, who offer support in decisions for the Executive Director (Szczygiel, Pinto, & Santana, 2011). The initiation of the primary health care reform took place before the launch of the study; however, at the time being its progress was not yet sufficiently attained. Moreover, from the perspective of stroke patients, difficulties existed in distinguishing a new concept of Family Health Units from traditional health centers. The situation did not change over the study span with the advance of the reform, demonstrating stroke patient are not prone to adapting to new situation easily.

From a perspective of time, primary health care reform attempts to its implementation along last years have had in their intention reinforcing this level of care toward the community, with an importance given to autonomy of units, organizational and managerial flexibility, continuous improvement, teamwork and modernization. The new organizational model of primary health care has been considered more complex, not without a reason, than the traditional model of health care. It requires more qualified and rigorous players with an objective to give prompt and adequate response to the current health care demand (Ministério da Saúde, 2014).

Reconfiguration of ACES, initiated in 2012 on basis on Ordinance no. 308/2012, Ordinance no. 310/2012, Ordinance no. 394-A/2012, and Ordinance no. 394-B/2012 reduced the number of so far existing ACES combining them into greater organizational structures. Contracting primary health care, bearing in mind different target populations, now even more diversified within more embracing geographic zone by each ACES, is organized in two processes: external and internal contracting. External contracting is executed between ARS and particular ACES, formally accomplished by Performance Plans and signed by a proper contract. Internal contracting is executed between ACES and particular functional units, formally accomplished by signing a Commitment Letter. The contracting model currently applied in the health care system is presented in Figure 97. This model of contracting with ACES needs to be adapted to specificity of Local Health Units and their role of providing primary health care, according to Decree Law no. 102/2009 (Ministério da Saúde, 2014).



Source: Adapted from Ministério da Saúde (2014)

Figure 97. Contracting model of an ARS with ACES (external) and ACES with respective functional units (internal)

8.2. Limitations and suggestions for future research

The present study, as any research, has been subject of a number of limitations that need to be mentioned at this point. An effort was made for the most suitable study design and for finding alternatives to situations arising during empirical part of the work.

8.2.1. Limitations of the study

As any empirical study, this one also encountered challenges and its limiting aspects need to be referenced here. An additional impact was exerted due to a level of its complexity, in terms of total duration of data acquisition, application of quantitative and qualitative methods and their variety, and specificity of subjects of the study, not only because of dealing with human population, but mostly because this was an elder and vulnerable, in several aspects, group.

Conducting the study in the district of Aveiro limited the geographic range and eventual further generalization of results. The study began in the hospital where first data were collected, and required a six-month follow-up. In order to keep the contact with patients, those were traced, what did not prevent from losing respondents due to a number of different reasons, independent from the HOMECARE project team responsible for patients case management.

A lower number of patients who interacted with certain care and support entities made impossible proceeding with further statistical analyses for these institutions. Existence of missing values could result in some loss of statistical power.

Patients evaluated by case managers as not able, by reasons deemed by them as justifiable, to be interviewed were not visited at the sixth-month follow-up, thus, the initial number of participants dropped into 102 at that time, limiting the amount of data to be analyzed.

Entities taking part in the study and evaluated with the Careperf service quality measure were assessed per type of service and not per entity. That needs to be reminded while interpreting the data of this study. Ideally, we would like to have sufficient data to attribute subjects to each participating entity, which were numerous and analyze them individually. Here, the application of the Careperf and robust statistical analysis was possible in case of HIP. Also, analysis of service quality and satisfaction was not performed for physiotherapy clinics as a number of patients used more than one clinic and those cases had to be excluded.

When applying a questionnaire composed with several options of response, it was found that respondents used to have sometimes difficulties in determining the level of agreement/disagreement with the statement made. This happened while employing the SS-QoL and Careperf measures. The Careperf was based on the SERVPERF instrument and pretested although no serious problems at the time were detected. Identified difficulties can, however, be related to both, cognitive impairment due to cerebrovascular accident and age of respondents. The total sample provided a global vision of stroke patients' profile. It is recommended that further studies, especially those applied to elder respondents, use a refined version of the

Careperf, with five and not seven options of response. The SS-QoL, on the other hand, had a few items which happen to not apply too well to the Portuguese reality and needed to be explained to the interviewee. There was, for instance, an item asking whether a person felt difficulty in preparing food. In fact, traditionally, most of Portuguese elder men do not prepare their meals alone and they did not do so, either, before stroke. Moreover, respondents of both genders, living in nursing homes would not be preparing their meals. The original SS-QoL did not take this possiblitity into consideration, by not having included an option 'Does not know/Does not answer/Does not apply'. The recommendation would be to amend it to the instrument.

In confirmatory analysis, the model of the Careperf measure of service quality resulted in two dimensions composed by two items. In exploratory analysis, these dimensions were found to have three items each. In the dimension of Assurance, CP_H7 (with loading 0.82, communality 0.68, and item-total correlation 0.64) was withdrawn in the course of confirmatory analysis. In the dimension of Responsiveness, CP_H17 (with loading 0.79, communality 0.63 and item-total correlation 0.49) was withdrawn from the model in the confirmatory analysis. Deleting the item was a naturally plausible solution, nonetheless, brought another dilemma, which was having a component composed of two items considered by some academics as frail and unstable (Costello & Osborne, 2005). This belief is not totally accepted in the scientific environment, however, opinions vary (Hulin, 2001). Raubenheimer (2004) admits that scales with two items per factor should be seen as an exception but tolerates their application. Other scholars do not see reasons to believe why two items would not represent well a construct. However, the predominant opinion is that in a multidimensional scale, a significant loading of three items in each of the factors of the scale is a required minimum in order to guarantee a feasible result (Raubenheimer, 2004). The fact of a two-item dimension in the measure should be at this point mentioned.

One important limitation identified during interviews with patients in the 6th-month follow-up was some anxiety and suspiciousness in what questions related to income, eventual social support they or their family were receiving, and in general, financial issues, concerned. Another restraint was a very frequent presence of a caregiver during the visit and a conversation with the participant – not a surprise, bearing in mind that interviews took place in the respondent's current place of stay, in great majority of cases, the own or relatives' residence. This fact, in itself, does not bring any harm; in contrary, a need to make questions, share difficulties in daily life after stroke or simply to talk seems absolutely natural. However, what was noticed in some cases, caregivers presented a tendency to respond questions directed to the patient. Furthermore, a presence of a caregiver during the interview when opinions and perceptions on social support of family were discussed was highly undesirable. Special precautionary steps were made prior to the visit to guarantee undisturbed communication with the interviewee; nonetheless, in a number of cases a presence of a caregiver was unavoidable.

During meetings in the 6th-month follow-up, patients were requested to assess service quality, and satisfaction with care in entities not evaluated quantitatively. One of the issues to be discussed at the time was their perception of first aid which was provided to them when their cerebrovascular accident occurred. As it turned out, respondents presented several difficulties in distinguishing the entity which effectively transported them to the Stroke Unit of HIP, whether it was the INEM, whether a fire department. In some cases a reason was health condition of a patient, who might have been dazed or even unconscious. However, a number of patients who did remember their experience with first aid admitted to not know who was an actual service provider in their case. From narratives of participants who did provide testimony and opinion regarding aspects of service quality of first aid, they seemed confused when it came to conversation about satisfaction with that particular service. Opinions were unclear. Therefore, it was decided to include the element to the analysis of service quality evaluated by those who remembered the experience by means of narratives but do not evaluate satisfaction with first aid as this assessment might run the risk to be biased. While this decisions constitute a restraint in the study as it limits the number of data to be analyzed, a research is not only about the quantity of data but also about their quality.

One of the components of the present study was a set of interviews carried out with key informants of entities providing care and support to stroke patients. For that purpose, the preliminary step was to identify all entities constituting the network of care for stroke survivors in the district of Aveiro. This identification faced a few challenges. Still, it was definitely a minor part of the institutions under analysis, and, as a result, a database demonstrating a strength of a collaboration between each of the entity in the study contained almost 260 000 entries.

After having analyzed an impact of the Church from the experiences with participants and with the interviews conducted in the 6th month of the study, the decision fell into not including these institutions into the analysis of the intensity of collaboration linkages. The reason behind that was twofold: (a) from data gathered so far, it might be expected that partnerships with these institutions and thus the strength of collaboration with others would be of a low level; (b) after having made some discernment in the district, the amount of the Church entities to be included in the analysis would need to be tremendously high since the analysis should not be limited to the Catholic Church only. Taking into consideration other religious convictions, the list of care and support care providers for stroke survivors would consist of religious organizations in its major part, with, the most expectably, no interaction with other care providers as an outcome in network analysis. Therefore, it was decided to withdraw religious institutions from network analysis.

While in the phase of interviews with representatives of entities providing care and assistance to stroke survivors, despite all efforts, an interview with a representative of a medium or/and long-term rehabilitation unit of the RNCCI did not take place. The first institution refused recording the interview what did not allow the use of data for further analysis. Another entity refused to join the study. An interview with the third rehabilitation unit could not take place due to absence of the person in charge. The perspective of a medium and/or long-term rehabilitation unit would be extremely valuable for the purpose of this research, especially bearing in mind participation of a convalescence unit in that phase of the study. A number of care, support and assistance providers for stroke patients is limited in terms of typology and specified due to the nature of services they provide. A perspective of one more service provider in this context might add much to the potential view toward collaborative linkages existing currently in Portugal on the Macro, Meso and Micro Levels on analysis. An interview with the Social Security was impossible for reasons independent on the researcher.

A limitation could be also considered a problem with generalization of the results due to the limited number of interviews carried out, yet, it is to emphasize that this element of the study had in its intention to only analyze perceptions of care service providers, those directly and not directly related to health services delivery, about collaboration between institutions that might in some way contribute to care, support and assistance provision to stroke survivors. It was not planned or intended to collect information on matters related to legislation or collaboration management process related to collaboration between care organizations in order to further validate a theoretical approach or generalize gathered results for a certain population.

8.2.2. Suggestions for future research

To our knowledge, no research on intersectoral partnerships in stroke survivors, employing the network theory as a conceptual basis, investigating their status and relationship intensity with patients' perceived service quality and satisfaction with received care and their quality of life, has ever been carried out, either in Portugal, or in any other country. In fact, no analogous study has ever been conducted applied to any other health condition.

The present research opens door for further work in several connotations, by continuing initited work which has unlocked interesting aspects deserving to be investigated, making an attempt to verify the results within another context perhaps with another methodology for their external validation and exploring deeper other topics that arose throughout the study span.

More specifically, as it is the first research of this kind, further studies are required and desired to verify the status of intersectoral collaborative environment in Portugal. This is a particularly recent field of research, at least in what the empirical part concerns, and proper theoretical constructs and methodologies are still under discussion on how to embrace intersectoriality. Of especial relevance would be the application and testing the proposed framework of the intensity of collaboration in the multi-sector care setting.

Another interesting line for future research would be to conclude the validation process of the Careperf measure of service quality developed within this study. Principal component analysis with seven components proved their unidimensionality. CFA used maximum likelihood estimation and resulted in some modifications in the factor structure. The final model showed a suitable fit according to the existing standard criteria. It would be of much interest to verify remaining validation criteria for the Careperf instrument.

Finally, it also would be very appealing for future research to conduct another study of quality of life with stroke patients with the use of the SS-QoL instrument on a larger population of subjects to observe how results would compare with the current study and enable to proceed its validity.

REFERENCES

19th World Conference on Health Promotion and Health Education. (2007). Crossing sectors: Dialogue on intersectoral action. *Dialogue Report*. Vancouver.

Aaronson, N. K. (1988). Quality of life: What is it? How should it be measured? *Oncology, 2*(5), 69-76.

Abramovay, R. (2000). O capital social dos territórios: Repensando o desenvolvimento rural. *Economia Aplicada, IV*(2), 379-397.

Abreu, A., & Peixoto, J. (2009). Demografia, mercado de trabalho e imigração de substituição: Tendências, políticas e prospectiva no caso português. *Análise Social, XLIV*(193), 719-746.

Achrol, R. S. (1997). Changes in the theory of interorganizational relations in marketing: Toward a network paradigm. *Journal of the Academy of Marketing Science, 25*(1), 56-71.

Afkhamebrahimi, A., & Esfehani, M. N. (2012). Patients' expectation and satisfaction with their health providers. *Global Journal of Community Psychology Practice, 4*(3).

Ahgren, B., Axelsson, S. B., & Axelsson, R. (2009). Evaluating intersectoral collaboration: A model for assessment by service users. *International Journal of Integrated Care, 9*, 1-10.

Ahlsiö, B., Britton, M., Murray, V., & Theorell, T. (1984). Disablement and quality of life after stroke. *Stroke, 15*(5), 886-890.

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine, 48*(8), 977-988.

Aleamoni, L. M. (1976). The relation of sample size to the number of variables in using factor analysis techniques. *Educational and Psychological Measurement, 36*, 879-883.

Aled, J., & Bugge, C. (2006). Improving understanding and rigour through triangulation: An exemplar based on patient participation in interaction. *Journal of Advanced Nursing, 55*(5), 612-621.

Alexadiou, N., & Ozga, J. (2000). Modernising education governance in England and Scotland: Devolution and control. *European Educational Research Journal, 1*(4), 676-691.

Alter, C., & Hage, J. (1993). *Organisations Working Together Englewood Cliffs*. N.J: Prentice Hall.

Altman, D. G., & Bland, J. M. (1994). Presentation of numerical data. *British Medical Journal, 312*, 572.

Altman, D. G., & Bland, J. M. (1995). Quartiles, quintiles, centiles, and other quantiles. *British Medical Journal, 310*, 298.

Anderson, E. W., Fornell, C., & Lehmann, D. R. (1994). Customer satisfaction, market share, and profitability: Findings from Sweden. *Journal of Marketing, 58*(3), 53-66.

Anderson, E. W., & Sullivan, A. G. (1993). The antecedents and consequences of customer satisfaction in firms. *Marketing Science, 12*(2), 125-143.

Andersson, C. M., Bjaras, G., Tillgren, P., & Ostenson, C. G. (2005). A longitudinal assessment of inter-sectoral participation in a community-based diabetes prevention programme. *Social Science & Medicine, 61*(11), 2407-2422.

Andersson, L. (1998). Loneliness research and interventions: a review of the literature. *Aging and Mental Health, 2*(4), 264-274.

Andreasson, S., & Winge, M. (2010). Innovations for sustainable health and social care. Value-creating health and social care processes based on patient need. *VINNOVA Report*.

Angeleri, F., Angeleri, V. A., Foschi, N., Giaquinto, S., & Nolfe, S. (1993). The influence of depression, social activity, and family stress on functional outcome after stroke. *Stroke, 24*, 1478-1483.

Aragon, S. J., & Gesell, S. B. (2003). A patient satisfaction theory and its robustness across gender in emergency departments: A multigroup structural equation modeling investigation. *American Journal of Medical Quality, 18*(6), 229-241.

Araujo, L., & Easton, G. (1996). Networks in socio-economic systems: A critical review. In Iacobucci, D. (Ed.), *Networks in marketing*. Thousand Oaks, London and New Delhi: Sage, 63-107.

Argyle, M. (1991). *Cooperation. The basis of sociability*. London: Routhledge.

Ashman, D. (2001). Civil society collaboration with business: Bringing empowerment back in. *World Development, 29*(7), 1097-1113.

Astrom, M., Asplund, K., & Astrom, T. (1992). Psychosocial function and life satisfaction after stroke. *Stroke, 23*(4), 527-531.

Atkinson, M., & Maxwell, V. (2007). Driving performance in a multi-agency partnership using outcome measures: A case study. *Measuring Business Excellence, 11*(2), 12-22.

Attias-Donfut, C., Ogg, J., & Wolff, F.-C. (2008). Evolution of social support. In Borsch-Supan, A., Brugiavini, A., Jurges, H., Keptyn, A., Mackenbach, J., Siegrist, J., & Weber, G. (Eds), *Health, ageing, and retirement in Europe (2004-2007) - Starting the longitudinal dimension*. Mannheim: MEA.

Austin, J. (2000). *The collaboration challenge: How nonprofits and businesses succeed through strategic alliances*. San Francisco: Jossey-Bass Publishers.

Austin, J., Reficco, E., & SEKN Research Team. (2004). Building cross-sector bridges. In Austin, J., Reficco, E., Berger, G., Fischer, R. M., Gutiérrez, R., Koljatic, R., Lozano, G., Ogliastri E., & SEKN Team (Eds), *Social partnering in Latin America; lessons drawn from* *collaborations of businesses and civic society organizations*. Cambridge, MA: Harvard University Press.

Axelsson, R., & Axelsson, S. B. (2006). Integration and collaboration in public health: A conceptual framework. *International Journal of Health Planning and Management, 21*, 75-88.

Badri, M. A., Attia, S., & Ustadi, A. M. (2009). Healthcare quality and moderators of patient satisfaction: Testing for causality. *International Journal of Health Care Quality Assurance, 22*(4), 382-410.

Bailey, D., & Koney, K. (2000). *Strategic alliances among health and human services organizations: From affiliations to consolidations*. Thousand Oaks, CA: Sage.

Baker, T. L., & Taylor, S. A. (1997). Patient satisfaction and service quality in the formation of customers' future purchase intentions in competitive health service settings. *Health Marketing Quarterly, 15*(1), 1-15.

Balloch, S., & Taylor, M. (2001). *Partnership working: policy and practice*. Bristol: The Policy Press.

Bardach, E. (1998). *Getting agencies to work together: The practice and theory of managerial craftsmanship*. Washington, DC: Brookings Institution Press.

Bardin, L. (2006). *Análise de conteúdo*. Lisboa: Edições 70.

Barnes, J. A. (1972). *Social networks*. Reading, MA: Addison-Wesley.

Barrett, P. T., & Kline, P. (1981). The observation to variable ratio in factor analysis. *Personality study and group behavior, 1*, 23-33.

Barros, P., & Gomes, J.-P. (2002). *Os sistemas nacionais de saúde da União Europeia, principais modelos de gestão hospitalar e eficiência no Sistema Hospitalar Português*. Lisbon: Faculdade de Economia da Universidade Nova de Lisboa/GANEC-Gabinete de Análise Económica.

Barros, P., Machado, S., & Simões, J. (2011). Portugal: Health system review. *Health Systems in Transition.* European Observatory on Health Systems and Policies, *12*, 1-156.

Barros, P., & Simões, J. (2007). Portugal: Health system review. *Health Systems in Transition, 9*(5), 1-140.

Bartel, D., Igras, S., & Chamberlain, J. (2007). *Building partnerships for health in conflict affected settings: A practical guide to beginning and sustaining inter-agency partnerships*. London: CARE International.

Bateson, J., Eiglier, P., Langeard, E., & Lovelock, C. (1978). *Testing a conceptual framework for consumer service marketing*. Cambridge, MA: Marketing Science Institute.

Batt, P. J., & Purchase, S. (2004). Managing collaboration within networks and relationships. *Industrial Marketing Management, 33*(3), 169-174.

Beattie, M., Lauder, W., Atherton, I., & Murphy, D. J. (2014). Instruments to measure patient experience of health care quality in hospitals: A systematic review protocol. *Systematic Reviews, 3*(4).

Bech, P., Olsen, L. R., Kjoller, M., & Rasmussen, N. K. (2003). Measuring well-being rather than absense of distress symptoms. A comparison of the SF-36 mental health subscale and the WHO-Five well-being scale. *International Journal of Methods in Psychiatric Research, 12*(2), 85-91.

Belle, D. (1983). The impact of poverty on social networks and supports. *Mariage and Family Review, 5*(4), 89-103.

Bentler, P. M., & Bonett, D. G. (1980). Significance tests and the analysis of goodness of fit in the analysis of covariance structures. *Psychological Bulletin, 88*, 588-606.

Berger, I. E., Cunningham, P. H., & Drumwright, M. E. (2004). Social alliances: Company-nonprofit collaboration. *California Management Review, 47*(1), 58-90.

Berry, L. L., & Parasuraman, A. (1997). Listening to the customer: The concept of a service quality information system. *Sloan Management Review, 38*(3), 65-76.

Bickman, L. (1996). A continuum of care: More is not always better. *American Psychologist, 51*(7), 689-701.

Bitner, M. J., & Hubbert, A. R. (1994). Encounter satisfaction versus overall satisfaction versus quality. In Rust, R. T., & Oliver, R. L. (Eds), *Service quality: New directions in theory and practice*. London: Sage.

Black, L. J., Cresswell, A. M., Pardo, T. A., Thompson, F., Canestraro, D. S., Cook, M., Luna, L. F., Martinez, I. J., Andersen, D. F., & Richardson, G. P. (2002). *A dynamic theory of collaboration: A structural approach to facilitating intergovernmental use of information technology*. Proceedings of the 36th Hawaii International Conference on System Sciences (HICSS’03).

Blagescu, M., & Young, J. (2005). Partnering and accountability: Current thinking and approaches among agencies supporting civil society organizations. *Working paper 255*. London: Overseas Development Institute.

Blankenburg Holm, D., Eriksson, K., & Johanson, J. (1996). Business networks and cooperation in international business relationships. *Journal of International Business Studies, 27*(5), 1033-1053.

Blaug, M. (1994). *Teoria Ekonomii [Theory of Economics]*. Warsaw: PWN.

Bloemer, J., & Ruyter, K. (1995). Integrating service quality and satisfaction: Pain in the neck or marketing opportunity? *Journal of Consumer Satisfaction, Dissatisfaction and Complaining Behavior, 8*, 44-52.

Boccalettia, S., Latorab, V., Morenod, Y., Chavezf, M., & Hwanga, D.-U. (2006). Complex networks: Structure and dynamics. *Physics Reports, 424*, 175-308.

Bogdan, R. C., & Biklen, S. K. (1992). *Qualitative research in education*. Boston: Allyn and Bacon.

Bollen, K. A. (1989). *Structural equations with latent variables*. New York: Wiley.

Bolton, R. N., & Drew, J. H. (1991). A multistage model of customers' assessments of service quality and value. *Journal of Consumer Research, 17*, 375-384.

Bonsignore, E. M., Dunne, C., Rotman, D., Smith, M., Capone, T., Hansen, D. L., & Schneiderman, B. (2009). *First steps to netviz nirvana: Evaluating social network analysis with NodeXL*. Paper presented at the International Conference on Computational Science and Engineering (IEEE).

Bookman, A., & Harrington, M. (2007). Family caregivers: A shadow workforce in the geriatric health care system? *Journal of Health Politics, Policy and Law, 32*(6), 1005-1041.

Borden, L. M., & Perkins, D. F. (1999). *Assessing your collaboration: A self evaluation tool*. Retrieved 10 September 2011, from http://www.joe.org/joe/1999april/tt1.php.

Borgatti, S. P. (2005). Centrality and network flow. *Social Networks, 27*(1), 55-71.

Borgatti, S. P., & Everett, M. G. (2006). A graph-theoretic perspective on centrality. *Social Networks, 28*(4), 466-484.

Borgatti, S. P., Mehra, A., Brass, D. J., & Labianca, G. (2009). Network analysis in the social sciences. *Science, 323*(5916), 892-895.

Borge, L., Martinsen, E. W., Ruud, T., Watne, O., & Friis, S. (1999). Quality of life, loneliness and social contact among long-term psychitaric patients. *Psychiatric Services, 50*(1), 81-84.

Boston College. (2014). *Lubben Social Network Scale*. Retrieved 20 March 2010, from http://www.bc.edu/schools/gssw/lubben/

Boulding, W., Glickman, S. W., Manary, M. P., Schulman, K. A., & Staelin, R. (2011). Relationship between patient satisfaction with inpatient care and hospital readmission within 30 days. *The American Journal of Managed Care, 17*(1), 41-48.

Bowers, M. R., Swan, J. E., & Koehler, W. F. (1994). What attributes determine quality and satisfaction with health care delivery? *Health Care Management Review, 19*(4), 49-55.

Bowling, A., Banister, D., Sutton, S., Evans, O., & Windsor, J. (2002). A multidimensional model of the quality of life in older age. *Aging & Mental Health, 6*(4), 355-371.

Bowling, A., Rowe, G., Lambert, N., Waddington, M., Mahtani, K. R., Kenten, C., Howe, A., & Francis, S. A. (2012). The measurement of patients' expectations for health care: A review and psychometric testing of a measure of patients expectatons. *Health Technology Assessment, 16*(30), 1-509.

Bracke, P., Christaens, W., & Wauterickx, N. (2008). The pivotal role of women in informal care. *Journal of Family Issues, 29*(10), 1348-1378.

Brady, M. K., Cronin, J. J., & Brand, R. R. (2002). Performance-only measurement of service quality: A replication and extension. *Journal of Business Research, 55*(1), 17-31.

Brass, D. J., Butterfield, K. D., & Skaggs, B. C. (1998). Relationships and unethical behavior: A social network perspective. *The Academy of Management Review, 23*(1), 14-31.

Brass, D. J., Galaskiewicz, J., Greve, H. R., Tsai, W. (2004). *Taking stock of networks and organizations: A multilevel perspective*. Academy of Management Journal, 47(6), 765-817.

Briassoulis, H. (2004). *Policy integration for complex problems: What, why and how*. Paper presented at the Berlin Conference on Greening Policies: Interlinkages and Policy Integration, Berlin.

Brinkerhoff, J. M. (2002a). Assessing and improving partnership relationships and outcomes: A proposed framework. *Evaluation and Program Planning, 25*(3), 215-231.

Brinkerhoff, J. M. (2002b). *Partnership for international development: Rhetoric or results?* Boulder, CO: Lynne Rienner.

Bristow, G., Entwhistle, T., Hines, F., Martin, S., Morgan, K., & Pithouse, A. (2003). *Partnerships between the public, private and voluntary sectors in Wales*. Cardiff: Cardiff University.

Brook, R. H., Park, R E., & Chassin, M. R. (1990). Predicting the appropriate use of carotid endarterectomy, upper gastrointestinal endoscopy, and coronary angiography. *New England Journal of Medicine, 323*(17), 1173–1177.

Brown, L. D., & Kalegaonkar, A. (1999). Addressing civil society's challenges: support organizations as emerging institutions. *IDR Reports* (Vol. 15). Institute for Development Research, Boston, MA.

Browne, G., Roberts, J., Gafni, A., Byrne, C., Kertyzia, J., & Loney, P. (2004). Conceptualizing and validating the human services integration measure. *International Journal of Integrated Care, 19*(4).

Bryan-Brown, C. W., & Dracup, K. (1996). Outcomes, endpoints, and expectations. *American Journal of Respiratory and Critical Care Medicine, 5*(2), 87-89.

Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*(1), 97-113.

Bryson, J. M., Crosby, B. C., & Stone, M. M. (2006). The design and implementation of cross-sector collaborations: Propositions from the literature. *Public Administration Review, 66* (Special issue), 44-55.

Buck, D., Jacoby, A., Massey, A., & Ford, G. (2000). Evaluation of measures used to assess quality of life after stroke. *Stroke, 31*(8), 2004-2010.

Buehler, J. W., Whitney, E. A., & Berkelman, R. L. (2006). Business and public health collaboration for emergency preparedness in Georgia: A case study. *BMC Public Health, 6*(285).

Burns, N., & Grove, S. K. (2005). *The practice of nursing research: Conduct, critique, and utilization* (5th ed.). St. Louis: Elsevier Saunders.

Burt, R. S. (1987). A note on strangers, friends and happiness. *Social Networks, 9*, 311-331.

Burt, R. S. (1992). *Structural holes*. Cambridge: Harvard University Press.

Buse, K., & Harmer, A. M. (2007). Seven habits of highly effective global public–private health partnerships: Practice and potential. *Social Science & Medicine, 64*(2), 259-271.

Byrne, K., Sims-Gould, J., Frazee, K., & Martin-Mathews, A. (2011). “I'm satisfied… but”: Clients’ and families’ contingent responses about home care. *Home Health Care Services Quarterly, 30*(4), 161-177.

Caldas de Almeida, J. M. (2009). Portuguese National Mental Health Plan (2007-2016). Executive Summary. *Mental Health in Family Medicine 6*(4), 233-244.

Calman, K. C. (1984). Quality of life in cancer patients - An hypothesis. *Journal of Medical Ethics, 10*(3), 124-127.

Cameron, A., & Lart, R. (2003). Factors promoting and obstacles hindering joint working: A systematic review of the research evidence. *Journal of Integrated Care, 11*(2), 9-17.

Campbell, A., Converse, P. E., & Rodgers, W. L. (1976). *The quality of American life: Perceptions, evaluations, and satisfactions*. New York, NY: Sage.

Campbell, K. E., Marsden, P. V., & Hurlbert, J. S. (1986). Social resources and socioeconomic status. *Social Networks, 8*(1), 97-117.

Canadian Institute for Environmental Law and Policy. (2005). *Partnerships for sustainability: How to make a partnership work*. Toronto: CIELAP.

Caplan, K., & Jones, D. (2002). Partnership indicators. Measuring the effectiveness of multi-sector approaches to service provision. *Practitioner Note Series*: BPD Water and Sanitation Cluster.

Carod-Artal, J., Egido, J. A., González, J. L., & Varela de Seijas, E. (2000). Quality of life among stroke survivors evaluated 1 year after stroke: Experience of a stroke unit. *Stroke, 31*(12), 2995-3000.

Carr, A. J., Gibson, B., & Robinson, P. G. (2001). Is quality of life determined by expectations or experience? *British Medical Journal, 322*(7296), 1240-1243.

Carr, A. J., & Higginson, I. J. (2001). Are quality of life measures patient centred? *British Medical Journal, 322*(7298), 1357-1360.

Cartwright, D., & Harary, F. (1956). Structural balance: A generalisation of Heider's theory. *Psychological Review, 63*, 277-293.

Carvalhais, M. & Sousa, L. (2013). Qualidade dos cuidados domiciliares em enfermagem a idosos dependentes. *Saúde e Sociedade, 22*(1), 160-172.

Chalamon, I., Chouk I., & Heilbrunn, B. (2014). *Typology of patients' expectations towards the health-care system: A semiotic approach*. Retrieved 23 March 2014, from http://www.researchgate.net/profile/Isabelle_Chalamon/publication/228392078_Typology_of_Patients_Expectations_towards_the_Health-Care_System_A_Semiotic_Approach/links/02e7e528a7bdd17ecc000000.pdf

Charles, C., & McNulty, S. (1998). *Partnering for results. Assessing the impact of intersectoral partnering*. USAID: Academy for Educational Development.

Christensen, C., & Larson, J. R. (1993). Collaborative medical decision making. *Medical Decision Making, 13*(4), 339-346.

Cina, C. (1989). Creating an effective customer satisfaction program. *Journal of Services Marketing, 3*(1), 5-14.

Clairborne, N., & Lawson, H. A. (2005). An intervention framework for collaboration. *Families in Society. The Journal of Contemporary Social Services, 86*(1), 93-103.

Clarke, J., & Glendinning, C. (2002). Partnership and the remaking of welfare governance. In Glendinning, C., Powell, M., & Rummery, K. (Eds), *Partnerships, New Labour and the Governance of Welfare*. Bristol: Policy Press.

Clarke, P., Marshall, V., Black, S. E., & Colantonio, A. (2002). Well-being after stroke in Canadian seniors: Findings from the Canadian Study of Health and Aging. *Stroke, 33*(4), 1016-1021.

Cleary, P. D., Greenfield, S., Mulley, A. G., Pauker, S. G., Schroeder, S. A., Wexler, L., & et al. (1991). Variation in length of stay and outcomes for six medical surgical conditions in Massachusetts and California. *The Journal of the American Medical Association, 266*(1), 73-79.

Cole, F. L. (1988). Content analysis: Process and application. *Clinical Nurse Specialist, 2*(1), 53-57.

Coleman, J. S. (1988). Social capital in the creation of human capital. *American Journal of Sociology, 94* (Issue suplement), S95-S120.

Constitution of the Republic of Portugal, art. 63 C.F.R. (1976, revision of 2005).

Cook, K. S. (1977). Exchange and power in networks of interorganizational relations. *Sociological Quarterly, 18*(1), 62-82.

Correia, M., Silva, M. R., Matos, I., Magalhães, R., Lopes, J. C., Ferro, J. M., & Silva, M. C. (2004). Prospective community-based study of stroke in Northern Portugal. Incidence and case fatality in rural and urban populations. *Stroke, 35*(9), 2048-2053.

Costa-Font, J. (2010). Family ties and the crowding out of long term care insurance. *Oxford Review of Economic Policy, 26*(4), 691-712.

Costa-Font, J., Gori, C., & Santana, S. (2011). Financing long-term care in Southwest Europe: Italy, Portugal and Spain. In Costa-Font, J., & Courbage, C. (Eds), *Financing long-term care in Europe*. Houndmills: Palgrave Macmillan.

Costa, L. F., Rodriguez, F. A., Travieso, G., & Boas, P. R. V. (2006). Characterization of complex networks: A survey of measurements. *Advances in Physics, 56*(1), 167-242.

Costello, A. B., & Osborne, J. W. (2005). Best practices in explanatory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment. Research and Evaluation, 10*(7), 1-8.

Coulson, A. (2005). A plague on all your partnerships: Theory and practice in regeneration. *International Journal of Public Sector Management, 18*(2), 151-163.

Coulter, A., & Ellins, J. (2006). *Patient-focused interventions. A review of the evidence*. London: The Health Foundation.

Council of the European Union. (2007). Country profile: Portugal. *Joint report on social protection and social inclusion*.

Cousins, P. D. (2002). A conceptual model for managing long-term inter-organisational relationships. *European Journal of Purchasing and Supply Management, 8*(2), 71-82.

Creswell, J. (2008). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks: Sage Publication.

Cronin, J., Steven, J., & Taylor, J. (1994). SERVPERF versus SERVQUAL: Reconciling performance-based and perceptions-minus-expectations measurement of service quality. *Journal of Marketing, 58*, 125-131.

Cronin, J. J., Brady, M. K., & Hult, G. T. (2000). Assessing the effects of quality, value, and customer satisfaction on consumer behavioral intentions in service environments. *Journal of Retailing, 76*(2), 193-218.

Cronin, J. J., & Taylor, S. A. (1992). Measuring service quality: A reexamination and extension. *Journal of Marketing, 6*, 55-68.

Crow, R., Gage, H., Hampson, S., Hart, J., Kimber, A., Storey, L., & Thomas, H. (2002). The measurement of satisfaction with healthcare: Implications for practice from a systematic review of the literature. *Health Technology Assessment, 6*(32), 1-244.

Crowley, L., & Karim, A. (1995). Conceptual model of partnering. *Journal of Management in Engineering, 11*(5), 33-39.

CSDH (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *Final report of the Commission on Social Determinants of Health*. Geneva: World Health Organization.

Cuthbert, P. F. (1996). Managing service quality in HE: Is SERVQUAL the answer? Part 2. *Managing Service Quality, 6*(3), 31-35.

Czepiel, J. A., Solomon, M. R., Suprenant, C. F., & Gutman, E. G. (1985). *Service encounters: An overview. The service encounter: managing employee customer interaction in service business*. Lexington: Lexington Books.

Dabholkar, P. A. (1996). Consumer evaluations of new technology-based self-service operations: An investigation of alternative models. *International Journal of Research in Marketing, 13*(1), 29-51.

Danaher, P. J. & Haddrell, V. (1996). A comparison of question scales used for measuring customer satisfaction. *International Journal of Service Industry Management, 7*(4), 4-26.

Dawes, S. S., & Eglene, O. (2004). *New models of collaboration for delivering government services: A dynamic model drawn from multi-national research*. Paper presented at the Proceedings of the 2004 annual national conference on Digital Government Research, Seattle, WA.

de Haan, R., Aaronson, N., Limburg, M., Hewer, R. L., & van Crevel, H. (1993). Measuring quality of life in stroke. *Stroke, 24*(2), 320-327.

de Haan, R., Limburg, M., Bossuyt, P., van der Meulen, J., & Aaronson, N. (1995). The clinical meaning of ranikin 'handicap' grades after stroke. *Stroke, 26*(11), 2027-2030.

Deich, S. (2001). *A guide to successful public-private partnerships for and out-of-school time community school initiatives*. Washington, DC: The Finance Project.

de Reuck, J. (2009). Management of stroke-related seizures. *Acta Neurologica Belgica, 109*(4), 271-276.

Dewey, H. M., Thrift, A. G., Mihalopoulus, C., Carter, R., Macdonnel, R. A. L., McNeil, J. J., & Donnan, G. A. (2002). Informal care for stroke survivors. Results from the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke, 33*, 1028-1033.

DHS (2004). *Measuring consumer health outcomes in public mental health services in Victoria, Melbourne*. Melbourne: Victorian Government Mental Health Branch.

DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education, 40*(8), 314-321.

DiMaggio, P. J., & Powell, W. W. (1991). The iron cage revisited: Institutional isomorphism and collective rationality in organisational fields. In Powell, W. W., & DiMaggio, P. J. (Eds), *The new institutionalism in organisational analysis*. Chicago: The University of Chicago Press.

Donabedian, A. (1988). The quality of care: how can it be assessed? *The Journal of the American Medical Association, 260*(12), 1743-1748.

Donabedian, A. (1990). The seven pillars of quality. *Archives of Pathololology & Laboratory Medicine, 114*(11), 1115-1118.

Donabedian, A. (1996). Evaluating the quality of care. *Milbank Memorial Fund Quarterly, 8*(5), 401-407.

dos Santos, A. S. (2007). *Validação da escala de avaliação da qualidade de vida na doença cerebrovascular isquémica para a língua portuguesa*. Tese de Doutoramento. Universidade de São Paulo, São Paulo.

Dowling, B., Powell, M., & Glendinning, C. (2004). Conceptualising successful partnerships. *Health and Social Care in the Community, 12*(4), 309-317.

Duarte, M., & Paúl, C. (2006/2007). Avaliação do ambiente institucional – público e privado: Estudo comportamental dos idosos. *Revista Transdisciplinar de Gerontologia Universidade Sénior Contemporânea, 1*(1), 509-529.

Durkheim, E. (1951). *Suicide: A study in sociology*. London: Routledge.

Dyer, J. H., & Singh, H. (1998). The relational view: Cooperative strategy and sources of interorganizational competitive advantage. *Academy of Management Review, 23*, 660-679.

Edwards, B., Goodwin, M., Pemberton, S., & Woods, M. (2000). *Partnership working in rural regeneration: Governance and empowerment*. Bristol: Policy Press in association with the Joseph Rowntree Foundation.

Eiglier, P. (1977). *A note on the commonality of problems in service management: A field study, in marketing consumer services. New Insights.* Cambridge: Marketing Science Institute.

Eiglier, P., & Langeard, E. (1977). A new approach to service marketing. In Eigler, P. (Ed.), *Marketing Consumer Services: New Insights*. Cambridge: Marketing Science Institute.

Eilbert, K. W., & Lafronza, V. (2005). Working together for community health - A model and case studies. *Evaluation and Program Planning, 28*, 185-199.

Ekstam, L., Uppgard, B., & von Koch L. (2007). Functioning in everyday life after stroke: A longitudinal study of elderly people receiving rehabilitation at home. *Scandinavian Journal of Caring Sciences, 21*(4), 434-446.

Emerson, R. M. (1972). Social exchange theory. *Annual Review of Sociology, 2*, 335-362.

Erickson, F. (1986). Qualitative methods in research on teaching. *Handbook of research on teaching*. New York: Macmilan.

Eurobarometer (2007). *Health and long-term care in the European Union*. Special Eurobarometer - TNS Opinion and Social, No. 283/Wave 67.3. European Commission.

Eurostat (2008). *Population Statistics*. Retrieved 06 March 2010, from http://epp.eurostat.ec.europa.eu/portal/page/portal/population/data/database.

Eurostat (2010). Europe in figures. Eurostat yearbook 2010. *Eurostat Statistical Books*. Luxembourg: European Commission.

Eurostat (2014). Causes of death - standardised death rate per 100 000 inhabitants - annual data. *Eurostat. Your key to European statistics*. Retrieved 22 April 2014, from http://epp.eurostat.ec.europa.eu/portal/page/portal/statistics/search_database.

Evers, S. M., Strijs, J. N., Ament, A. J., van Genugten, M. L., Jager, J. H., & van den Bos, G. A. (2004). International comparison of stroke cost studies. *Stroke, 2004*(35), 1209-1215.

Eweje, G. (2007). Strategic partnerships between MNEs and civil society: The post-WSSD perspectives. *Sustainable Development, 15*(1), 15-27.

Fallowfield, L. (1990). *The missing measurement in health care*. London: Souvenir Press.

Fan, R. (2007). Which care? Whose responsibility? And why family? A Confuncian account of long-term care for the elderly. *Journal of Medicine and Philosophy, 32*(5), 495-517.

Fassino, S., Leombruni, P., Abbate Daga, G., Brustolin, A., Rovera, G. G., & Fabris, F. (2002). Quality of life in dependent older adults living at home. *Archives of Gerontology and Geriatrics, 35*(1), 9-20.

Fehr, E. (2004). Human behaviour: Don’t lose your reputation. *Nature, 432*(7016), 449-450.

Fenton, J. J., Jerant, A. F., Bertakis, K. D., & Franks, P. (2012). The cost of satisfaction: A national study of patient satisfaction, health care utilization, expenditures, and mortality. *Archives of Internal Medicine, 172*(5), 405-411.

Ferrans, C., & Powers, M. (1985). Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science, 8*(1), 15-24.

Ferreira, S. (2003). *The past in the present Portuguese social security reform*. Paper presented at the ESPAnet Changing European Societies - the role for social policy, Copenhagen.

Field, A. (2005). *Discovering Statistics Using SPSS* (2nd ed.). London: Sage.

Field, A. (2009). *Discovering Statistics Using SPSS* (3rd ed.). London: Sage.

Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment, 2*(14).

Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spiegelhalter, D., & Cox, D. (1992). Quality of life measures in health care. In: Applications and issues in assessment. *British Medical Journal, 305*(6861), 1074-1077.

Fletcher, A. E., Dickinson, E. J., & Philp, I. (1992). Review: Audit measures. Quality of life instruments for everyday use with elderly patients. *Age Aging, 21*, 142-150.

Floch, J. M. (1988). The contribution of structural semiotics to the design of a hypermarket. *International Journal of Research in Marketing, 4*(3), 233-253.

Floch, J. M. (2001). *Semiotics, marketing and communication*. London: Palgrave MacMillan.

Forsyth, T. (2005). Building deliberative public-private partnerships for waste management in Asia. *Geoforum, 36*(4), 429-439.

Francis, J. & Netten, A. (2004). Raising the quality of home carea study of service users' views. *Social Policy and Administration, 38*(3), 290-305.

Freeman, L. C. (1977). A set of measures of centrality based upon betweenness. *Sociometry, 40*, 35-41.

Freeman, L. C. (1979). Centrality in social networks: Conceptual clarification. *Social Networks, 1*, 215-239.

Freeman, L. C. (2004). *The development of social network analysis: A study in the sociology of science*. Vancouver: Empirical Press.

Freixo, M. J. (2010). *Metodologia científica. Fundamentos, métodos e técnicas*. Lisbon: Instituto Piaget.

Frey, B. B., Lohmeier, J. H., Lee, S. W., & Tollefson, N. (2006). Measuring collaboration among grant partners. *American Journal of Evaluation, 27*(3), 383-392.

Frey, J. H., & Fontana, A. (2000). The interview. In Denzin, N. K., & Lincoln, Y. S. (Eds), *Handbook of qualitative research*. London: Sage Publications.

Friedkin, N. (1981). The development of structure in random networks: An analysis of the effects of increasing network density on five measures of structure. *Social Networks, 3*, 41-52.

Friedman, M. (1970). The social responsibility of business is to increase its profits. *New York Times Magazine, 13 September*, 122-126.

Frost, F. A., & Kumar, M. (2000). INTSERVQUAL: An internal adaptation of the GAP model in a large service organization. *Journal of Services Marketing, 14*(5), 358-377.

Fruchterman, T. M. J., & Reingold, E. M. (1991). Graph drawing by force-directed placement. *Software-Practice and Experience, 21*(11), 1129-1164.

Fuller-Love, N. (2009). Formal and informal networks in small businesses in the media industry. *International Entrepreneurship and Management Journal, 5*(3), 271-284.

Gagnon, M., Rejean, H., Dube, M., & Dubois, M.-F. (2006). Development and validation of the Health Care Satisfaction Questionnaire (HCSQ) in elders. *Journal of Nursing Measurement, 14*(3), 190-204.

Gajda, R. (2004). Utilising collaboration theory to evaluate strategic alliances. *American Journal of Evaluation, 25*(1), 65-77.

Gamm, L. (1981). An introduction to research in interorganizational relations. *Journal of Voluntary Action Research, 10*(1), 18-52.

Gamson, W. (1961). A theory of coalition formation. *American Sociological Review, 26,* 373-382.

Garton, L., Haythornwaite, C., & Wellman, B. (1999). Studying on-line social networks. In Jones, S. (Ed.), *Doing Internet Research*. Thousand Oaks, CA: SAGE.

Gauthier, F. (1987). À la recherche de configurations dans une étude de cas: Une rotation d'axes qualitatifs dans un espace de caractéristiques tri-dimensionalles. *L'interprétation des données dans le recherche qualitative*. Toronto: University of Montreal.

Gill, L., & White, L. (2009). A critical review of patient satisfaction. *International Journal of Health Care Qaulity Assurance, 22*(1), 8-19.

Gill, T. M., & Feinstein, A. R. (1994). A critical appraisal of the quality of quality-of-life measurements. *The Journal of the American Medical Association, 272*(8), 619-626.

Gilles, P. (1998). Effectiveness of alliances and partnerships for health promotion. *Health Promotion International, 13*(2), 99-120.

Glickman, S. W., Boulding, W., Manary, M., Staelin, R., Roe, M. T., Wolosin, R. J., Ohman, E. M, Peterson, E. D., & Schulman, K. A. (2010). Patient satisfaction and its relationship with clinical quality and inpatient mortality in acute myocardial infarction. *Circulation: Cardiovascular Quality and Outcomes, 3*(2), 188-195.

Glouberman, S., & Millar, J. (2003). Evolution of the determinants of health, health policy, and health information systems in Canada. *American Journal of Public Health, 93*(3), 388-392.

Googins, B. K., & Rochlin, S. A. (2000). Creating the partnership society: Understanding the rhetoric and reality of cross-sectoral partnerships. *Business and Society Review, 105*(1), 127-144.

Gorusch, R. L. (1983). *Factor analysis*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Gough, I. R., Furnival, C. M., Schilder, I., & Grove, W. (1983). Assessment of the quality life of patients with advanced cancer. *European Journal of Cancer and Clinical Oncolology 19,* 1161-1165.

Granger, C. V., Hamilton, B. B., & Gresham, G. E. (1988). The stroke rehabilitation outcome study-Part I: General description. *Archives of Physical Medicine and Rehabilitation, 69*(7), 506-509.

Granovetter, M. (1973). The strength of weak ties. *American Journal of Sociology, 78*, 1360-1380.

Gray, A. (2002). *Integrated service delivery and regional co-ordination: A literature review*. Wellington: Gray Matter Research Ltd.

Gray, B. (1989). *Collaborating: finding common ground for multi-party problems*. San Francisco: Jossey-Bass.

Green, T. L., & King, K. M. (2010). Functional and psychosocial outcomes 1 year after mild stroke. *Journal of Stroke and Cerebrovascular Diseases, 19*(1), 10-16.

Greenwald, H. P. (2008). *Challenges in cross-sectoral partnerships: An organizational perspective*. Paper presented at the Consortium on Collaborative Governance Mini-Conference.

Groene, O. (2011). Patient centredness and quality improvement efforts in hospitals: Rationale, measurement, implementation. *International Journal for Quality in Health Care, 23*(5), 531-537.

Grönroos, C. (1984). A service quality model and its marketing implications. *European Journal of Marketing, 18*(4), 36-44.

Grönroos, C. (1990). *Service management and marketing: Managing the moment of truth in service competition*. Boston: Lexington Books.

Grönroos, C. (2000). *Service management and marketing: A customer relationship management approach*. Chichester: Wiley.

Grönroos, C. (2007). *Service management and marketing: Customer management in service competition*. West Sussex: Wiley.

Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Communications and Technology Journal, 30*(4), 233-252.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In Denzin, N. K. & Lincoln, Y. S. (Eds), *Handbook of qualitative research*. London: Sage.

Guerreiro, I. (2010). Rede Nacional de Cuidados Integrados e Plano Nacional de Saúde: Presente e futuro. *Pensar saúde. Plano nacional de Saúde 2011-2016* (Vol. 3). Alto Comisariado de Saúde.

Gummesson, E. (1987). The new marketing: developing long-term interactive relationships. *Long Range Planning, 20*, 10-20.

Guyatt, G. H., Feeny, D. H., & Patric, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine, 118*, 622-629.

Guyatt, G. H., & Jaeschke, R. (1990). Measurements in clinical trials: choosing the appropriate approach. In Schumaker, S. A, et al. (Eds), *Quality of life assessments in clinical trials*. New York, NY: Raven Press Publishers.

Haacke, C., Althaus, A., Spottke, A., Siebert, U., Back, T., & Dodel, R. (2006). Long-term outcome after stroke: Evaluating health-related quality of life using utility measurements. *Stroke, 37*(1), 193-198.

Haanstra, T., van der Berg, T., Ostelo, R. W., Poolman, R. W., Jansma, I. P., Cuijpers, P., & de Wet, H. C. W. (2012). Systematic review: Do patient expectations influence treatment outcomes in total knee and total hip arthroplasty? *Health and Quality of Life Outcomes, 10*(152).

Habana-Hafner, S., & Reed, H. B. (1989). *Partnerships for community development: Resources for practitioners and trainers*. Amherst, Mass.: Center for Organizational and Community Development, University of Massachusetts at Amherst.

Hackett, M. L., Duncan, J. R., Anderson, C. S., Broad, J. B., & Bonita, R. (2000). Health-related quality of life among long-term survivors of stroke. Results from the Auckland Stroke Study, 1991-1992. *Stroke, 31*(2), 440-447.

Haines, V. A., & Hurlbert, J. S. (1992). Network range and health. *Journal of Health and Social Behavior, 33*, 254-266.

Hair, J. F. J., Black, W. C., Babin, B. J., & Anderson, R. E. (2010). *Multivariate data analysis. A global perspective* (7th ed.): Pearson Prentice Hall.

Hamedani, A. G., Wells, C. K., Brass, L. M., Kernan, W. N., Viscoli, C. M., Maraire, J. N., Awaid, I. A., & Horwitz, R. I. (2001). A quality-of-life instrument for young hemorrhagic stroke patients. *Stroke, 32*(3), 687-695.

Hamilton, W. D. (1963). The evolution of altruistic behaviour. *American Naturalist, 97*(896), 354-356.

Hank, K., & Stuck, S. (2008). Volunteer work, informal help and care among the 50+ in Europe: further evidence for “linked” productive activities at older ages. *Social Science Research, 37*, 1280-1291.

Hardiman, S. J., & Katzir, L. (2013). *Estimating clustering coefficients and size of social networks via random walk*. Paper presented at the International World Wide Web Conference, Rio de Janeiro, Brazil.

Hare, R., Rogers, H., Lester, H., McManus, R. J., & Mant, J. (2006). What do stroke patients and their carers want from community services? *Family Practice, 23*(1), 131-136.

Harel, D., & Koren, Y. (2000). *A fact multi-scale method for drawing large graphs*. In Marks, J. (Ed.), Graph Drawing (Vol. 1984). Springer-Verlag.

Harris, E., Wise, M., & Howe, P. (1995). *Working together: Intersectoral action for health.* AGPS.

Harris, L. R., & Brown, G. T. L. (2010). Mixing interview and questionnaire methods: Practical problems in aligning data. *Practical Assessment Research & Evaluation, 15*(1).

Hastings, A. (1996). Unravelling the Process of "Partnership" in Urban Regeneration Policy. *Urban Studies, 33*(2), 253-268.

Hatala, J.-P. (2006). Social network analysis in human resource development: A new methodology. *Human Resource Development Review, 5*(1), 45-71.

Hatcher, L. (1994). *A step-by-step approach to using the SAS® system for factor analysis and structural equation modeling*. Cary, N.C: SAS Institutte, Inc.

Hawe, P., Webster, C., & Shiell, A. (2004). A glossary of terms for navigating the field of social network analysis. *Journal of Epidemiology and Community Health*, *58*(12), 971-975.

Hawley, A. H. (1950). *Human ecology*. New York: Rowland Press.

Haythornwaite, C. (1996). Social network analysis: An approach and technique for the study of information exchange. *Library and Information Science Research, 18,* 323-342.

Hebert, J., Durand, P. J., Dubuc, N., Tourigny, A., & the PRISMA Group. (2003). PRISMA: A new model of integrated service delivery for the frail older people in Canada. *International Journal of Integrated Care, 3*, e08.

Helfenbein, S., & Severo, C. A. (2004). *Scaling up HIV/AIDS programs: A manual for multisectoral planning*. Boston: Management Sciences for Health.

Hervas-Angulo, A., Cabases-Hita, J. M., & Forcen-Alonso, T. (2006). Costs deriving from strokes from a social perspective: A retrospective incidence approach with a follow-up at three years. *Revista de Neurologia, 43*(9), 518-525.

Hill, A., Griffiths, S., & Gillam, S. (2007). *Public health and primary care: Partners in population health*. New York: Oxford University Press.

Hill, C. (2002). *Network literature review: Conceptualizing and evaluating networks*. Southern Alberta Child and Youth Health Network.

Hill, D. J. (1986). Satisfaction and consumer services. In Lutz, R. J. (Ed.), *Advances in Consumer Research,* Vol. 13. Provo, UT: Association for Consumer Research.

Hill, C. J., Neeley, S. E. (1988). Differences in the consumer decision process for professional vs. generic services. *Journal of Services Marketing*, *2*(1), 17-23.

Hoang, H., & Antoncic, B. (2003). Network-based research in entrepreneurship: A critical review. *Journal of Business Venturing*, *18*, 165-187.

Hobart, J. C., Lamping, D. L., & Thompson, A. J. (1996). Evaluating neurological outcome measures: The bare essentials. *Journal of Neurology, Neurosurgery and Psychiatry, 60*(2), 127-130.

Hobart, J. C., Williams, L. S., Moran, K., & Thompson, A. J. (2002). Quality of life measurement after stroke: Uses and abuses of the SF-36. *Stroke, 33*(5), 1348-1356.

Hodge, G. A., & Greve, C. (2007). Public private partnership: An international performance review. *Public Administration Review, May/June 2007*, 545-558.

Hogl, K. (2002). *Inter-sectoral co-ordination*. Paper presented at the COST-Action E19 National Forest Programmes in the European Context, Vienna.

Hogue, T. (1993). *Community-based collaboration: Community wellness multiplied*. Bend, OR: Chandler Center for Community Leadership.

Hörnquist, J. O. (1982). The concept of quality of life. *Scandinavian Journal of Social Medicine, 10*(2), 57-61.

Hörnquist, J. O. (1990). Quality of life. *Scandinavian Journal of Public Health, 18*(1), 69-79.

Horsman, J., Furlong, W., Feeny, D., & Torrance, G. (2003). The Health Utilities Index (HUI®): Concepts, measurement properties and applications. *Health and Quality of Life Outcomes, 1*(54).

Horwath, J., & Morrison, T. (2007). Collaboration, integration and change in children's services: Critical issues and key ingredients. *Child Abuse & Neglect, 31*(1), 55-69.

Hoskins, C. N., & Mariano, C. (2004). *Research in nursing and health: Understanding and using quantitative and qualitative methods*. New York: Springer Publishing Company.

Hosmer, D. W., & Lemeshow, S. (2000). *Applied Logistic Regression* (2nd ed.). New York: John Wiley & Sons.

Howard, J. A., & Sheth, J. N. (1969). *The theory of buyer behavior*. New York: Wiley.

Hu, L. T., & Bentler, P. M. (1989). Fit indices in covariance structure modeling: Sensitivity to underparameterized model misspecification. *Psychological Methods, 3*(4), 424-453.

Hudson, B. (1987). Collaboration in social welfare: A framework for analysis. *Policy and Politics, 15*(1), 175-182.

Hudson, B. (2006). Integrated team working part II: Making the inter-agency connections. *Journal of Integrated Care, 14*(2), 26-36.

Hudson, B., Exworthy, M., Peckham, S., & Callaghan, G. (1999). *Locality partnerships: The early primary care group experience.* Leeds: Nuffield Institute for Health.

Hudson, B., & Hardy, B. (2002). What is "successful" partnership and how can it be measured? In Glendinning, C., Powell, M., & Rummery, K. (Eds), *Partnerships, new labour and the governance of welfare*. Bristol: The Policy Press.

Hudson, B., Hardy, B., Henwood, M., & Wistow, G. (1997). *Inter-agency collaboration: Final report*. Leeds: Nuffield Institute for Health Community Care Division.

Hughes, J., & Weiss, J. (2007). Simple rules for making alliances work. *Harvard Business Review, 85*(11), 122-131.

Hulin, C. (2001). Cronbach’s alpha on two-item scales. *Journal of Consumer Psychology, 10*(1-2), 55.

Hunt, S. M., McKenna, S. P., McEwen, J., Backett, E., M., Williams, J. & Papp, E. (1980). A quantitative approach to perceived health status: A validation study. *Journal of Epidemiology & Community Health, 34*(4), 281-286.

Hunter, A., & Riger, S. (1986). The meaning of community in community mental health. *Journal of Community Psychology, 14*, 25-69.

Hunter, D. J. (2000). Disease management: Has it a future? *British Medical Journal, 320*(7234), 530.

Huxham, C. (1996). *Creating collaborative advantage*. London: Sage.

Huxham, C. (2000). The challenge of collaborative governance. *Public Management, 2*(3), 337-357.

IBM Corporation Inc. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM, Corp. Retrieved 20 November 2013 from http://www-01.ibm.com/software/analytics/spss/products/statistics/index.html

IBM Corporation Inc. IBM AMOS for Windows, Version 21.0 Armonk, NY: IBM, Corp. Retrieved 12 September 2014 from http://www14.software.ibm.com/webapp/download/byproduct.jsp

INE (2011). *Portugal. Censos 2011*. Retrieved 3 June 2012, from www.ine.pt

Instituto de Solidariedade, Emprego e Segurança Social. (2014). *Carta Social. Capacidade de respostas sociais*. Retrieved 2 September 2014 from http://www.cartasocial.pt/index1.php

Jackson, C., Nicholson, C., Doust, J., Cheung, L., & O’Donnell, J. (2008). Seriously working together: Integrated governance models to achieve sustainable partnerships between health care organisations. *Medical Journal of Australia, 188*(8), S57-60.

Jacob, L. (2002). *Ajudante sénior: Uma hipótese de perfil profissional para as IPSS*. Lisboa: ISCTE.

Jain, S. K., & Gupta, G. (2004). Measuring Service Quality: SERVQUAL vs. SERVPERF Scales. *Vikalpa, 29*(2), 25-37.

Jarillo, J. C. (1988). On strategic networks. *Strategic Management Journal, 9*(1), 31-39.

Jessop, B. (1997). The governance of complexity and the complexity of governance: Preliminary remarks on some problems and limits of economic guidance. In Amin, A., & Hausner, J. (Eds), *Beyond Market and Hierarchy*. Cheltenham: Edward Elgar.

Johanson, J., & Mattsson, L. (1988). Internationalisation in industrial systems - A network approach. In Hood, N., & Vahlne, J. E. (Eds), *Strategies in global competition: Selected papers from the Prince Bertil Symposium at the Institute of International Business, Stockholm School of Economics*. London: Croom Helm.

Joreskog, K. G., & Sorbom, D. (1984). *LISREL VI users guide* (3rd ed.). Moorsville, IN: Scientific Software.

Jorgensen, M. (2006). *Evaluating cross-sector partnerships*. Paper presented at the conference on public-private partnerships In The Post-World Summit on Sustainable Development Context, Copenhagen Business School, 14 August 2006.

Kagan, S. L. (1991). *United we stand: Collaboration for child care and early education services*. New York: Teachers College Press.

Kalegaonkar, A., & Brown, L. D. (2000). *Intersectoral cooperation: Lessons for practice IDR Reports* (Vol. 16). Boston: Institute for Development Research.

Katz, L. (1953). A New Status Index Derived from Sociometric Index. *Psychometrika*, *18*(1), 39-43.

Kickbusch, I., & Quick, J. (1998). Partnerships for health in the 21st century. *World Statistics Quarterly, 51*, 68-74.

Kickert, W. J. M., Klijn, E.-H., & Koppenjan, J. F. M. (1997). *Managing complex networks*. London: Sage.

Kind, P. (2001). Measuring quality of life in evaluating clinical interventions: An overview. *Annals of Medicine, 33*(5), 323-327.

King, R. B. (1996). Quality of life after stroke. *Stroke*, *27*, 1467-1472.

Kirk, J., & Miller, M. L. (1986). *Reliability and validity in qualitative research* (Vol. 1). Beverly Hills: Sage.

Kitzmuller, G., Asplund, K., & Haggstrom, T. (2012). The long-term experience of family life after stroke. *Journal of Neuroscience Nursing, 44*(1), E1-E13.

Klaus, P. (1985). Quality epiphenomenon: The conceptual understanding of quality in face-to face service encounters. In Czepiel, J. A., Solomon, M. R., Suprenant, C. F., & Gutman, E. G. (Eds), *The service encounter: Managing employee customer interaction in service business*. Lexington, MA: Lexington Books.

Kline, P. (1999). *The handbook of psychological testing*. London: Routledge.

Kline, R. B. (2005). *Principles and practice of structural equation modeling: Methodology in the social sciences*. New York: Guilford Press.

Klitgaard, R. (2004). Evaluation of, for, and through partnership. In Liebenthal, A., Feinstein, O., & Ingram, G. (Eds), *Evaluation and development: The partnership dimension*. New Brunswick: Transaction Publishers.

Kohli, M., Hank, K., & Kunemund, H. (2009). The social connectedness of older Europeans: Patterns, dynamics and contexts. *Journal of European Social Policy, 19*(4), 327-340.

Koller, M., Klinkhammer-Schalke, M., & Lorenz, W. (2005). Outcome and quality of life in medicine: A conceptual framework to put quality of life research into practice. *Urologic Oncology, 23*(3), 186-192.

Koosam, V. K. (2013). Overview on Strokes. *Indian Journal of Medicine and Healthcare, 2*(7), 277-280.

Kreuter, M. W., & Lezin, N. A. (1998). *Are consortia/collaboratives effective in changing health status and health systems? A critical review of the literature*. Atlanta: Health 2000.

Krippendorff, K. (1980). *Content analysis. An introduction to its methodology*. Beverly Hills, CA: Sage.

Krzych, L. J. (2007). Interpretation of the statistical analysis of data [Interpretacja wynikow analizy statystycznej danych]. *Jakosc w Medycynie, 4*(3), 315-321.

Kutner, M. H., Nachtsheim, C. J., & Neter, J. (2004). *Applied linear regression models*. Chicago: McGraw-Hill Irwin.

Kwa, V. I. H., Limburg, M., & de Haan, R. J. (1996). The role of cognitive impairment in the quality of life after ischemic stroke. *Journal of Neurology, 243*(8), 599-604.

Labi, M. L. C., Phillips, T. F., & Gresham, G. E. (1980). Psychosocial disability in physically restored long-term stroke survivors. *Archives of Physical Medicine and Rehabilitation, 61*, 561-565.

Lafferty, W. M., & Hovden, E. (2003). Environmental policy integration: Towards an analytical framework. *Environmental Politics, 12*(3), 1-22.

Lai, S. M., Studenski, S., Duncan, P. W., & Perera, S. (2002). Persisting consequences of stroke measured the Stroke Impact Scale. *Stroke, 33*, 1840-1844.

Lalonde, M. (1974). *A new perspective on the health of Canadians*. Ottawa, Canada: Minister of Supply and Services.

Landreth, H., & Colander, D. C. (2005). *History of the Economic Thought*. Warsaw: PWN.

Langhorne, P., & Holmqvist, L. W. (2007). Early supported discharge after stroke. *Journal of Rehabilitation Medicine, 39*(2), 103-108.

Lasker, R. D., Weiss, E. S., & Miller, R. (2001). Partnership synergy: A practical framework for studying and strengthening the collaborative advantage. *Milbank Q, III-IV, 79*(2), 179-205.

Lasswell, H. D., Lerner, D., & Pool, I. S. (1952). *The comparative study of symbols*. Stanford: Stanford University Press.

Lauri, S., & Kyngäs, H. (2005). *Developing nursing theories [Hoitotieteen Teorian Kehittäminen]*. Vantaa, Finland: Werner Söderström Osakeyhtiö.

Lawrence, T. B., Phillips, N., & Hardy, C. (1999). Watching whale watching: Exploring the discursive foundations of collaborative relationships. *Journal of Applied Behavioral Science, 35*(4), 479-502.

Lawton, M., Winter, L., Kleban, M. H., & Ruckdeschel, K. (1999). Affect and quality of life. Objective and subjective. *Journal of Aging and Health, 11*, 169-198.

Leathard, A. (2005). Evaluating interagency working in health and social care: Politics, policies and outcomes for service users. In Taylor, D., & Ballock, S. (Eds), *The politics of evaluation*. Bristol: Policy Press.

Lee, H., Lee, Y., & Yoo, D. (2000). The determinants of perceived service quality and its relationship with satisfaction. *Journal of Services Marketing, 14*(3), 217-231.

Leek, S., & Canning, L. (2011). Entering and developing a service network. *Journal of Services Marketing, 25*(1), 58-67.

Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. In Lewis, R. J. (Ed.), *Qualitative research practice: A guide for social research students and researchers*. Thousand Oaks, CA: Sage.

Legido-Quigley, H., McKee, M., Nolte, E., & Glinos, I. A. (2008). Assuring the quality of health care in the European Union. A case for action. *Observatory Studies Series No. 12*. World Health Organization on behalf of the European Observatory on Health Systems and Policies.

Lehman, A. F. (1995). Measuring quality of life in a reformed health system. *Health Affairs, 14*(3), 90-101.

Lei de Bases da Saúde. *Aprovada pela Lei n.º 48/90, de 24 de Agosto, com as alterações introduzidas pela Lei n.º 27/2002, de 8 de Novembro*.

Lessard-Hérbert, M., Goyette, G., & Boutin, G. (2008). *Investigação qualitativa. Fundamentos e práticas.* Lisbon: Instituto Piaget.

Leutz, W. (1999). Five laws for integrating medical and social services: Lessons from the United States and the United Kingdom. *Millbank Quarterly, 77*(1), 77-110.

Lewis, J. M. (2005). A network approach for researching partnerships in health. *Australia and New Zealand Health Policy, 2*(22).

Li, L., Young, D., Xiao, S., Zhou, X., & Zhou, L. (2004). Psychometric properties of the WHO Quality of Life questionnaire (WHOQOL-100) in patients with chronic diseases and their caregivers in China. *Bulletin of the World Health Organization, 82*(7), 493-502.

Lietchty, M. S., & Churchill, J., G.A. (1979). *Conceptual insights into consumer satisfaction with services*. Paper presented at the AMA Educator’s Conference Proceedings, Chicago.

Lim, J. W., Yi, J., & Zebrack, B. (2008). Acculturation, social support, and quality of life for Korean immigrant breast and gynecological cancer patients. *Ethnicity & Health, 13,* 243-260.

Lim, P. C., & Tang, N. K. H. (2000). A study of patients’ expectations and satisfaction in Singapore hospitals. *International Journal of Health Care Quality Assurance, 13*(7), 290-299.

Linder-Pelz, S. (1982). Toward a theory of patient satisfaction. *Social Science & Medicine, 16*(5), 577-582.

Ling, T. (2000). Unpacking partnership: The case of health care. In Clarke, J., Gewirtz, S., & McLaughlin, E. (Eds), *New managerialism, new welfare?* London: Sage.

Lohr, K. N. (1990). *Institute of Medicine Medicare: A strategy for quality assurance* (Vol. I). Washington, DC: Institute of Medicine.

Lubben, J., & Gironda, M. (2003). Centrality of social ties to the health and well-being of older adults. In Berkman, B., & Harootyan, L. (Eds), *Social work and health care in an aging society*. New York: Springer Publishing Company.

Lubben, J., & Gironda, M. (2004). Measuring social networks and assessing their benefits. In Phillipson, C., Allan, G., & Morgan, D. (Eds), *Social networks and social exclusion: sociological and policy perspectives*. Aldershot: Ashgate.

Luke, D., & Harris, J. (2007). Network analysis in public health: History, methods, and applications. *Annual Review of Public Health, 28,* 69-93.

Lund, M. (1985). The development of investment and commitment scales for predicting continuity of personal relationships. *Journal of Social and Personal Relationships, 2*(1), 3-23.

Lutz, B. J., & Young, M. E. (2010). Rethinking intervention strategies in stroke family caregiving. *Rehabilitation Nursing, 35*(4), 152-160.

Lyden, P. D., & Hantson, L. (1998). Assessment scales for the evaluation of stroke patients. *Journal of Stroke and Cerebrovascular Diseases, 7*(2), 113-127.

Lynch, L. B., Butt, Z., Heinemann, A., Victorson, D., Nivinski, C. J., Perez, L., & Cella, D. (2008). A qualitative study of quality of life after stroke: The importance of social relationships. *Journal of Rehabilitation Medicine, 40*(7), 518-523.

Lynch, P. (2000). Networking in the homestay sector. *The Service Industries Journal, 20*(3), 95-116.

Macdonald, G., & Leary, M. R. (2005). Does social exclusion hurt? The relationship between social and physical pain. *Psychological Bulletin, 131*(2), 202-223.

Mackay, J., & Mensah, G. (2004). *Atlas of heart disease and stroke*. Geneva, Switzerland: World Health Organization in collaboration with the US Centers for Disease Control and Prevention.

Malley, J., & Fernández, J.-L. (2010). Measuring quality in social care services: Theory and practice. *Annals of Public and Cooperative Economics, 81*(4), 559-582.

Malley, J., Sandhu, S., & Netten, A. (2006). *Younger adults understanding of questions for a service user*. Experience survey. PSSRU Discussion Paper 2360, University of Kent.

Mannell, R. C., & Kleiber, D. A. (1997). *A social psychology of leisure, Venture Publications, StateCollege, PA*. State College, PA: Venture Publications.

Marcussen, K., Ritter, C., & Munetz, M. R. (2010). The effect of services and stigma on quality of life for persons with serious mental illnesses. *Psychiatric Services, 61*(5), 489-494.

Marôco, J. (2010). *Análise estatística com PASW Statistics (ex-SPSS)*. Lisbon: Report Number.

Marsden, P. V. (1990). Network data and measurement. *Annual Review of Sociology, 16*, 435-463.

Martin-Misener, R., & Valaitis, R. (2008). *A scoping literature review of collaboration between primary care and public health.* A report to the Canadian Health Services Research Foundation.

Martins, R. (2006). Special importância do AVC para a população Portuguesa. *Revista Saúde Pública*, 4.

Masniak, D. (2003). *Environmental insurance*. Cracow: Kantor Publishing Zakamycze.

Mastekaasa, A., & Moum, T. (1984). The perceived quality of life in Norway: Regional variations and contextual effects. *Social Indicators Research, 14*, 385-419.

Mattessich, P. W., Murray-Close, M., & Monsey, B. R. (1994). *Collaboration: What makes it work*. St. Paul, Minnesota: Amherst H. Wilder Foundation.

Mattessich, P. W., Murray-Close, M., & Monsey, B. R. (2001). *Collaboration: What makes it work*. St. Paul, Minnesota: Amherst H. Wilder Foundation.

Mattsson, J. (1992). A service quality model based on ideal value standard. *International Journal of Service Industry Management*, *3*(3), 18-33.

Mayring, P. (2000). Qualitative content analysis. *Forum: Qualitative Social Research, 1*(2), Art. 20.

Mays, G. P., Halverson, P. K., & Kaluzny, A. D. (1998). Collaboration to improve community health: trends and alternative models. *The Joint Commission Journal on Quallity Improvement, 24*(10), 518-540.

McAllister, D. J. (1995). Affect- and cognition-based trust as foundation for interpersonal cooperation in organizations. *Academy of Management Journal, 38*(1), 24-59.

McEwen, S., Mayo, N., & Dauphinee, S. (2000). Inferring quality of life from performance-based assessments. *Disability and Rehabilitation, 22*(10), 456-463.

McIllwain, J. S. (1999). Organized crime: A social network approach. *Crime, Law & Social Change, 32*, 301-323.

McKevitt, C., Redfern, J., La-Placa, V., & Wolfe, C. D. (2003). Defining and using quality of life: a survey of health care professionals. *Clinical Rehabilitation, 17*(8), 865-870.

McKinley, R. K., Stevenson, K., Adams, S., & Manku-Scott, T. K. (2002). Meeting patient expectations of care: The major determinant of satisfaction with out-of-hours primary medical care? *Family Practice, 19*(4), 333-338.

McKinnon, R. (2009). A case for public-private partnerships in health: Lessons from an honest broker. *Preventing Chronic Disease*, *6*(2), A72.

McLaughlin, H. (2004). Partnerships: Panacea or pretence? *Journal of Interprofessional Care, 18*(2), 103-113.

McNulty, T., & Ferlie, E. (2002). *Reengineering health care. The complexities of organizational transformation.* New York: Oxford University Press.

Mellor, P, & Green, S., (2002). A novel approach to modeling the prescribing decision, integrating physician and patient influences. *International Journal of Market Research, 44*(4), 449-491.

Mena, C., Humphries, A., & Wilding, R. (2009). A comparison of inter- and intra-organizational relationships. Two case studies from UK food and drink industry. *International Journal of Physical Distribution & Logistics Management, 39*(9), 762-784.

Meyer, J. W., & Rowan, B. (1977). Institutional organizations: Formal structures as myth and ceremony. *American Journal of Sociology, 80,* 340-363.

Michalos, A. C. (2007). Education, happiness and wellbeing. *Social Indicators Research, 87,* 347-366.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks: SAGE Publications.

Ministério da Saúde. (2004). *Plano Nacional de Saúde 2004-2010. Mais saúde para todos* (Vol. I - Prioridades).

Ministério da Saúde. (2011). *Plano Nacional de Saúde 2011-2016*.

Ministério da Saúde. (2015). *Operacionalização da metodologia de contratualizaçãopara os cuidados de saúde primários no ano de 2014*. ACSS.

Ministry of Health. (2005). *New Zealand intersectoral initiatives for improving the health of local communities. An updated literature review examining the ingredients for success*. Wellington.

Minkman, M. M., Ahaus, K. T., & Huijsman, R. (2009). A four phase development model for integrated care services in the Netherlands. *BMC Health Services Research, 9*(42).

Mitchell, J. (1973). Networks, norms and institutions. In Boissevain, J., & Mitchell, J. (Eds), *Network analysis studies in human interaction*. The Hague: Mouton.

Mitchell, J. C. (1969). The concept and use of social networks. In Mitchell, J. C. (Ed.), *Social networks in urban situations*. Manchester: University of Manchester Press.

Mitchell, P. F. (2009). A discourse analysis on how service providers in non-medical primary health and social care services understand their roles in mental health care. *Social Science & Medicine, 68*(7), 1213-1220.

Molina, J. L. (2004). La ciencia de las redes. *Apuntes de Ciencia y Tecnologia, 11*, 36-42.

Mota-Pinto, A., Rodrigues, V., Botelho, A., Veríssimo, M. T., Morais, A., Alves, C., Rosa, M. S., & de Oliveira, C. R. (2011). A socio-demographic study of aging in the Portuguese population: the EPEPP study. *Archives of Gerontology and Geriatrics, 52*(3), 304-308.

Moutinho, M., Magalhães, R., Correia, M., & Silva, M. C. (2013). Avaliação da via verde do acidente vascular cerebral de Portugal: Caracterização e prognóstico dos ptilizadores. *Acta Médica Portuguesa, 26*(2), 113-122.

Murdoch, J. (2000). Networks: a new paradigm of rural development? *Journal of Rural Studies, 16*(4), 407-419.

Murray, V. (1998). *Interorganizational collaboration in the non-profit sector* (Vol. 2). Boulder, CO: Westview Press.

National clinical guideline for stroke. (2012). *Intercollegiate stroke working party*. London: Royal College of Physicians.

Netuveli, G., & Blane, D. (2008). Quality of life in older ages. *British Medical Bulletin, 85*(1), 113-126.

Neuman, W. L. (1997). *Social research methods: Qualitative and quantitative approaches* (3rd ed.). Needham Heights, MA: Allyn and Bacon.

Newman, M. E. J. (2005). A measure of betweenness centrality based on random walks. *Social Networks, 27*(1), 39-54.

Niemi, M. L., Laaksonen, R., Kotila, M., & Waltimo, O. (1988). Quality of life 4 years after stroke. *Stroke, 19*(9), 1101-1107.

Nikolic, I. A., & Maikisch, H. (2006). Public-private partnerships and collaboration in the health sector. An overview with case studies from recent European experience. *HNP Discussion Paper*. Washington: The International Bank for Reconstruction and Development / The World Bank.

Nyeck, S., Morales, M., Ladhari, R., & Pons, F. (2002). 10 years of service quality measurement: Reviewing the use of the SERVQUAL instrument. *Cuadernos de Diffusion, 7*(13), 101-107.

O'Looney, J. (1997). Making progress towards service integration: Learning to use evaluation to overcome barriers. *Administration in Social Work, 21*(3-4), 31-65.

O'Mahony, P. G., Rodgers, H., Thomson, R. G., Dobson, R., & James, O. F. W. (1998). Is the SF-36 suitable for assessing health status of older stroke patients? *Age and Ageing, 27*(1), 19-22.

O'Neill, M., Lemieux, V., Groleau, G., Fortin, J.-P., & Lamarche, P. A. (1997). Coalition theory as a framework for understanding and implementing intersectoral health-related interventions. *Health Promotion International, 12*(1), 79-87.

O'Toole, L. J. (1997). Treating networks seriously: Practical and research-based agendas in public administration. *Public Administration Review, 57*(1), 45-51.

OECD (2012a). Country notes: Recent changes in migration movements and policies. *Portugal International Migration Outlook*. OECD, 262-263.

OECD (2012b). Health at a Glance: Europe 2012. *Health at a Glance: Europe*. OECD Publishing.

OECD (2012c). *OECD Health Data 2012*. Retrieved 1 July 2012, from http://www.oecd.org

Office of the Auditor-General. (2006). Achieving public sector outcomes with private sector partners. *Performance audit report*. Wellington.

Oh, H. (1999). Service quality, customer satisfaction and customer value: A holistic perspective. *International Journal of Hospitality Management, 18*, 67-82.

Ojo, O. (2010). The relationship between service quality and customer satisfaction in the telecommunication industry: Evidence from Nigeria. *BRAND. Broad Research in Accounting, Negotiation, and Distribution, 1*(1), 88-100.

Oliva-Moreno, J., Aranda-Reneo, I., Vilaplana-Prieto, C., Gonzalez-Dominguez, A., & Hidalgo-Vega, A. (2013). Economic valuation of infomal care in cerebrovascular accident survivors in Spain. *BMC Health Services Research, 13*(508).

Oliver, A., & Ebers, M. (1998). Networking network studies: An integrative framing of conceptual dimensions in the study of interorganizational relationships. *Organization Studies, 19*(4), 549-583.

Oliver, R. L. (1980). A cognitive model of the antecedents and consequences of satisfaction decisions. *Journal of Retailing, 17(4),* 460-469.

Oliver, R. L. (1989). Processing of the satisfaction response in consumption: A suggested framework and research propositions. *Journal of Consumer Satisfaction, Dissatisfaction and Complaining Behavior, 2*, 1-16.

Oliver, R. L. (1993a). Cognitive, affective, and tribute base of the satisfaction response. *Journal of Consumer Research, 20* (December), 418-430.

Oliver, R. L. (1993b). A conceptual model of service quality and service satisfaction: Compatible goals, different concepts. *Advances in Services Marketing and Management, 2*, 65-85.

Olson, J. C., & Dover, P. (1976). Effects of expectation creation and disconfirmation on belief elements of cognitive structures. In Anderson, B. (Ed.), *Advances in Consumer Research*. Chicago: Association for Consumer Research.

Olubunmi, O. A. (2007). Recent advances in the management of cerebro-vascular accident. *Benin Journal of Postgraduate Medicine, 9*(1), 28-40.

Opara J. A., & Jaracz, K. (2010). Quality of life of post-stroke patients and their caregivers. *Journal of Medicine and Life, 3*(3), 216-20.

Oppenheim, A. (1992). *Questionnaire design, interviewing and attitude measurement*. London: Pinter Publisher.

Ordway, S. H. (1953). Resources and the American dream: Including a theory of the Limit of Growth. New York: Ronald Press.

Osborne, S. P. (2000). *Public-private partnerships: Theory and practice in international perspective.* London: Routledge.

Otte, E., & Rousseau, R. (2002). Social network analysis: A powerful strategy, also for the information sciences. *Journal of Information Science, 28*, 441-453.

Page, L., Brin, S., Motwani, R., & Winograd, T. (1999). *The PageRank citation ranking: Bringing order to the Web*. Stanford InfoLab.

Page, T. J., & Spreng, R. A. (2002). Difference scores versus direct effects in service quality measurement. *Journal of Service Research, 4*(3), 184-192.

Palazzolo, M., Grippa, F., Booth, A., Rechner, S. Bucuvalas, J., & Gloor, P. (2011). Measuring social network structure of clinical teams caring for patients with complex conditions. *Procedia - Social and Behavioral Sciences, 26*, 17-29.

Palmer, J., & Richards, I. (1999). Get knitted: Network behaviour in the new economy. *The Journal of Knowledge Management, 3*(3), 191-202.

Parasuraman, A., Berry, L., & Zeithaml, V. (1988). SERVQUAL: A multiple-item scale for measuring consumer perceptions of service quality. *Journal of Retailing, 64*(1), 12-40.

Parasuraman, A., Zeithaml, V., & Berry, L. (1985). A conceptual model of service quality and its implications for future research. *Journal of Marketing, 49*, 41-50.

Parasuraman, A., Zeithaml, V. A., & Berry, L. L. (1994). Reassessment of expectations as a comparison standard in measuring service quality: Implications for further research. *Journal of Marketing, 58*(1), 111-124.

Pascoe, G. (1983). Patient satisfaction in primary health care: A literature review and analysis. *Evaluation and Program Planning, 6*(3-4), 185-210.

Patel, M. D., Tilling, K., Lawrence, E., Rudd, A. G., Wolfe, C. D., & McKevitt, C. (2006). Relationship between long-term stroke disability, handicap and health-related quality of life. *Age Ageing, 35*(3), 273-279.

Patrick, D. L., & Deyo, R. A. (1989). Generic and disease-specific measures in assessing health status and quality of life. *Medical Care, 27*(Suppl. 3), S217-232.

Patrick, D. L., & Erickson, P. (1993). *Health status and health policy. Allocating resources to health care*. Oxford: Oxford University Press.

Patterson, P. G., & Johnson, L. W. (1993). Disconfirmation of expectation and the gap model of service quality: An integrated paradigm. *Journal of Consumer Satisfaction, Dissatisfaction and Complaining Behavior, 6,* 90-99.

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. London: Sage Publications.

Peake, S., Gallagher, G., & Valentine, N. (2008). *Health equity through intersectoral action: An analysis of 18 country case studies*. WHO and Minister of Health of Canada.

Pearce, J. A., & Doh, J. P. (2005). The high impact of collaborative social initiatives. *MIT Sloan Management Review, 46*(3), 29-40.

Peters, B. G. (1998). Managing horizontal government: The politics of coordination. *Research paper no. 21*. Canadian Centre for Management Development.

Peterson, N. L. (1991). Interagency collaboration under Part H: The key to comprehensive, multidisciplinary, coordinated infant/toddler intervention services. *Journal of Early Intervention*, *15*(1), 89-105.

Pfeffer, J., & Salancik, G. R. (1978). *The external control of organizations*. New York: Harper & Row.

Pfeffer, N., & Coote, A. (1991). *Is quality good for you? A critical review of quality assurance in welfare services*. London: Institute for Public Policy Research.

Philip, G., & Hazlett, S. A. (1997). The measurement of service quality: A new P-C-P attributes model. *International Journal of Quality & Reliability Management, 14*(3), 260-286.

Pickard, S., Johnson, J. A., Penn, A., Lau, F., & Noseworthy, T. (1999). Replicability of the SF-36 summary scores by the SF-12 in stroke patients. *Stroke, 30*, 1213-1217.

Pierce, S. D. (2002). *Bridging differences and building collaboration the critical role of leadership*. Concept paper: The Synergos Institute.

Pierce, S. D. (2004). *Bridging the social divide: a grounded view of partnership-building in Latin America, Southeast Asia, Southern Africa and North America*. The Synergos Institute.

Pierson, C. (2006). *Beyond the welfare state? The new political economy of welfare*. Cambridge: Polity Press.

Pisco, L. (2006). Main lines of action for reforming primary health care in Portugal. *Primary Health Care, 15*(2), 63-66.

Polenske, K. R. (2004). Competition, colaboration and cooperation: An uneasy triangle in networks and firms and regions. *Regional Studies, 38*(9), 1029-1043.

Polit, D. F., & Beck, C. T. (2004). *Nursing research. Principles and methods*. Philiadelphia: Lippincott Williams & Wilkins.

Popay, J. (2003). Qualitative research and the epidemiological imagination: A vital relationship. *Gaceta Sanitaria, 17*(Suppl. 3), 58-63.

Population Reference Bureau. (2009). Social support, networks, and happiness. *Today's Research on Aging, 17*, June, 1-6.

Pordata. (2013). Taxa de desemprego: total e por sexo. *Base de dados - Portugal contemporâneo*. Retrieved 18 March 2014, from http://www.pordata.pt.

Powell, M., Exworthy, M., & Berney, L. (2001). Playing the game of partnership. In Sykes, R., Bochel, C., & Ellison, N. (Eds), *Social Policy Review 13*. Bristol: The Policy Press in association with Social Policy Association.

Powell, M., & Glendinning, C. (2002). Introduction. In Glendinning, C., Powell, M., & Rummery, K. (Eds), *Partnerships, new labour and the governance of welfare*. Bristol: The Policy Press.

Pratt, J., Gordon, P., & Plampling, D. (1999). *Working whole systems*. London: King’s Fund.

Prefontaine, L., Ricard, L., Sicotte, H., Turcotte, D., & Dawes, S. (2000). *New models of collaboration for public service delivery: Worldwide trends*. Working Paper prepared for CEFRIO.

Presidência do Conselho de Ministros (2004). *Homens e mulheres entre a família e o trabalho*. Lisboa: MSST and CITE.

Presser, S., Rothgeb, J., Couper, J., Lessler, J., Martin, E., Martin, J., & Singer, E. (2004). *Methods for testing and evaluating survey questionnaires*. Hoboken, NJ: Wiley

Primary Care Trust Network. (2010). Where next for health and social care integration? NHS Confederation. *Resources, Issue 8*. Retrieved 20 March 2010, from http://www.nhsconfed.org/Publications/Pages/health-socialcare-integration.aspx

Provan, K. G., & Kenis, P. (2007). Modes of network governance: Structure, management, and effectiveness. *Journal of Public Administration Research and Theory, 18*(2), 229-252.

Provan, K. G., & Milward, H. B. (2001). Do networks really work? A framework for evaluating public-sector organizational networks. *Public Administration Review, 61*(4), 414-423.

Pryke, S. D. (2005). Towards a social network theory of project governance. *Construction Management and Economics, 23*(9), 727-239.

Public Health Agency of Canada. (2002). *What determines health?* Retrieved 5 May 2012, from http://www.phac-aspc.gc.ca/index-eng.php.

Public Health Institute for the California Endowment. (1998). *Partnership for the public's health: challenges and opportunities*. Oakland, California.

Putnam, R. D. (1988). Diplomacy and domestic politics: the logic of two-level games. *International Organization, 42*(3), 427-460.

Quaresma, M. (1996). *Cuidados familiares às pessoas muito idosas*. Núcleo de Documentação Técnica e Divulgação, Direcção Geral da Acção Social. Vol. 5.

Ragin, C. C., & Becker, H. S. (1992). *What is a case? Exploring the foundations of social inquiry*. Cambridge: Cambridge University Press.

Raleigh, V. S., & Foot, C. (2010). *Getting the measure of quality. Opportunities and challenges*. London: The King's Fund.

Rampersad, G., Quester, P., & Troshani, I. (2010). Examining network factors: Commitment, trust, coordination and harmony. *Journal of Business & Industrial Marketing, 25*(7), 487-500.

Raposo, M. L., Alves, H. M., & Duarte, P. A. (2008). Dimensions of service quality and satisfaction in healthcare: A patient's satisfaction index. *Service Business, 3*(1), 85-100.

Raubenheimer, J. (2004). An item selection procedure to maximise scale reliability and validity. *SA Journal of Industrial Psychology, 30*(4), 59-64.

Read, L. (1993). The new era of quality of life assessment. In Walker, S., & Rosser, R. (Eds), *Quality of life assessment: Key issues in the 1990s*. Dordrecht: Kluwer.

Reich, M. R. (2002). *Public-private partnerships for public health*. Cambridge: Harvard University Press.

Rein, M., Stott, L., Yambayamba, K., Hardman, S., & Reid, S. (2005). *Working together: A critical analysis of cross-sector partnerships in Southern Africa*. Cambridge: Cambridge University Programme for Industry.

Richman, W., Keisler, S., Weisband, S., & Drasgow, F. (1999). A meta-analytic study of social desirability distortion in computer-administered questionnaires, traditional questionnaires, and interviews. *Journal of Applied Psychology, 84*(5), 754-775.

Rigby, H., Gubitz, G., Eskes, G., Reidy, Y., Christian, C., Grover, V., & Phillips, S. (2009). Caring for stroke survivors: baseline and 1-year determinants of caregiver burden. *International Journal of Stroke, 4*(3), 152-158.

Rigby, H., Gubitz, G., & Phillips. S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4*(4), 285-292.

Riley, D., & Eckenrode, J. (1986). Social ties: Subgroup differences in costs and benefits. *Journal of Personality and Social Psychology, 51*(4), 770-778.

Ring, P. S., & Van de Ven, A. H. (1992). Structuring cooperative relationships between organisations. *Strategic Management Journal, 13*(7), 483-498.

Roloff, J. (2008). A life cycle model of multi-stakeholder networks. *Business Ethics: A European Review, 17*(3), 311-325.

Rourke, L., Anderson, T., Garrison, D. R., & Archer, W. (2000). Methodological issues in the content analysis of computer conference transcripts. *International Journal of Artificial Intelligence in Education, 12*(1), 8-22.

Rousseau, D. M., Sitkin, S. B., Burt, R. S., & Camerer, C. (1998). Not so different after all: A cross discipline view of trust. *Academy of Management Review, 23*(3), 393-404.

Rowley, J. E. (1996). Customer compatibility management: An alternative perspective on student-to-student support in higher education. *International Journal of Educational Management, 10*(4), 15-20.

Rowley, T. J. (1997). Moving beyond dyadic ties: A network theory of stakeholder influences. *Academy of Management Review, 22*(4), 887-910.

Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data*. London: Sage Publications.

Rudan, I., Chopra, M., Kapiriri, L., Gibson, J., Ann Lansang, M., Carneiro, I., & et al. (2008). Setting priorities in global child health research investments: Universal challenges and conceptual framework. *Croatian Medical Journal, 49*(3), 307-317.

Rust, R. T., & Oliver, R. L. (1994). *Service quality: New directions in theory and practice*. Thousand Oaks, CA: Sage Publications.

Rutten, R. P. J. H., & Boekema, F. W. M. (2004). The spatial dimension of inter-firm learning: case study and conceptualization In Cooke, P. H., & Piccaluga, A. (Eds), *Regional economies as knowledge laboratories*. Cheltenham: Edward Elgar.

Sá, M. J. (2009). AVC - primeira causa de morte em portugal. *Revista da Faculdade de Ciências da Saúde 6,* 12-19.

Saladin, L. K. (2000). Measuring quality of life post-stroke. *Neurology Report, 24,* 133-139.

San Martin-Rodriguez, L., Beaulieu, M. D., D’Amour, D., & Ferrada-Videla, M. (2005). The determinants of successful collaboration: A review of theoretical and empirical studies. *Journal of Interprofessional Care, 19* (Suppl. 1), 132-147.

Santana, P. (2002). Poverty, social exclusion and health in Portugal. *Social Science & Medicine, 55*(1), 33-45.

Santana, S. (2010). Reforming long-term care in Portugal: Dealing with the multidimensional character of quality. *Social Policy & Administration, 44*(4), 51-528.

Santana, S., Szczygiel, N., & Redondo, P. (2014). Integration of care systems in Portugal: Anatomy of recent reforms. *International Journal of Integrated Care, 14*, July-September, e014.

Saraceno, Ch, & Naldini, M. (2003). *Sociologia da família*. Lisbon: Editorial Stampa.

Sasser, W. E., Olsen, R. P., & Wyckoff, D. D. (1978). *Management of service operations*. Boston: Allyn & Bacon.

Saxena, G., & Ilbery, B. (2008). Integrated rural tourism. *Annals of Tourism Research, 35*(1), 233-254.

Schmidt, S., & Bullinger, M. (2003). Current issues in cross-cultural quality of life instrument development. *Archives of Physical Medicine and Rehabilitation, 84*(4), 29-35.

Scholtens, B. (2008). A note on the interaction between corporate social responsibility and financial performance. *Ecological Economics, 68*(1-2), 46-55.

Scott, D. (2005). Inter-organisational collaboration in family-centred practice: a framework for analysis and action. Australian Social Work, 58(2), 132-141.

Scott, J. (1997). *Network analysis: a handbook*. London: Sage Publications.

Scott, J. (2000). *Network analysis: a handbook* (2nd ed.). Newbury Park: Sage.

Scott, N., Baggio, R., & Cooper, C. (2008). *Network analysis and tourism. From theory to practice*. Clevedon: Channel View Publications.

Seeman, T., & Berkman, L. (1988). Structural characteristics of social networks and their relationships with social support in the elderly. *Social Science & Medicine, 26*(7), 737-749.

Segurança Social. (2012). *Instituições particulares de solidariedade social registadas na Segurança Social*. Retrieved 10 September 2012, from www2.seg-social.pt.

Seigmann, A. E., & Elinson, J. (1977). Newer sociomedical indicators: Implications for evaluation of health services. *Medical Care, 15* (Suppl.), 84-92.

Seitanidi, M. M., & Ryan, A. (2007). A critical review of forms of corporate community involvement: From philanthropy to partnerships. *International Journal of Nonprofit and Voluntary Sector Marketing, 12*(3), 247-266.

Selsky, J. W., & Parker, B. (2005). Cross-sector partnerships to address social issues: Challenges to theory and practice. *Journal of Management, 31*(6), 849-873.

Seshamani, M. & Gray, A. (2002). The impact of ageing on expenditures in the National Health Service. *Age Ageing, 31*(4), 287-294.

Shannon, M. A., & Schmidt, C. H. (2002). Theoretical approaches to understanding intersectoral policy integration. In Tikkanen, I., Gluck, P., & Pajouja, H. (Eds), *Cross-sectoral policy impacts on forests*. Joensuu: European Forest Institute.

Shaw, G. (2009). *When it comes to patient experience, executives are enthusiastic, ambivalent, and a little cluless*. Patient Experience Leadership Survey. HealthLeaders Media: Toshiba.

Shetty, P. (2012). Grey matter: Ageing in developing countries. *The Lancet, 379*(9823), 1285-1287.

Shih, D., & Johnson, D. (1978). Avowed happiness as an overall assessment of the quality of life. *Social Indicators Research, 5*(1), 475-492.

Shortell, S. M., Zukoski, A. P., Alexander, J. A., Bazzoli, G. J., Conrad, D. A., Hasnain-Wynia, R., Sofaer, S., Chan, B. Y., Casey, E., & Margolin, F. S. (2002). Evaluating partnerships for community health improvement: Tracking the footprints. *Journal of Health Politics Policy and Law, 27*(1), 49-91.

Shostack, L. (1977). Breaking free from product marketing. *Journal of Marketing, 41*, 73-80.

Siekierski, J., & Rutkowska, M. (2008). Sustainable development as a concept in economics. In Spychalski, G., & Malicki, M. (Eds), *Development of human capital in rural areas* Szczecin: University of Szczecin Scientific Publishers.

Sih, A., Hanser, S. F., & McHugh, K. A. (2009). Social network theory: New insights and issues for behavioral ecologists. *Behavioral Ecology and Sociobiology, 63*(7), 975-988.

Silva, D. H. (2007). Cooperação internacional em ciência e tecnologia: Oportunidades e riscos. *Revista Brasileira de Política Internacional, 50*(1), 5-28.

Silva, K. L., & Trevenzoli Rodrigues, A. (2010). Ações intersetoriais para promoção da saúde na estratégia saúde da família: experiências, desafios e possibilidades. [Intersectorial actions for health promotion in family health strategy: experiences, challenges, and possibilities]. *Revista Brasileira de Enfermagem, 63*(5), 762-769.

Silverman, D. (2000). *Doing qualitative research: A practical handbook*. London: Sage.

Simões, J. (2012). *The Portuguese healthcare system: Successes and challenges*. Healthcare Systems - Portugal: Medical Solutions.

Skevington, S. M. (1999). Measuring quality of life in Britain: WHOQOL-100. *Journal of Psychosomatic Research, 47*(5), 449-459.

Skevington, S. M., Bradshaw, J., & Saxena, S. (1999). Selecting national items for the WHOQOL: Conceptual and psychometric considerations. *Social Science & Medicine, 48*(4), 473-487.

Slater, R., Frederickson, J., Thomas, C., Wield, D., & Potter, S. (2007). A critical evaluation of partnerships in municipal waste management in England. *Resources, Conservation and Recycling, 51*, 643-664.

Smith, K. W., Avis, N. E., & Assmann, S. F. (1999). Distinguishing between quality of life and health status in quality of life research: A meta analysis. *Quality of Life Research, 8*(5), 447-459.

Smyth, H., & Edkins, A. (2007). Relationship management in the management of PFI/PPP projects in the UK. *International Journal of Project Management, 25*(3), 232-240.

Sobral, J. M. (2004). O Norte, o Sul, a raça, a nação - representações da identidade nacional portuguesa (séculos XIX-XX). *Análise Social, XXXIX* (171), 255-284.

Softonic International S.A. (2010). *Microsoft Excel for Windows*.

Sowa, J. E. (2008). Implementing interagency collaboration. Exploring variation in collaborative ventures in human service organistaions. *Administration and Society, 40*(3), 298-323.

Spilker, B., Simpson, R. L., & Tilson, H. H. (1992). Quality of life bibliography and indexes: 1991 update. *Journal of Clinical Research and Pharmacoepidemiology, 6*, 205-266.

Spiro, A., & Bosse, R. (2000). Relations between health-related quality of life and well-being. *International Journal of Aging and Human Development, 50*(4), 297-318.

Spreng, R. A., & Mackoy, R. D. (1996). An empirical examination of a model of perceived service quality and satisfaction. *Journal of Retailing, 72*(2), 201-214.

Spreng, R. A., & Singh, A. K. (1993). An empirical assessment of the SERVQUAL scale and the relationship between service quality and satisfaction. In Peter, D., & Cravens, W. (Eds), *Enhancing knowledge development in marketing*. Chicago: American Marketing Association.

Stahl, T., Wismar, M., Ollila, E., Lahtinen, E., & Leppo, K. (Eds). (2006*). Health in All Policies: prospects and potentials.* Ministry of Social Affairs and Health.

Steel, N., Melzer, D., Shekelle, P. G., Wenger, N. S., Forsyth, D., & McWilliams, B. C. (2004). Developing quality indicators for older adults: Transfer from the USA to the UK is feasible. *Quality and Safety in Health Care, 13,* 260-264.

Steiger, J. H. (1990). Structural model evaluation and modification: An interval estimation approach. *Multivariate Behavioural Research, 25*, 173-180.

Stephenson, K., & Zelen, M. (1989). Rethinking centrality: Methods and examples. *Social Networks, 11*(1), 1-37.

Stevens, J. P. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Hillsdale, NJ: Erlbaum.

Stewart, A., Petch, A., & Curtice, L. (2003). Moving towards integrated working in health and social care in Scotland: From maze to matrix. *Journal of Interprofessional Care, 17*(4), 335-350.

Stewart, A. L., Greenfield, S., Hays, R. D., Wells, K., Rogers, W. H., Berry, S. D., McGlynn, E. A., & Ware, J. E. J. (1989). Functional status and well-being of patients with chronic conditions: Results from the Medical Outcomes Study. *The Journal of the American Medical Association, 262*, 907-913.

Stineman, M. G., Maislin, G., Fiedler, R. C., & Granger, C. V. (1997). A prediction model for functional recovery in stroke. *Stroke, 28,* 550-556.

Stokowski, P. A. (1992). Social networks and tourist behavior. *American Behavioral Scientist, 36*(2), 212-221.

Streiner, D. L., & Norman, G. R. (1995). *Health measurement scales: A practical guide to their development and use* (2nd ed.). New York: Oxford University Press.

Stuifbergen, M. C., & van Delden, J. J. M. (2011). Filial obligations to elderly parents: A duty to care? *Medicine, Health Care and Philosophy, 14*(1), 63-71.

Svenkeler, I. H., Nowak, M., Misselwitz, B., Kugler, C., & et al. (2002). Timecourse of health-related quality of life as determined 3, 6 and 12 months after stroke. Relationship to neurological deficit, disability and depression. *Journal of Neurology, 249*(9), 1160-1167.

Sullivan, H., & Skelcher, C. (2002). *Working across boundaries. Collaboration in public services*. Basingstoke: Palgrave.

Swan, J. E., & Combs, L. J. (1976). Product performance and consumer satisfaction: A new concept. *Journal of Marketing, 40*, 25-33.

Szczygiel, N., Pinto, D., & Santana, S. (2011). Toward patient-centered and economically sustainable care: Advances in the primary health care reform in Portugal. In Bojar, W. (Ed.), *Dylematy funkcjonowania sektora opieki zdrowotnej [Dilemmas of the health care sector functioning]*. Bydgoszcz: Bel Studio Sp. z o.o.

Szumilas, M. (2010). Explaining odds ratios. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 19*(3), 227-229.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics*. Boston: Pearson/Allyn and Bacon.

Tam, J. L. M. (2007). Linking quality improvement with patient satisfaction: A study of a health service centre. *Marketing Intelligence & Planning, 25*(7), 732-745.

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach’s alpha. *International Journal of Medical Education, 2,* 53-55.

Taylor, S. A., & Cronin, J. J., Jr. (1994). Modeling patient satisfaction and service quality. *Journal of Healthcare Marketing, 14*(1), 34-44.

Tennyson, R. (2003). *The partnering toolbook*. London: IBLF-GAIN.

Testa, M. A., & Simonson, D. C. (1996). Assessment of quality-of-life outcomes. *The New England Journal of Medicine, 334*(13), 835-840.

Thaden, L. L., & Rotolo, T. (2009). The measurement of social networks: A comparison of alter-centered and relationship-centered survey designs. *Connections, 29*(2), 15-25.

Theeke, L. A., Goins, R. T., Moore, J., & Campbell, H. (2012). Loneliness, depression, social support, and quality of lifein older chronically ill Appalachians. *The Journal of Psychology, 146*(1-2), 155-171.

Theixos, H. (2013). Adult children and eldercare: The moral considerations of filial obligations. *Michigan Family Review, 17*(1), 65-73.

The European Parliament and the Council. (2009). *Directive on the promotion of energy from renewable sources and amending and subsequently repealing Directives 2001/77/EC and 2003/30/EC., 2009/28/EC of 23 April 2009*.

The Public Health Agency of Canada. (2008). *Core competencies for public health in Canada*. Release 1.0. Ottawa.

The World Bank. (2014). *World Development Indicators*. Retrieved 18 March 2014, from http://data.worldbank.org/data-catalog/world-development-indicators.

Thomson, A. M., Perry, J. L., & Miller, T. K. (2009). Conceptualizing and measuring collaboration. *Journal of Public Administration, Research and Theory, 19*(1), 23-56.

Tichy, N. M., Tushman, M. L., & Fombrun, C. (1979). Social network analysis for organizations. *Academy of Management Review, 4*(4), 507-519.

Ting, D. H. (2004). Service quality and satisfaction perceptions: Curvilinear and interaction effect. *International Journal of Bank Marketing, 22*(6), 407-420.

Tones, K., & Green, J. (2004). *Health promotion: Planning and strategies*. London: SAGE Publications.

Trivers, R. L. (2002). *Natural selection and social theory: Selected papers of Robert L. Trivers. (Evolution and Cognition Series)*. Oxford University Press. Oxford, 1-345.

Truelsen, T., Begg, S., & Mathers, C., Satoh, T. (2002). *The global burden of cerebrovascular disease in the year 2000*. Geneva, World Health Organization working paper. Retrieved 12 December 2012, from http://www.who.int/healthinfo/statistics/bod_cerebrovasculardiseasestroke.pdf.

Truelsen, T., Piechowski-Jozwiak, B., Bonita, R., Mathers, C., Bogousslavsky, J., & Boysen, G. (2006). Stroke incidence and prevalence in Europe: a review of available data. *European Journal of Neurology, 13*(6), 581-598.

Tsouna-Hadjis, E., Vemmos, K. N., Zakopoulos, N., & Stamatelopoulos, S. (2000). First stroke recovery process: The role of family and social support. *Archives of Physical Medicine and Rehabilitation, 81*(7), 881-887.

Umberson, D., & Montez, J. K. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behaviour, 51*(1), S54-S66.

United Nations General Assembly. (2003). Enhanced cooperation between the United Nations and all relevant partners, in particular the private sector. *Report of the Secretary-General. UN Doc. No. A/58/227*.

Utting, P., & Zammit, A. (2006). Beyond pragmatism: Appraising UN-business partnerships. *Markets, Business and Regulation Programme Paper Number 1*. United Nations Research Institute for Social Development.

Uzzi, B. (1996). The sources and consequences of embeddedness for the economic performance of organizations. *American Sociological Review, 61*(4), 674-698.

Uzzi, B. (1997). Social structure and competition in interfirm networks: The paradox of embeddedness. *Administrative Science Quarterly, 42*, 35-67.

Valente, T. W., Coronges, K. A., Stevens, G. D., & Cousineau, M. R. (2008). Collaboration and competition in a children’s health initiative coalition: A network analysis. *Evaluation and Program Planning, 31*(4), 392-402.

Valentijn, P. P., Schepman, S. M., Opheij, W., & Bruijnzeels, M. A. (2013). Understanding integrated care: A comprehensive conceptual framework based on the integrative functions of primary care. *International Journal of Integrated Care, 13*, e010. Retrieved 23 March 2014, from www.ijic.org/index.php/ijic/article/view/886/1979

Vandamme, R., & Leunis, J. (1993). Development of a multiple-item scale for measuring hospital service quality. *International Journal of Service Industry Management, 4*(3), 30-49.

van de Velde, S., Bracke, P. & Levecque, K. (2010). Gender differences in depression in 23 European countries. Cross-national variation in the gender gap in depression. *Social Science & Medicine, 71*(2), 305-313.

van Gijn, J. (1992). Measurement of outcome in stroke prevention trials. *Cerebrovascular Diseases, 2* (Suppl. 1), 23-34.

van Heughten, C., Visser-Meily, A., Post, M., & Lindeman, E. (2006). Care for carers of stroke patients: Evidence-based clinical practice guidelines. *Journal of Rehabilitation Medicine, 38*(3), 153-158.

Varricchio, C. G., & Ferrans, C. E. (2010). Quality of life assessments in clinical practice. *Seminars in Oncology Nursing, 26*(1), 12-17.

Viitanen, M., Fugl-Meyer, K. S., Bernspang, B., & Fugl-Meyer, A. R. (1988). Life satisfaction in long term survivors after stroke. *Scandinavian Journal of Rehabilitation Medicine, 20*, 17-24.

Vinokur, A. D., Price, R. H., & Caplan, R. D. (1996). Hard times and hurtful partners: How financial strain affects depression and relationship satisfaction of unemployed persons and their spouses. *Journal of Personality and Social Psychology, 7*(1), 166-179.

Waddell, S. (2000). A "win-win" role for civil society in business strategy. *Journal for Nonprofit Management*, *4*(1), 23-43.

Waddock, S. A. (1989). Understanding social partnerships. *Administration & Society, 21*(1), 78-100.

Waldfogel, J. (1997). The new wave of service integration. *Social Services Review, 71*(3), 463-484.

Wallen, H. R., & Lachman, M. E. (2000). Social support and strain from partner, family, and friends: Costs and benefits for men and women in adulthood. *Journal of Social & Personal Relationships, 17*(1), 5-30.

Ware, J. E. J. (2000). SF-36 health survey update. *Spine, 25*(24), 3130-3139.

Ware, J. E. J., & Sherbourne, C. D. (1992). The MOS 36-item shortform health survey (SF-36) I. Conceptual framework and item selection. *Medical Care, 30*(6), 473-483.

Warner, M. (2003). *Partnerships for sustainable development: Do we need partnership brokers. Programme on optimizing the development performance of corporate of corporate investment*. London: Overseas Development Institute.

Wasserman, S., & Faust, K. (1994). *Social network analysis: Methods and applications*. New York: Cambridge University Press.

Watt, D., Wertzel, W., & Brannan, G. (2005). Patient expectations of emergency department care: phase I - A focus group study. *Canadian Journal of Emergency Medicine, 7*(1), 12-16.

Webster, C. (1989). Can consumers be segmented on the basis of their service quality expectations? *The Journal of Services Marketing, 3*(2), 77-92.

Wegener, B. (1989). *Mobility and the structure and sex composition of social ties*. Utrecht, The Netherlands: Pres. Int. Sociol. Assoc. Res. Commun.

Wei-Skillern, J. (2010). Networks as a type of social entrepreneurship to advance population health. *Preventing Chronic Disease: Public Health Research, Practice and Policy, 7*(6), A120.

Weingarten, S. R., Stone, E., Green, A., Pelter, M., Nessim, S., Huang, H., & Kristopaitis, R. (1995). A study of patient satisfaction and adherence to preventive care practice guidelines. *The American Journal of Medicine, 99*, 590-596.

Weiss, E. S., Miller Anderson, R., & Lasker, R. D. (2002). Making the most of collaboration: Exploring the relationship between partnership synergy and partnership functioning. *Health Education and Behaviour, 29*, 683-698.

Wellman, B. (1983). Network analysis: Some basic principles. *Sociological Theory, 83*, 155-200.

Wellman, B., Mosher, C., Rottenberg, C., & Espinoza, V. (1987). *The sum of the ties does not equal a network: The case of social support.* Paper presented at the Annual Meeting of the American Sociological Association, Chicago.

Wenger, G. C., Dykstra, P. A., Melkas, T. & Knipscheer, K. C. P. M. (2007). Social embeddedness and late-life parenthood: Community activity, close ties, and support networks. *Journal of Family Issues, 28*(11), 1419-1456.

Wenger, S. C., Davies, R., Shahtahmasebi, S., & Scott, A. (1996). Social isolation and loneliness in old age: Review and model refinement. *Ageing and Society, 16*(3), 333-358.

West, S. A., El Mouden, C., & Gardner, A. (2011). Sixteen common misconceptions about the evolution of cooperation in humans. *Evolution and Human Behavior*, *32*(4), 231-262.

Wetherell, C., Plakans, A., & Wellman, B. (1994). Social networks, kinship, and community in Eastern Europe. *Journal of Interdisciplinary History, 24*, 639-663.

Wettenhall, R. (2005). The public-private interface: Surveying the history. In Hodge, G., & Greve, C. (Eds), *The challenge of public-private partnerships: Learning from international experience*. Northampton: Edward Edjar Publishing Inc.

Whetten, D. (1981). Interorganizational relations: A review of the field. *Journal of Higher Education, 52*(1), 1-28.

WHO (1946). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (*Official Records of the World Health Organization, no. 2*, p. 100) and entered into force on 7 April 1948.

WHO (1978). *Declaration of Alma Ata*. International Conference on Primary Health Care. Retrieved 6 December 2011, from http://www.who.int/publications/almaata_declaration_en.pdf

WHO (1988). Monitoring trends and determinants in cardiovascular disease. *Journal of Clinical Epidemiology 41*, 105-114.

WHO (1996a). Health interview surveys: Towards international harmonization of methods and instruments. *European Series no. 58*. Copenhagen: WHO Regional Publications.

WHO (1996b). *The Ljubljana Charter on Reforming Health Care*. Retrieved 10 December 2011, from http://www.euro.who.int/en/who-we-are/policy-documents/the-ljubljana-charter-on-reforming-health-care,-1996

WHO (1997). *Intersectoral action for health. A cornerstone for Health-in-All in the twenty-first century*. Report of the international conference, 20-23 April 1997, Halifax, Nova Scotia, Canada. Geneva: World Health Organization.

WHO (1998). *Health promotion evaluation: Recommendations to policymakers*. Copenhagen: WHO Regional Office for Europe.

WHO (2005). *The 6th Global Conference on Health Promotion*. Retrieved 10 March 2012, from http://www.who.int/healthpromotion/conferences/6gchp/en/

WHO (2008). *The World Health Report 2008. Primary health care - Now more than ever*. Geneva: WHO.

WHO (2010a). *Portugal. Health system performance assessment*. Copenhagen: Ministério de Saúde. Alto Comissariado de Saúde.

WHO (2010b). *The World Health Report. Health systems financing: the path to universal coverage*. Geneva: World Health Organization.

WHO. Retrieved 20 January 2012 from http://www.who.int.

WHO (2012). *Public–private partnerships for health*. Retrieved 14 May 2012, from http://www.who.int/trade/glossary/story077/en/index.html.

WHOQOL Group. (1995). The World Health Organization Quality of Life assessment (WHOQOL). Position paper from the World Health Organization. *Social Science & Medicine, 41*, 1403-1409.

WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28,* 551-558.

Wilde, B., Starrin, B., Larsson, G., & Larsson, M. (1993). Quality of care from a patient perspective - A grounded theory study. *Scandinavian Journal of Caring Sciences, 7*(2), 113-120.

Williams, L.S. (1998). Health-related quality of life outcomes in stroke. *Neuroepidemiology, 17,* 116 -120.

Williams, L. S., Weinberger, M., Harris, L. E., Clark, D. O., & Biller, J. (1999). Development of a Stroke-Specific Quality of Life Scale. *Stroke, 30*(7), 1362-1369.

Williams, P., Crow, A., Evans, L., Rogers, S., & Sullivan, H. (2006). *People, plans and partnerships: A national evaluation of community strategies in Wales*. Cardiff: WAG.

Williams, P., & Sullivan, H. (2007). Working in collaboration: Learning from theory and practice. *Literature review for the National Leadership and Innovation Agency for healthcare*. NHS Wales GIG CYMRU.

Williamson, O. E. (1991). Comparative economic organization: The analysis of discrete structural alternatives. *Administrative Science Quarterly, 36*, 269-296.

Wilson, A., & Charleton, K. (1997). *Making partnerships work*. York: JRF.

Wilson, B. (2000). The Lone Ranger is dead: Success today demands collaboration. *College & Research Libraries News, 161*(8), 698–701.

Wilson, S. (1977). The use of ethnographic techniques in educational research. *Review of Educational Research, 47*, 245-265.

Winckler, N. C., & Molinari, G. T. (2011). Competição, colaboração, cooperação e coopetição: Revendo os conceitos em estratégias interorganizacionais. *Revista ADMpg Gestão Estratégica, 4*(1).

Winkworth, G. (2004). *All hands on deck: Government service delivery, partnerships and participation - Centrelink: a case study*. Sydney: Sydney University.

Winkworth, G. (2005). Partnering the 800 pound gorilla: Centrelink working locally to create opportunities for participation. *Australian Journal of Public Administration, 64*(3), 24-34.

Wismeijer, A. A. J., Vingerhoets, A. A., J. M., & de Vries, J. (2010), Quality of life-related concepts: Theoretical and practical issues. In Preedy, V. R., Watson, R. R. (Eds), *Handbook of disease burdens and quality of life measures*. Heidelberg: Springer.

Wyller, T. B., Holmen, J., Laake, P., & Laake, K. (1998). Correlates of subjective well-being in stroke patients. *Stroke, 29*, 363-367.

Yamakawa, Y., Satoh, S., Sawa, S., Ohta, H., & Asada, T. (2005). Efficacy of milnacipran on postroke depression on inpatient rehabilitation. *Psychiatry and Clinical Neurosciences, 59*(6), 705-710.

Yamazaki, H., Slingsby, B. T., Takahashi, M., Hayashi, Y., Sugimori, H., & Nakayama, T. (2009). Characteristics of qualitative studies in influential journals of general medicine: A critical review. *Bioscience Trends, 3*(6), 202-209.

Yan, X., & Su, X. G. (2009). *Linear regression analysis. Theory and computing*. Singapore: World Scientific.

Yoo, D. K. (1996). A study on quality perceptions and satisfaction for medical service marketing. *Journal of Korea Academy Nursing Administration, 2*(1), 97-114.

Young, J., & Forster, A. (2007). Review of stroke rehabilitation. *British Medical Journal, 334*(7584), 86-90.

Zammuto, R. F., Keaveney, S. M., & O'Connor, E. J. (1996). Rethinking student services: Assessing and improving service quality. *Journal of Marketing in Higher Education, 7*(1), 45-69.

Zandbelt, L. C., Smets, E. M. A., Oort, F. J., Godfried, F. J., & de Haes, H. C. J. (2004). Satisfaction with the outpatient encouter - A comparison of patients' and physicians' views. *Journal of General Internal Medicine, 19*(11), 1088-1095.

Zeithaml, V. A. (1981). *How consumer evaluation processes differ between goods and services*. Chicago: AMA.

Zeithaml, V. A. (1987). *Defining and relating price, perceived quality and perceived value*. Cambridge, MA: Marketing Science Institute.

Zeithaml, V. A. (1988). Consumer perceptions of price quality and value: A means-end model and synthesis of evidence. *Journal of Marketing, 5* (July), 2-22.

Zeithaml, V. A., Berry, L. L., & Parasuraman, A. (1988). Communication and control processes in the delivery of service quality. *Journal of Marketing, 52*(2), 35-48.

Zeithaml, V. A., Berry, L. L., & Parasuraman, A. (1993). The nature and determinants of customer expectations of service. *Journal of the Academy of Marketing Science, 21*(1), 1-12.

Zeithaml, V. A., Parasuraman, A., & Berry, L. L. (1990). *Delivering quality service: Balancing customer perceptions and expectations*. New York: The Free Press.

Zhou, L. (2004). A dimension-specific analysis of performance-only measurement of service quality and satisfaction in China's retail banking. *Journal of Services Marketing, 18*(7), 534-546.

Zingerli, C., Bisang, K., & Zimmermann, W. (2004). *Towards policy integration: Experiences with intersectoral coordination in international and national forest policy*. Paper presented at the Berlin Conference on the Human Dimension of Global Environmental Change "Greening of Policies – Interlinkages and Policy Integration", Berlin.

APPENDICES

Patient ID

Evaluation date
(dd/mm/yy)

APPENDICE 1: Socio-demographic profile

Socio-demographic profile

1. Gender:

○1 Female ○2 Male

2. Age:

_______ years

3. Race:

○1 Caucasian (white)

○2 Negroid (black)

○3 Mongoloid (yellow)

4. Civil status:

○1 Married

○2 Informal relation

○3 Single

○4 Widowed

○5 Divorced

○6 Separated

○99 DK/DA

5. Who are you living with?

○1 Alone

○2 Spouse

○3 Family members other than spouse

○4 With friends

○5 With private caregiver

○6 Nursing home

○7 Spouse and family members other than spouse

○8 Spouse and private caregiver

○9 Spouse, family members other than spouse and private caregiver

○10 Other

○99 DK/DA

6. What is average monthly income of your household?

○1 Up to 500 euros

○2 Between 500 and 750 euros

○3 Between 750 and 1000 euros

○4 Between 1000 and 1500 euros

○5 Between 1500 and 2000 euros

○6 Above 2000 euros

○99 DK/DA

7. What is the highest education level you have completed?

○1 None

○2 Primary education (1st cycle or equivalent) / 4th grade / Former primary

○3 Basic education (2nd cycle or equivalent) / 6th grade / Former preparatory cycle

○4 Basic education (3rd cycle or equivalent) / 9th grade / Former unified

○5 Secondary school (12th grade)

○6 Professional or technological education (level 1 or 2)

○7 Professional or technological education equivalent to 12th grade

○8 Higher vocational training of short duration (up to 2 years)

○9 Higher vocational training of short duration (3 years)

○10 Bachelor

○11 Graduation

○12 Post-graduation

○13 Master's degree

○14 PhD

○99 DK/DA

8. What is your occupation/profession?

○1 Manager/responsible for the job of others

○2 Health professional with responsibility for treatments, higher education, with license or authorized to practice as a physician, psychologist, physiotherapist, nurse

○3 Other, such as lawyer, consultant, professor, researcher, secretary, artist

○4 Health care assistant, without formal responsibility for treatments, with short or non-formal training/education, without licence to practice

○5 Specialized professional (with formal education, during at least one year of full-time or equivalent, for example plumber with training, graduated cook, mechanic with a formal training)

○6 Semi-skilled or non-specialized worker (without training or formal training with short duration; example: cleaning staff, driver, and kindergarten assistant)

○99 DK/DA

9. Which of the following statements best describes your current activity or what you have done in the last month?

○1 Employed on a contract

○2 Self-employed or independent professional

○3 Student

○4 Unemployed

○5 Disabled or on a leave

○6 Retired

○7 In the army

○8 Housekeeper/parental leave

○9 Other

○99 DK/DA

10. Which of the following options best describes your house regarding its comfort level?

○1 House/luxurious apartment with all the comforts

○2 House/apartment not luxurious, spacious and comfortable

○3 Modest home/apartment, well-built and in good condition, bright and airy, with kitchen and toilet

○4 Housing that has no running water, sanitation or electricity, poorly constructed or degraded, lack of lighting or ventilation, roof made of wood or zinc

○5 Unhealthy housing wood, tin, cardboard or clay, tin roof or straw

○6 Other

○99 DK/DA

ID do doente

Data de avaliação
(dd/mm/aa)

Perfil sócio-demográfico

1. Sexo

○1 Feminino ○2 Masculino

2. Qual é a sua idade?

_______anos

3. Raça

○1 Caucasóide (branca)

○2 Negróide (preta)

○3 Mongolóide (amarela)

4. Qual é a sua situação familiar?

○1 Casado

○2 União de facto

○3 Solteiro

○4 Viúvo

○5 Divorciado

○6 Separado

○99 NS/NR

5. Com quem vive?

○1 Sozinho

○2 Cônjuge

○3 Familiares que não cônjuge

○4 Com amigos

○5 Com empregado

○6 Lar

○7 Cônjuge e familiares que não cônjuge

○8 Cônjuge empregado

○9 Cônjuge e familiares que não cônjuge e empregado

○10 Outro

○99 NS/NR

6. Qual é aproximadamente, o rendimento médio mensal do seu agregado familiar, depois de descontos?

○1 Até 500 euros

○2 De 500 a 750 euros

○3 De 750 a 1000 euros

○4 De 1000 a 1500 euros

○5 De 1500 a 2000 euros

○6 Superior a 2000 euros

○99 NS/NR

7. Qual é o nível de escolaridade mais elevado que terminou?

○1 Nenhum

○2 Ensino básico (1º ciclo ou equivalente) /4ª classe/Antiga primária

○3 Ensino básico (2º ciclo ou equivalente) /6º ano/Antigo ciclo preparatório

○4 Ensino básico (3º ciclo ou equivalente) /9º ano/Antigo unificado

○5 Ensino secundário (12º ano)

○6 Ensino profissional ou tecnológico (nível 1 ou 2)

○7 Ensino profissional ou tecnológico equivalente ao 12º ano

○8 Formação profissional superior de curta duração (até 2 anos)

○9 Formação profissional superior de curta duração (3 anos)

○10 Bacharelato

○11 Licenciatura

○12 Pós-graduação

○13 Mestrado

○14 Doutoramento

○99 NS/NR

8. Qual é a sua ocupação/profissão?

○1 Gestor, gerente, patrão, responsável pelo trabalho de outros

○2 Profissional da área de saúde, com responsabilidades por tratamentos, formação superior, licença ou autorização para exercer, como médico, psicólogo, fisioterapeuta, enfermeiro

○3 Outro, como, por exemplo, advogado, consultor, professor, investigador, secretária, artista

○4 Assistentes da área de saúde, sem responsabilidade formal por tratamentos, com formação de curta duração ou não formal, sem licença para exercer

○5 Trabalhador especializado (com formação formal a tempo inteiro de pelo menos um ano ou equivalente, por exemplo, canalizador com formação, cozinheiro diplomado, mecânico com formação formal)

○6 Trabalhador semi-especializado ou não especializado (sem formação formal ou com formação formal de curta duração; exemplo, pessoal da limpeza, motorista, assistente de jardim infantil)

○99 NS/NR

9. Qual destas afirmações melhor descreve a sua situação actual ou o que fez no mês passado?

○1 Trabalho remunerado: por conta de outrem

○2 Trabalho remunerado: por conta própria, ou profissão liberal

○3 Estudante

○4 Desempregado

○5 Incapacitado ou de baixa

○6 Reformado

○7 Em serviço militar

○8 Doméstico / A cuidar de crianças (p.ex. em licença de paternidade)

○9 Outro

○99 NS/NR

10. Qual das seguintes frases descreve melhor a sua casa em relação ao conforto?

○1 Casa ou andar luxuoso com todo o conforto

○2 Casa ou andar que sem ser luxuoso é espaçoso e confortável

○3 Casa ou andar modesto, bem construído e em bom estado de conservação, bem iluminado e arejado, com cozinha e WC

○4 Habitação que não tem água canalizada, saneamento ou electricidade, mal construída ou degradada, escassez de iluminação ou ventilação, telhado de madeira ou de zinco

○5 Habitação insalubre de madeira, lata, cartão ou barro, telhado de zinco ou de palha

○6 Outro

○99 NS/NR

Patient ID

Evaluation date
(dd/mm/yy)

APPENDICE 2: Patients' expectations[1]

Patient's expectations at discharge from the stroke unit

1. **Within the next 6 months, with which entities do you expect to have contacts in any form related with your health condition? (Please, answer with 'Yes', 'Maybe' or 'No' for all entities you expect to interact with.**

Health center	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
City council	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Fire department	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
IPSS	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Church	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Parish council	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Misericórdia	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Rehabilitation unit	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Hospital	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
The Social Security	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
A caregiver (informal or contracted)	○1 Yes	○2 Maybe	○3 No	○99 DK/DA
Other (specify)	○1 Yes	○2 Maybe	○3 No	○99 DK/DA

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[1] Measures were identified according to the following rule: if applied within the duration of the HOMECARE project, with the logos of the 7th Framework Programme for Research and Technological Development, the HOMECARE project and the University of Aveiro, if beyond the time span of the HOMECARE project, with the logo of the University of Aveiro.

☐	☐	☐

Patient ID

☐	☐	☐	☐	☐	☐

Evaluation date
(dd/mm/yy)

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2. **In case you need specialized equipment (a wheelchair, an articulated bed) do you know where to head for?**

   ○1 Yes ○2 Maybe ○3 No ○99 DK/DA

3. **Do you expect to receive the community support in order to find services/treatments that you might need?**

   ○1 Yes ○2 Maybe ○3 No ○99 DK/DA

4. **Do you expect to receive community support to satisfy your needs, in case of necessity? (e.g., to adapt the house to your needs)**

   ○1 Yes ○2 Maybe ○3 No ○99 DK/DA

5. **Do you think that, if you need, you will receive help from your family, neighbors and friends?**

   ○1 Yes ○2 Maybe ○3 No ○99 DK/DA

6. **Do you think you are able to pay for health services that you may need?**

   ○1 Yes ○2 Maybe ○3 No ○99 DK/DA

7. **How do you consider support that the community provides currently to cases such as yours?**

   ○1 Very bad ○2 Bad ○3 Reasonable

   ○4 Good ○5 Very good ○99 DK/DA

ID do doente

Data de avaliação
(dd/mm/aa)

Expectativas do doente à saída do hospital

1. **Durante os próximos 6 meses, com que entidades espera ter contactos de alguma forma relacionados com o seu estado de saúde? (Por favor, responda com 'Sim', 'Talvez' ou 'Não' para todas as entidades com que espera ter o contacto).**

Centro de saúde	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Câmara municipal	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Bombeiros	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
IPSS	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Paróquia	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Junta de freguesia	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Misericórdia	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Unidade de reabilitação	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Hospital	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Segurança Social	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Cuidador (familiar ou contratado)	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR
Outro (especifique)	○1 Sim	○2 Talvez	○3 Não	○99 NS/NR

ID do doente

Data de avaliação
(dd/mm/aa)

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2. **Caso precise de equipamento especializado (cadeira de rodas, cama articulada, etc.), sabe onde se dirigir?**

○1 Sim ○2 Talvez ○3 Não ○99 NS/NR

3. **Espera receber apoio da comunidade para encontrar os serviços/tratamentos de que possa precisar?**

○1 Sim ○2 Talvez ○3 Não ○99 NS/NR

4. **Espera receber apoio da comunidade para satisfazer as suas necessidades, caso precise? (por exemplo, adaptar a casa às suas necessidades)**

○1 Sim ○2 Talvez ○3 Não ○99 NS/NR

5. **Acha que, se precisar, vai receber apoio da sua família, vizinhos ou amigos?**

○1 Sim ○2 Talvez ○3 Não ○99 NS/NR

6. **Acha que consegue pagar por serviços de saúde que possa vir a precisar?**

○1 Sim ○2 Talvez ○3 Não ○99 NS/NR

7. **Como é que considera o apoio que a comunidade dá, neste momento, aos casos como o seu?**

○1 Muito mau ○2 Mau ○3 Razoável

○4 Bom ○5 Muito bom ○99 NS/NR

Patient ID

Evaluation date
(dd/mm/yy)

APPENDICE 3: Patients’ experiences

Patient’s experiences at the end of the study

In the last six months, with which frequency have you had contacts somehow related with stroke you suffered from (e.g. medical appointments, treatments, exams, care) with the following entities?

Hospital[1]	.... time(s)	Which?....................
Rehabilitation unit	.... time(s)	Which?....................
Health centre	.... time(s)	Which?....................
City council	.... time(s)	Which?....................
Parish council	.... time(s)	
Fire department	.... time(s)	
IPSS	.... time(s)	
Church	.... time(s)	
Charitable institution	.... time(s)	
The Social Security	.... time(s)	
Formal caregiver	....	
Informal caregiver	....	

---

[1] apart from staying in the institution right after stroke

ID do doente

Data de avaliação
(dd/mm/aa)

Experiências do doente no final do estudo

Nos últimos seis meses, com que frequência teve contactos de alguma forma relacionados com a trombose que sofreu há seis meses atrás (consultas, tratamentos, exames, cuidado), com as seguintes entidades?

Hospital[1]	.... vez(es)	Qual?....................
Unidade de reabilitação	.... vez(es)	Qual?....................
Centro de saúde	.... vez(es)	Qual?....................
Câmara municipal	.... vez(es)	Qual?....................
Junta de freguesia	.... vez(es)	
Bombeiros	.... vez(es)	
IPSS	.... vez(es)	
Paróquia	.... vez(es)	
Misericórdia	.... vez(es)	
Segurança Social	.... vez(es)	
Cuidador formal	....	
Cuidador informal	....	

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[1] além da permanência logo depois do AVC

APPENDICE 4: SERVPERF items applied to the present study

Item content
Q1. XYZ has up-to-date equipment (e.g. diagnosis equipment)
Q2. Physical facilities of XYZ are visually appealing (e.g. appointment rooms, waiting rooms, bathrooms)
Q3. Professionals of XYZ are well dressed and appear neat
Q4. The appearance of XYZ physical facilities is in keeping with the type of services provided
Q5. When XYZ schedules a service with the patient at certain time, it does so
Q6. When a problem (e.g. doubts) arises, XYZ is sympathetic and reassuring
Q7. XYZ is dependable
Q8. XYZ provides its service at the time it promises to do so (e.g. make treatments at scheduled time, delivers meals on time)
Q9. XYZ keeps its records accurately (e.g. appointments realized, medication, exams)
Q10. XYZ does not tell patients exactly when services will be performed
Q11. You do not receive prompt service from employees of XYZ
Q12. Employees of XYZ are not always willing to help patients
Q13. Employees of XYZ are too busy to respond to patient requests promptly
Q14. One can trust employees of XYZ
Q15. A patient feels safe in contacts with employees of XYZ
Q16. Employees of XYZ are correct (they treat a patient with courtesy and politeness)
Q17. Employees get adequate support from XYZ to well perform their tasks
Q18. XYZ does not give individual attention
Q19. Employees of XYZ do not give a patient personal attention
Q20. Employees of XYZ do not comprehend the patient’s needs
Q21. XYZ does not have the patient’s interest at heart
Q22. Operating hours of XYZ are not convenient to all patients

Source: Adapted from Cronin and Taylor (1992)

Patient ID

Evaluation date
(dd/mm/yy)

APPENDICE 5: Careperf service quality measure

Careperf – service quality measure

The following questions relate to your opinion about the entity you interacted with after stroke.

For each affirmation, please, indicate until which extent you believe the entity can be characterized by the designated characteristic.

Marking 1 means that you disagree strongly with the affirmation in cause; marking 7 means that you strongly agree with it.

There are no right or wrong answers here: we are only looking for your perception of the entity which services you used.

1. The entity knows a patient's record (e.g. previous exams and results, medication)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

2. Professionals of the entity use comprehensible language

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

3. When the entity schedules a service with a patient at certain time, it does so

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

4. Professionals of the entity do not provide information on services and treatments available at other institutions

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

5. Professionals of the entity encourage patients to speak of their situation with family and friends

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

6. You do not receive prompt service from the entity employees

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

Patient ID

Evaluation date (dd/mm/yy)

7. Employees of the entity are correct (they treat a patient with courtesy and politeness)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

8. When a problem (e.g. doubts) arises, the entity is sympathetic and reassuring

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

9. Employees of the entity do not respect the privacy of patients

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

10. Professionals of the entity inform about entities that might help in patient's specific case (e.g. appointments, transportation by firemen, social support, exams, spiritual support)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

11. A patient feels safe in contacts with the entity employees

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

12. Employees of the entity are not always willing to help patients

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

13. When necessary, the entity contacts the entity who treated a patient before (e.g. family doctor, fire department)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

14. The entity has conditions guaranteeing that patient's data are not accessed by unauthorized persons

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

15. Appearance of physical facilities of the entity keeps with the type of provided service

Patient ID					Evaluation date (dd/mm/yy)				

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

16. The entity does not give individual attention

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

17. Employees of the entity are too busy to respond to patients’ requests promptly

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

18. The entity is dependable

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

19. The entity provides its service at the time it promises to do so (e.g. makes treatments at scheduled time, delivers meals on time)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

20. Employees of the entity do not comprehend patients’ needs

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

21. Professionals of the entity treat patient information confidentially

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

22. Employees get adequate support from the entity to well perform their tasks

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

23. Professionals of the entity explain what to do in order to avoid similar situations in the future [i.e. cerebrovascular accident]

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

Patient ID

Evaluation date (dd/mm/yy)

---

24. The entity does not tell patients exactly when services will be provided

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

25. The entity does not have patients' interest at heart

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

26. The entity professionals are well-dressed and appear neat

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

27. The entity keeps its records accurately (e.g. realized appointments, medication, exams)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

28. The entity physical facilities are visually appealing (e.g. appointment rooms, waiting rooms, bathrooms)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

29. Employees of the entity do not give patients personal attention

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

30. Professionals of the entity put patients in contact with entities that may be useful in their case (e.g. appointments, transportation by firemen, social support, exams, spiritual support)

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

31. The entity operating hours are not convenient to all patients

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

32. The entity has up-to-date equipment (e.g. diagnosis equipment)

Strongly						Strongly

disagree						agree
1	2	3	4	5	6	7

33. One can trust employees of the entity

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

34. The entity has conditions that guarantee privacy

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

The following affirmations relate to your feelings toward the entity you had contacts with. Please, respond putting a cross on the number that best describes your perceptions.

35. Globally, I consider services provided by the entity

Very bad						Very good
1	2	3	4	5	6	7

36. Relatively to the services provided by the entity, I consider myself generally

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7

37. If something similar happened to me in the future, I would like to be treated by this entity

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

38. If it was necessary to pay more for services of the entity, I would be willing to do so

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

39. If something similar happened to my relative or a friend, I would try that (s)he was treated by this entity

Strongly disagree						Strongly agree
1	2	3	4	5	6	7

Thank you very much for your collaboration.

ID do doente

Data de avaliação
(dd/mm/aa)

Careperf – instrumento de medida da qualidade de serviço

As questões que se seguem relacionam-se com a sua opinião sobre a entidade com que interagiu depois do AVC.

Para cada afirmação indique até que ponto acredita que a entidade em questão possui a característica indicada.

Assinalar 1 quer dizer que discorda muito com a afirmação feita, enquanto assinalar 7 quer dizer que concorda muito.

Não há respostas certas ou erradas: o que nos interessa é a sua percepção sobre a entidade cujos serviços usou.

1. A entidade conhece o histórico de saúde do utente (exames e resultados anteriores, medicação)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

2. Os profissionais da entidade usam palavras que se consegue compreender

Discordo muito						Concordo muito
1	2	3	4	5	6	7

3. Quando a entidade marca um serviço com o utente, cumpre a marcação

Discordo muito						Concordo muito
1	2	3	4	5	6	7

4. Os funcionários da entidade não disponibilizam informações acerca de serviços e tratamentos disponíveis noutros lados

Discordo muito						Concordo muito
1	2	3	4	5	6	7

5. Os profissionais da entidade encorajam os utentes a falar da sua situação com a família e amigos, e a obter a sua ajuda

Discordo muito						Concordo muito
1	2	3	4	5	6	7

6. Sempre que se precisa, os funcionários da entidade demoram a atender

Discordo muito						Concordo muito
1	2	3	4	5	6	7

ID do doente

Data de avaliação
(dd/mm/aa)

---

7. Os funcionários da entidade são correctos (tratam o utente com cortesia, gentileza)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

8. Quando surge um problema (por exemplo, dúvidas), a entidade age de forma simpática e que transmita segurança

Discordo muito						Concordo muito
1	2	3	4	5	6	7

9. Os funcionários da entidade não respeitam a privacidade do utente

Discordo muito						Concordo muito
1	2	3	4	5	6	7

10. Os profissionais da entidade informam acerca das entidades que podem ajudar a resolver o caso do utente (consultas, transporte por bombeiros, apoio social, apoio camarário, apoio paroquial, exames)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

11. O utente sente-se seguro nos contactos com os funcionários da entidade

Discordo muito						Concordo muito
1	2	3	4	5	6	7

12. Os funcionários da entidade nem sempre demonstram boa vontade em ajudar os utentes

Discordo muito						Concordo muito
1	2	3	4	5	6	7

13. Quando é preciso, a entidade contacta quem tratou do doente antes de ele chegar à entidade (médico de família, bombeiros...)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

14. A entidade tem condições que garantem que os dados do doente não são vistos por pessoas não autorizadas

Discordo muito						Concordo muito
1	2	3	4	5	6	7

ID do doente ☐☐☐

Data de avaliação (dd/mm/aa) ☐☐☐☐☐☐

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15. As instalações físicas da entidade parecem adequadas ao tipo de serviço prestado

Discordo muito						Concordo muito
1	2	3	4	5	6	7

16. A entidade não disponibiliza um atendimento individualizado

Discordo muito						Concordo muito
1	2	3	4	5	6	7

17. Os funcionários da entidade estão demasiado ocupados e não conseguem responder aos pedidos do utente em tempo útil

Discordo muito						Concordo muito
1	2	3	4	5	6	7

18. Pode-se confiar nesta entidade

Discordo muito						Concordo muito
1	2	3	4	5	6	7

19. A entidade presta os serviços no tempo prometido (cumpre os horários de tratamentos, serve refeições à hora)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

20. Os funcionários da entidade não entendem as necessidades do utente

Discordo muito						Concordo muito
1	2	3	4	5	6	7

21. Os profissionais da entidade tratam os dados dos utentes de forma confidencial

Discordo muito						Concordo muito
1	2	3	4	5	6	7

22. Os funcionários recebem da entidade apoio adequado ao bom desempenho das suas tarefas

Discordo muito						Concordo muito
1	2	3	4	5	6	7

23. Os profissionais da entidade explicam o que fazer para evitar situações semelhantes no futuro

Discordo muito						Concordo muito

ID do doente		Data de avaliação (dd/mm/aa)

1	2	3	4	5	6	7

24. A entidade não comunica com precisão quando os cuidados serão prestados

Discordo muito						Concordo muito
1	2	3	4	5	6	7

25. A entidade não tem os interesses do utente em consideração

Discordo muito						Concordo muito
1	2	3	4	5	6	7

26. Os funcionários da entidade têm aparência cuidada

Discordo muito						Concordo muito
1	2	3	4	5	6	7

27. A entidade mantém os registos dos seus utentes actualizados (consultas realizadas, medicação, exames)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

28. As instalações físicas da entidade são agradáveis à vista

Discordo muito						Concordo muito
1	2	3	4	5	6	7

29. Os funcionários da entidade não dão aos utentes atenção pessoal

Discordo muito						Concordo muito
1	2	3	4	5	6	7

30. Os profissionais da entidade põem os utentes em contacto com entidades que podem resolver os seus casos (consultas, transporte por bombeiros, apoio social, apoio camarário, apoio paroquial, exames)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

31. O horário praticado pela entidade não convém a todos os seus utentes

Discordo muito						Concordo muito
1	2	3	4	5	6	7

32. A entidade tem meios técnicos modernos (equipamento de diagnóstico ou aparelhos)

☐☐☐		☐☐☐☐☐☐
ID do doente		Data de avaliação (dd/mm/aa)

Discordo muito						Concordo muito
1	2	3	4	5	6	7

33. Pode-se confiar nos funcionários da entidade						
Discordo muito						Concordo muito
1	2	3	4	5	6	7

34. A entidade tem condições que garantem a privacidade do utente						
Discordo muito						Concordo muito
1	2	3	4	5	6	7

As afirmações que se seguem têm a ver com os seus sentimentos para com hospital onde esteve. Por favor, responda assinalando uma cruz no número que melhor descreve as suas percepções.

35. Globalmente, considero os serviços prestados pela entidade						
Muito maus						Muito bons
1	2	3	4	5	6	7

36. Relativamente aos serviços prestados pela entidade, considero-me globalmente						
Muito insatisfeito						Muito satisfeito
1	2	3	4	5	6	7

37. Se me acontecesse algo semelhante no futuro, gostaria de ser tratado na mesma entidade						
Discordo muito						Concordo muito
1	2	3	4	5	6	7

38. Se fosse preciso pagar mais pelos serviços desta entidade, estaria disposto a fazê-lo						
Discordo muito						Concordo muito
1	2	3	4	5	6	7

39. Se acontecesse algo semelhante a um familiar ou amigo meu, tentaria que fosse tratado na mesma entidade						
Discordo muito						Concordo muito
1	2	3	4	5	6	7

Muito obrigado pela sua colaboração.

APPENDICE 6: Stroke-Specific Quality of Life Scale

Stroke Specific Quality of Life Scale (SS-QOL)

Scoring: each item shall be scored with the following key

Total help - Couldn't do it at all - Strongly agree	1
A lot of help - A lot of trouble - Moderately agree	2
Some help - Some trouble - Neither agree nor disagree	3
A little help - A little trouble - Moderately disagree	4
No help needed - No trouble at all - Strongly disagree	5

Energy

1. I felt tired most of the time. _____
2. I had to stop and rest during the day. _____
3. I was too tired to do what I wanted to do. _____

Family Roles

1. I didn't join in activities just for fun with my family. _____
2. I felt I was a burden to my family. _____
3. My physical condition interfered with my personal life. _____

Language

1. Did you have trouble speaking? For example, get stuck, stutter, stammer, or slur your words? _____
2. Did you have trouble speaking clearly enough to use the telephone? _____
3. Did other people have trouble in understanding what you said? _____
4. Did you have trouble finding the word you wanted to say? _____
5. Did you have to repeat yourself so others could understand you? _____

Mobility

1. Did you have trouble walking? (If patient can't walk, go to question 4 and score questions 2-3 as 1) _____
2. Did you lose your balance when bending over to or reaching for something? _____
3. Did you have trouble climbing stairs? _____
4. Did you have to stop and rest more than you would like when walking or using a wheelchair? _____
5. Did you have trouble with standing? _____
6. Did you have trouble getting out of a chair? _____

Mood

1. I was discouraged about my future. _____
2. I wasn't interested in other people or activities. _____
3. I felt withdrawn from other people. _____
4. I had little confidence in myself. _____
5. I was not interested in food. _____

Personality

1. I was irritable. _____
2. I was inpatient with others. _____
3. My personality has changed. _____

Self Care

1. Did you need help preparing food? _____
2. Did you need help eating? For example, cutting food or preparing food? _____
3. Did you need help getting dressed? For example, putting on socks or shoes, buttoning buttons, or zipping? _____
4. Did you need help taking a bath or a shower? _____
5. Did you need help to use the toilet? _____

Social Roles

1. I didn't go out as often as I would like. _____
2. I did my hobbies and recreation for shorter periods of time than I would like. _____
3. I didn't see as many of my friends as I would like. _____
4. I had sex less often than I would like. _____
5. My physical condition interfered with my social life. _____

Thinking

1. It was hard for me to concentrate. _____
2. I had trouble remembering things. _____
3. I had to write things down to remember them. _____

Upper Extremity Function

1. Did you have trouble writing or typing? _____
2. Did you have trouble putting on socks? _____
3. Did you have trouble buttoning buttons? _____
4. Did you have trouble zipping a zipper? _____
5. Did you have trouble opening a jar? _____

Vision

1. Did you have trouble seeing the television well enough to enjoy a show? _____
2. Did you have trouble reaching things because of poor eyesight? _____
3. Did you have trouble seeing things off to one side? _____

Work/Productivity

1. Did you have trouble doing daily work around the house? ____
2. Did you have trouble finishing jobs that you started? ____
3. Did you have trouble doing the work you used to do? ____

TOTAL SCORE ____

Reference

Williams L.S., Weinberger M., Harris L.E., Clark D.O., & Biller J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, *30*(7), 1362-9.

Patient ID	Evaluation date (dd/mm/yy)

APPENDICE 7: SS-QoL quality of life scale adapted to the Portuguese language

With this questionnaire we intend to know how you are dealing with your life after stroke. Each question relates to an activity or feeling. For each question think how you have acted or felt over the past week.

The following questions regard difficulties that some persons may feel after stroke. Mark with a cross the number that best describes problems you have had with performing a given activity **during the last week**.

DURING THE LAST WEEK:

SC1. Did you have trouble preparing food?

Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

SC2. Did you have trouble while eating? (e.g. cutting or swallowing food)

Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

SC4. Did you have trouble getting dressed? (e.g. putting on socks or shoes, buttoning buttons, or zipping)

Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

SC5. Did you have trouble taking a bath or shower?

Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

SC8. Did you have trouble using the toilet?

Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

V1. Did you have trouble seeing the television well enough to enjoy the show?

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Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

V2. Did you have trouble reaching for things because of poor eyesight?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

V3. Did you have trouble seeing things off to one side?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

L2. Did you have trouble speaking? (e.g. get stuck, stutter, stammer, or slur your words)

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

L3. Did you have trouble speaking clearly enough to use the telephone?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

L5. Did you have trouble speaking in a way that other people could understand you?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

L6. Did you have trouble finding the word you wanted to say?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

L7. Did you have trouble speaking to the point you had to repeat to be understood?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

M1. Did you have trouble walking? (if a patient cannot walk, go to question M7 and score M4 and M6 as 1)

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

Patient ID		Evaluation date (dd/mm/yy)

M4. Did you have trouble in maintaining balance when bending over or reaching for something?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

M6. Did you have trouble climbing stairs?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

M7. Did you have trouble walking or using a wheelchair to the point you had to stop?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

M8. Did you have trouble with standing?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

M9. Did you have trouble getting out of the chair?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

W1. Did you have trouble doing daily work around the house?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

W2. Did you have trouble finishing jobs that you started?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

W3. Did you have trouble doing the work you used to do?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

UE1. Did you have trouble writing or typing?

Patient ID

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(dd/mm/yy)

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

UE2. Did you have trouble putting on socks?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

UE3. Did you have trouble buttoning buttons?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

UE5. Did you have trouble zipping a zipper?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

UE6. Did you have trouble opening a jar?

Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
1	2	3	4	5

Indicate how much you agree or disagree with the following statements. Mark with a cross the number that best describes your opinion on each of the statements regarding the activities you have had **during the last week.**

DURING THE LAST WEEK:

T2. It was hard for me to concentrate

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

T3. I had trouble remembering things

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

T4. I had to write things down to remember them

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Evaluation date
(dd/mm/yy)

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

P1. I was irritable

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

P2. I was impatient with others

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

P3. My personality has changed

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

MD2. I was discouraged about my future

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

MD3. I was not interested in other people or activities

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

MD6. I felt withdrawn from other people

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

MD7. I felt little confidence in myself

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

MD8. I was not interested in food

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree

☐☐☐

Patient ID

☐☐☐☐☐☐

Evaluation date (dd/mm/yy)

1	2	3	4	5

FR5. I did not join in activities just for fun with my family

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

FR7. I felt I was burden for my family

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

FR8. My physical condition interfered with my life

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

SR1. I did not go out as often as I would like to

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

SR4. I did my hobbies and recreation for shorter periods of time than I would like

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

SR5. I did not see as many friends as I would like

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

SR6. I had sex less often than I would like

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

SR7. My physical condition interfered with my social life

Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

Patient ID

Evaluation date (dd/mm/yy)

E2. I felt tired most of the time				
Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

E3. I had to stop and rest often during the day				
Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

E4. I was too tired to do what I wanted to do				
Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
1	2	3	4	5

Source: Adapted from Williams et al. (1999)

ID do doente

Data de avaliação
(dd/mm/aa)

Escala de qualidade de vida SS-QoL adaptada à língua Portuguesa

Com este inquérito queremos saber como é que está a lidar com a sua vida depois do Acidente Vascular Cerebral. Cada pergunta questiona sobre uma actividade ou sentimento. Para cada questão, pense como é que actuou ou se sentiu durante a semana passada.

As perguntas que se seguem têm a ver com **dificuldades** que algumas pessoas podem sentir depois do AVC. Marque com uma cruz o número que melhor descreve os problemas que teve para executar essa actividade **durante a última semana**.

DURANTE A ÚLTIMA SEMANA:

SC1. Teve dificuldade em preparar a comida?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

SC2. Teve dificuldade em comer? (por exemplo, cortar ou engolir a comida)

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

SC4. Teve dificuldade em vestir-se? (por exemplo, calçar as meias ou sapatos, apertar botões ou correr o fecho)

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

SC5. Teve dificuldade ao tomar banho ou duche?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

SC8. Teve dificuldade em usar a sanita?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

V1. Teve dificuldade de visão que o impedissem de apreciar programas de televisão?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

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V2. Teve dificuldade em pegar em objectos devido a problemas de visão?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

V3. Teve dificuldade de visão de um dos lados?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

L2. Teve dificuldade em falar? (por exemplo, parou a meio de uma frase, gaguejou ou enrolou as palavras)

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

L3. Teve dificuldade em falar suficientemente claro para usar o telefone?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

L5. Teve dificuldade em falar de forma a que outras pessoas o percebessem?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

L6. Teve dificuldade em encontrar a palavra que queria usar?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

L7. Teve dificuldade em falar até ao ponto que precisou de se repetir para que os outros o percebessem?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

M1. Teve dificuldade em andar? (se não poder andar, marque 1 e salte para a pergunta M7)

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

M4. Teve dificuldade em manter equilíbrio ao curvar-se ou ao tentar pegar em alguma coisa?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade

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1	2	3	4	5

M6. Teve dificuldade em subir escadas?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

M7. Teve dificuldade em andar ou usar a cadeira de rodas ao ponto de ter que parar?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

M8. Teve dificuldade em ficar de pé?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

M9. Teve dificuldade ao levantar-se da cadeira?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

W1. Sentiu dificuldade em realizar tarefas domésticas diárias?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

W2. Sentiu dificuldade em terminar tarefas que iniciou?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

W3. Sentiu dificuldade ao realizar tarefa que costumava fazer antes?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

UE1. Sentiu dificuldade em escrever ou dactilografar?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

UE2. Sentiu dificuldade ao calçar meias?

Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

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UE3. Sentiu dificuldade ao apertar botões?				
Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

UE5. Sentiu dificuldade ao correr um fecho?				
Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

UE6. Sentiu dificuldade ao abrir um frasco?				
Não consegui de todo	Muita dificuldade	Alguma dificuldade	Pouca dificuldade	Nenhuma dificuldade
1	2	3	4	5

Diga até que ponto concorda ou discorda com as seguintes afirmações. Ponha uma cruz no número que melhor descreve a sua opinião em relação a cada uma das afirmações relativas a actividades que fez durante a última semana.

DURANTE A ÚLTIMA SEMANA:

T2. Foi-me difícil concentrar				
Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

T3. Senti dificuldade em lembrar coisas				
Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

T4. Tive que anotar coisas para me lembrar delas				
Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

P1. Estava irritável				
Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

P2. Estava impaciente com os outros				
Concordo muito	Concordo	Não concordo,	Discordo	Discordo muito

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	parcialmente	nem discordo	parcialmente	
1	2	3	4	5

P3. A minha maneira de ser mudou

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

MD2. Senti-me desanimado com o meu futuro

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

MD3. Não me interessei por outras pessoas ou actividades

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

MD6. Senti-me afastado das outras pessoas

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

MD7. Senti pouca confiança em mim mesmo

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

MD8. Não tinha vontade de comer

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

FR5. Não participei em acticidades de lazer com a minha família

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

FR7. Senti-me um peso para a minha família

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

FR8. A minha condição física interferiu com a minha vida familiar

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

ID do doente

Data de avaliação
(dd/mm/aa)

SR1. Não saí com a frequência com que gostaria

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

SR4. Dediquei menos tempo do que gostaria aos meus passatempos e outras actividades de lazer

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

SR5. Não vi tantos amigos quanto gostaria

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

SR6. Pratiquei sexo com menos frequência do que gostaria

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

SR7. A minha condição física interferiu com a minha vida social

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

E2. Senti-me cansado na maior parte do tempo

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

E3. Tive que parar e descansar frequentemente durante o dia

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

E4. Senti-me cansado demais para fazer o que gostaria de ter feito

Concordo muito	Concordo parcialmente	Não concordo, nem discordo	Discordo parcialmente	Discordo muito
1	2	3	4	5

Source: Adapted from Williams et al. (1999)

APPENDICE 8: Lubben Social Network Scale-18

LUBBEN SOCIAL NETWORK SCALE-18 (LSNS-18)

FAMILY: *Considering the people to whom you are related by birth, marriage, adoption, etc…*

1. How many relatives do you see or hear from at least once a month?

   0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

2. How often do you see or hear from relative with whom you have the most contact?

   0 = less than monthly 1 = monthly 2 = few times a month 3 = weekly 4= few times a week 5 = daily

3. How many relatives do you feel at ease with that you can talk about private matters?

   0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

4. How many relatives do you feel close to such that you could call on them for help?

   0 = none 1 = one 2 = two 3 = three or four 4= five thru eight 5 = nine or more

5. When one of your relatives has an important decision to make, how often do they talk to you about it?

   0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

6. How often is one of your relatives available for you to talk to when you have an important decision to make?

   0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

NEIGHBORS: *Considering those people who live in your neighborhood...*

7. How many of your neighbors do you see or hear from at least once a month?

   0 = none 1 = one 2 = two 3 = three or four 4= five thru eight 5 = nine or more

8. How often do you see or hear from the neighbor with whom you have the most contact?

   0 = less than monthly 1 = monthly 2 = few times a month 3 = weekly 4= few times a week 5 = daily

9. How many neighbors do you feel at ease with that you can talk about private matters?

   0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

10. How many neighbors do you feel close to such that you could call on them for help?

    0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

11. When one of your neighbors has an important decision to make, how often do they talk to you about it?

    0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

12. How often is one of your neighbors available for you to talk to when you have an important decision to make?

    0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

FRIENDSHIPS: *Considering your friends who do not live in your neighborhood…*

13. How many of your friends do you see or hear from at least once a month?

    0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

14. How often do you see or hear from the friend with whom you have the most contact?

    0 = less than monthly 1 = monthly 2 = few times a month 3 = weekly 4= few times a week 5 = daily

15. How many friends do you feel at ease with that you can talk about private matters?

    0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

16. How many friends do you feel close to such that you could call on them for help?

    0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more

17. When one of your friends has an important decision to make, how often do they talk to you about it?

    0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

18. How often is one of your friends available for you to talk to when you have an important decision to make?

    0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

LSNS-R total score is an equally weighted sum of these twelve items. Scores range from 0 to 90

Reference:

Boston College. (2014). *Lubben Social Network Scale*. Retrieved 20 March 2010, from http://www.bc.edu/schools/gssw/lubben/

ID do doente

Data de avaliação
(dd/mm/aa)

ESCALA DE REDE SOCIAL DE LUBBEN–18 (LSNS-18)

FAMÍLIA: *Considerando as pessoas com quem está relacionado quer por nascimento quer por casamento...*

1. Quantos familiares vê ou com quantos familiares fala pelo menos uma vez por mês?

   0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

2. Com que frequência vê ou fala com o familiar com quem tem mais contacto?

   0 = menos do que uma vez por mês 1 = mensalmente 2 = algumas vezes por mês 3 = semanalmente 4 = algumas vezes por semana 5 = diariamente

3. Com quantos familiares se sente à vontade para falar sobre a sua vida privada?

   0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

4. Com quantos familiares se sente próximo o suficiente para os poder chamar se precisar de ajuda?

   0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

5. Quando um dos seus familiares tem uma decisão importante para tomar, com que frequência fala consigo sobre isso?

   0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

6. Quando tem uma decisão importante para tomar, com que frequência um dos seus familiares está disponível para falar consigo sobre isso?

   0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

VIZINHOS: *Considerando as pessoas que vivem perto de si/no seu bairro...*

7. Quantos vizinhos vê ou com quantos vizinhos fala pelo menos uma vez por mês?

   0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

8. Com que frequência vê ou fala com o vizinho com quem tem mais contacto?

   0 = menos do que uma vez por mês 1 = mensalmente 2 = algumas vezes por mês 3 = semanalmente 4 = algumas vezes por semana 5 = diariamente

9. Com quantos vizinhos se sente à vontade para falar sobre a sua vida privada?
   0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

10. Com quantos vizinhos se sente próximo o suficiente para os poder chamar se precisar de ajuda?

0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

11. Quando um dos seus vizinhos tem uma decisão importante para tomar, com que frequência fala consigo sobre isso?

0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

12. Quando tem uma decisão importante para tomar, com que frequência um dos seus vizinhos está disponível para falar consigo sobre isso?

0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

AMIZADES: *Considerando os seus amigos que não vivem perto de si/no seu bairro...*

13. Quantos amigos vê ou com quantos amigos fala pelo menos uma vez por mês?

0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

14. Com que frequência vê ou fala com o amigo com quem tem mais contacto?

0 = menos do que uma vez por mês 1 = mensalmente 2 = algumas vezes por mês 3 = semanalmente 4 = algumas vezes por semana 5 = diariamente

15. Com quantos amigos se sente à vontade para falar sobre a sua vida privada?

0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

16. Com quantos amigos se sente próximo o suficiente para os poder chamar se precisar de ajuda?

0 = nenhum 1 = um 2 = dois 3 = três a quatro 4 = cinco a oito 5 = nove e mais

17. Quando um dos seus amigos tem uma decisão importante para tomar, com que frequência fala consigo sobre isso?

0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

18. Quando tem uma decisão importante para tomar, com que frequência um dos amigos está disponível para falar consigo sobre isso?

0 = nunca 1 = raramente 2 = às vezes 3 = frequentemente 4 = com muita frequência 5 = sempre

Source: Adapted from Boston College (2014)

Patient ID

Evaluation date
(dd/mm/yy)

APPENDICE 9: Guide of the interview with patients

Interview guide with patients

[READ] You were hospitalized due to stroke in Hospital Infante D. Pedro.

[DO NOT READ: if a patient was not hospitalized in a rehabilitation unit after, go to question (3)].

[READ] After discharge from the hospital, you went to a rehabilitation unit.

1. When did you know that rehabilitation unit existed: before or after your stroke? How did you know about the unit? (Somebody told you? Who?)

2. Anyone made a formal diagnosis of your needs? What was a function of that person in the rehabilitation unit?

3. Right now you are at home. Was it your choice? Do you think you have conditions? What are advantages and disadvantages of staying at home? In alternative, where would you like to be?

[DO NOT READ: prepare the list of entities the patient interacted with from the Experiences list]

[READ] In the last six months you had contacts with some support and care entities. In your case, these were X,Y,Z.

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4. Did anyone help you contact entity XYZ? Who? Where? In which way? (e.g. gave you the telephone number, the address, went there with you)

5. Who did you contact in the entity XYZ? (e.g. social worker, priest, volunteer, nurse, ...)

6. Did you use any time a telephone in order to speak/deal with your situation with the entity XYZ? If so, do you have any good or bad experience you wish you describe? (Was there a telephone number? Was the call answered? What was the issue? Was it solved?)

7. Did anyone make a formal diagnosis of your needs? What was a function of that person in the entity XYZ?

8. What sort of help did you receive from the entity XYZ (e.g. meals, technical aid, help with hygiene, help with domestic tasks, counselling, support, moral/spiritual help, financial help...)?

9. How many times did you have to go to the entity XYZ until you received what you needed?

Patient ID

Evaluation date
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10. Did professionals of the entity XYZ know about your case or you had to explain them your situation? In case you had more than one contact with the entity XYZ did you have to repeat everything about your situation again with your next visit?

11. Help that you received from the entity XYZ was the one you asked for? Considering your specific needs, do you think that what you received was adequate? Was is sufficient? Do you feel there were services/help that you needed but did not manage to obtain?

12. Was there anyone following your case with regularity, who evaluated your physical condition, health state and health improvements? Did anyone ever asked if you were satisfied?

13. Do you think that technical equipment of the entity XYZ was adequate for service delivery at a good level (modern, sufficient, clean, good maintenance condition)?

14. What is your opinion on employees’ appearance? (e.g. identification, adequate clothing, clean and neat)

15. How would you describe the way employees treated you? (well-educated? correct? considerate?) Do you have any good or bad experiences you would like to share?

16. What is your opinion about interest demonstrated by employees of the entity XYZ in your case?

17. With which promptitude did employees of the entity XYZ respond to your requests?

18. Did you feel confidence in capacities of persons dealing with your case in the entity XYZ? (e.g. employees looked at ease with tasks they were working with?)

19. Did you feel any time that employees of the entity XYZ did not understand your situation and needs? Did you ever feel misunderstood? Give examples.

20. Generally, do you think that the entity XYZ fulfilled the promise regarding the schedules? (If not, when, in which situation?)

21. Did you ever feel that your privacy was not respected? (e.g. persons not involved in your case were able to see/hear details about your situation?)

22. Do you think that your informal caregiver’s needs were considered by the entity XYZ?

23. Did the entity XYZ provide information about other services that have might helped in your case? If yes, did anyone from entity XYZ help you establish the contact?

24. Did you pay for services you provided by the entity XYZ? If yes, how? (everything on time, partially on time, nothing on time and payment made later). Did you get any reimbursement?

25. Relatively to the price, you consider the services of the entity XYZ

Very cheap	Cheap	Neither cheap nor expensive	Expensive	Very expensive	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

Very cheap	Cheap	Neither cheap nor expensive	Expensive	Very expensive	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

Very cheap	Cheap	Neither cheap nor expensive	Expensive	Very expensive	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

26. What did you like the most from you experience with the entity XYZ?

27. Relatively to the services provided by the entity XYZ, you consider yourself generally

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7

28. Do you consider sufficient information that exists about services and support for persons with problems similar to yours? Do you think that persons in a similar situation and/or with needs alike are aware of available services and help?

29. How do you consider support that the community provides currently to cases such as yours?

Very bad	Bad	Reasonable	Good	Very good	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

29b. Relatively to the functioning of the health and social care system as a whole, you consider yourself

Very dissatisfied						Very satisfied
1	2	3	4	5	6	7

30. What was a role of your family in that phase of your life?

31. How do you evaluate support you had after stroke from your family?

Very bad	Bad	Neither good nor bad	Good	Very good	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

32. What was a role of your neighbors in that phase of your life?

33. How do you evaluate support you had after stroke from your neighbors?

Very bad	Bad	Neither good nor bad	Good	Very good	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

34. What was a role of your friends in that phase of your life?

35. How do you evaluate support you had after stroke from your friends?

Very bad	Bad	Neither good nor bad	Good	Very good	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

36. How do you evaluate your health condition in this moment?

Very bad	Bad	Reasonable	Good	Very good	DK/DA
☐1	☐2	☐3	☐4	☐5	☐99

ID do doente

Data de avaliação
(dd/mm/aa)

Guião de entrevista com os doentes

[LER] O/A Sr/Srª esteve hospitalizado(a) devido a um AVC.

[NÃO LER: se o doente não foi hospitalizado numa unidade de reabilitação, salte à pergunta (3)].

[LER] Depois da alta do hospital foi para a unidade de reabilitação.

1. Quando é que soube que esta unidade existia: antes ou depois da trombose? Como é que soube da unidade? (Alguém lhe disse? Quem?)

2. Alguém lhe fez o diagnóstico formal das suas necessidades? Qual era a função dessa pessoa na unidade?

3. Neste momento está em casa. Foi a escolha sua? Acha que tem condições? Quais são vantagens e desvantagens de estar em casa? Em alternativa, onde é que queria estar?

[NÃO LER: preparar a lista das entidades com que o doente interagiu com base na ficha de Experiências]

[LER] Nos últimos seis meses teve contactos com algumas entidades. No seu caso, eram X, Y, Z...

4. Alguém o ajudou a contactar a entidade XYZ? Quem? Onde? De que forma? (e.g. deu-lhe o número de telefone, a morada, foi consigo?)

5. Quem é que contactou na entidade XYZ? (e.g. assistente social, padre, voluntário, enfermeiro,..)

6. Alguma vez usou o telefone para falar/tratar da sua situação com a entidade XYZ? Se sim, há algumas experiências boas ou más de que queira falar? (Havia o número de telefone? Atenderam? Qual foi o assunto? Foi resolvido?)

7. Alguém lhe fez o diagnóstico formal das suas necessidades? Qual era a função dessa pessoa na entidade XYZ?

8. Que tipo de ajuda obteve por parte da entidade XYZ? (e.g. refeições, ajudas técnicas, ajuda com higiene, ajuda com as tarefas de casa, aconselhamento, conforto, ajuda moral/espiritual, ajuda financeira,..)

9. Quantas vezes teve que ir à entidade XYZ até obter aquilo de que precisava?

ID do doente

Data de avaliação
(dd/mm/aa)

10. Os profissionais da entidade XYZ sabiam do seu caso ou teve que lhes explicar a sua situação? Caso tenha tido mais do que um contacto com a entidade XYZ, teve, da vez seguinte, que repetir tudo acerca da sua situação?

11. A ajuda que obteve da entidade XYZ foi aquela que pediu? Considerando as suas necessidades específicas, os serviços/ajuda que recebeu foram adequados? Foram suficientes? Sente que havia serviços/ajuda de que precisava mas não conseguiu obter?

12. Alguém esteve a seguir o seu processo com regularidade, avaliou a sua condição física, tentou saber do seu estado de saúde e das suas melhoras? Alguém alguma vez perguntou se estava satisfeito?

13. Acha que a entidade XYZ tinha meios técnicos adequados à boa prestação de serviços? (modernos, suficientes, limpos, em bom estado de conservação,..?)

14. Qual é a sua opinião acerca do aspecto dos funcionários? (e.g. identificação, roupa adequada, limpa?)

15. Como é que descreveria a forma como os funcionários o trataram? (bem-educados? correctos? atenciosos?) Teve algumas experiências boas ou más que queira partilhar?

16. Qual é a sua opinião acerca do interesse demonstrado pelos funcionários da entidade XYZ pelo seu caso?

17. Com que prontidão os funcionários da entidade XYZ responderam aos seus pedidos?

18. Sentiu confiança nas capacidades das pessoas que trataram do seu caso na entidade XYZ? (e.g. os funcionários estavam à vontade com as tarefas que executavam?)

19. Sentiu alguma vez que os funcionários da entidade XYZ não percebiam a sua situação e as suas necessidades? Alguma vez se sentiu incompreendido? Dê exemplos.

20. De uma forma geral, acha que a entidade XYZ cumpriu o estabelecido quanto aos horários? (se não, quando, em que situação?)

21. Alguma vez sentiu que a sua privacidade não foi respeitada? (por exemplo, pessoas não envolvidas no seu caso estavam a ver/ouvir detalhes sobre a sua situação?)

22. Acha que as necessidades do seu cuidador informal foram tidas em conta por parte da entidade XYZ?

23. A entidade XYZ disponibilizou-lhe informação sobre outros serviços úteis ao seu caso? Se sim, alguém da entidade XYZ o ajudou a estabelecer o contacto?

24. Pagou pelos serviços que recebeu por parte da entidade XYZ? Se sim, como? (tudo na hora, parte na hora, nada na hora). Foi comparticipado?

25. Relativamente ao preço, achou os serviços prestados pela entidade XYZ

Muito baratos	Baratos	Nem baratos nem caros	Caros	Muito caros	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

Muito baratos	Baratos	Nem baratos nem caros	Caros	Muito caros	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

Muito baratos	Baratos	Nem baratos nem caros	Caros	Muito caros	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

26. De que gostou mais na experiência com a entidade XYZ?

27. Relativamente aos serviços prestados pela entidade XYZ, considera-se globalmente

Muito insatisfeito						Muito satisfeito
1	2	3	4	5	6	7

Muito insatisfeito						Muito satisfeito
1	2	3	4	5	6	7

Muito insatisfeito						Muito satisfeito
1	2	3	4	5	6	7

28. Considera suficiente a informação que existe sobre os serviços/ajuda para pessoas com problemas semelhantes ao seu? Acha que pessoas na situação e/com necessidades semelhantes têm conhecimento dos serviços/ajuda disponíveis?

29. Como é que considera o apoio que a comunidade dá, neste momento, a casos como o seu?

Muito mau	Mau	Razoável	Bom	Muito bom	NS/NR
☐1	☐2	☐3	☐4	☐5	☐99

29b. Relativamente ao funcionamento de sistema de saúde e social como um todo considera-se:

Muito insatisfeito	Insatisfeito	Nem insatisfeito nem satisfeito	Satisfeito	Muito satisfeito	NS/NR
☐1	☐2	☐3	☐4	☐5	☐99

30. Qual foi o papel da família nesta fase da sua vida?

ID do doente

Data de avaliação
(dd/mm/aa)

31. Como é que avalia o suporte que teve da sua família após o AVC?

Muito mau	Mau	Nem bom nem mau	Bom	Muito bom	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

32. Qual foi o papel dos vizinhos nesta fase da sua vida?

33. Como é que avalia o suporte que teve dos seus vizinhos após o AVC?

Muito mau	Mau	Nem bom nem mau	Bom	Muito bom	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

34. Qual foi o papel dos amigos nesta fase da sua vida?

35. Como é que avalia o suporte que teve dos seus amigos após o AVC?

Muito mau	Mau	Nem bom nem mau	Bom	Muito bom	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

36. Neste momento, como é que avalia o seu estado de saúde?

Muito mau	Mau	Razoável	Bom	Muito bom	NS/NR/NA
☐1	☐2	☐3	☐4	☐5	☐99

APPENDICE 10: Guide of the interview with care and support providers

Entity:_________________________

Interview guide with care and support providers for patients who suffered a cerebrovascular accident

[READ]

Your institution makes part of a group of several entities that provide care or some type of support to persons who suffered a stroke in the district of Aveiro. I would like to speak to you about the way you perceive collaboration between these entities.

[READ]

1. Are you acquainted with any legislation stipulating rules of collaboration between your organization and entities with which you have contacts regarding support to persons who suffered a stroke? If yes, which?
2. What do you think about available legal information concerning collaboration between entities which provide care and services to patients after cerebrovascular accident?
3. How is organized the system that supports cases after cerebrovascular accident?
4. What formal orientations do exist in this moment for cerebrovascular accident?
5. What is a route for stroke patients after discharge from hospital?
6. What is available in the support network for patients who suffered a stroke?
7. Which State incentives aiming at promoting collaboration between health and social care institutions do you know?
8. How are financed services provided by your organization?
9. Have you noticed any differences over the last years regarding formal/professional systems that involve collaborating institutions?
10. How do you consider collaborative relations in their level of facilitation/difficulty? What are the main barriers and the main catalysts?

11. Does your organization have collaboration agreements with other entities that provide services or support to patients after stroke? If yes, with whom?

[*DO NOT READ, if the respondent answered 'no' to the question (11) go to question (13)*]

12. Who had an initiative to settle this collaboration agreement? How long has it lasted? Was it easy or difficult to implement? Why? What structures do exist under the scope of this collaboration? How does it function (on the operational level)?

[*DO NOT READ, this part is for consultation only*]

- *Elements of collaboration that function well and those which could be improved;*
- *Perception which leads the respondent to consider some of the aspects of collaboration as positive and others as not. Reasons for that vision;*
- *Relative opinion: positive/negative.*

[READ]

13. Above collaborative actions, or even in the absence of collaboration supported by an official agreement, does any informal activity based on goodwill of employees exist? Based on what? [*DO NOT READ, this part is for consultation only: additional activity that goes above formalized responsibilities: based on willingness to help and mutual trust, for instance*].

14. Does in your organization any method of evaluation of collaboration exist which would take into account the relation between cost and benefit?

15. In your understanding, what can be gains of collaboration?

16. What can an organization lose if making part of a collaborative agreement?

17. When several entities participate in care or support of a patient, do you think there should be someone coordinating this activity? If yes, shall they make part of the group or be from outside? Shall it be an individual or a group? In that group of entities, shall there be any common rules or each entity should make and control its own part of activities?

18. When a patient arrives, does your institution have access to previous information regarding health state necessary to make your work? Does any informatics system that allows you to consult the patient health condition exist?

19. In case of your organization, do you receive information concerning the patient from other entities which provide care or support to that patient? If yes, in which format and by which means? Is that information sufficient?

20. Does your organization offer patients information regarding other services useful in their cases? If yes, does anyone help them establish contacts with these external entities?

21. Do you think that persons who suffered a stroke are acquainted with available treatments and support? Do you consider sufficient information available about services and help existing for these patients? Is it easy to find that information?

22. How does your organization guarantee a level of skills adequate to service delivery for stroke patients? Does the organization have any criteria specific for the admission of employees? Do continuous training programs exist for employees? How do they function? How are employees who take part in these programs selected?

23. Do you think that employees of your organization have sufficient knowledge for good performance of their tasks?

24. When it comes to cases of patients with special needs, out of a typical profile of a stroke patient, do you think that employees have skills to deal with such situations?

25. What is your position regarding patient data sharing?

26. Until which extent are patients' data treated confidentially in your organization?

27. Is there any process of internal service quality control? Which instruments do you administer for that purpose? Which means? Who intervenes in the process?

28. Do you think that employees feel advantages, for them and for the organization, resulting from collaboration with other entities?

29. How do you evaluate the capacity to change, eventually, work methods in your organization? What is the level of flexibility of employees?

30. What is the level of development of interpersonal relations in your organization: what type of relations between employees does prevail, formal or informal?

31. How does daily communication in your organization work?

32. In case of your organization, what is the importance given to teamwork?

33. Do employees of your organization maintain relationships also outside the professional context?

34. How do you consider support that the community provides currently to cases such as yours?

Very bad	Bad	Neither good nor bad	Good	Very good	DK/ DA
☐1	☐2	☐3	☐4	☐5	☐99

Entity:________________________

Guião de entrevista com os provedores de cuidado e suporte para doentes que sofreram um AVC

[LER]

A sua instituição faz parte de um conjunto de várias entidades que, no distrito de Aveiro, fornecem cuidados ou algum tipo de serviço de apoio a pessoas que sofreram um acidente vascular cerebral. Gostaria de falar consigo acerca da forma como vê a colaboração que existe entre essas entidades.

[LER]

1. Tem conhecimento de alguma legislação que estipule regras de colaboração entre a sua organização e entidades com que tem contactos no âmbito do apoio a pessoas que sofreram um AVC? Se sim, qual?
2. O que acha de informação legal disponível acerca da colaboração entre entidades que fornecem cuidados e serviços a doentes após um AVC?
3. Que incentivos dados pelo Estado para promover a colaboração entre instituições conhece na área de saúde e social?
4. Como são financiados os serviços prestados pela sua organização?
5. Tem reparado algumas diferenças ao longo dos últimos anos no sentido de sistemas formais/ profissionais que envolvem entidades colaborantes?
6. Como considera a relação de colaboração quanto ao seu grau de facilitação/ dificuldade? Quais as principais barreiras e quais os principais catalisadores (facilitadores)?
7. A sua organização tem acordos de colaboração com outras entidades que prestam serviços ou apoio aos doentes após um AVC? Se sim, com quem?

[*NÃO LER: se o entrevistado respondeu ‘não’ à pergunta (7) salte para a pergunta (9)*]

8. Quem é que teve a iniciativa de estabelecer esse acordo de colaboração? Há quanto tempo dura? A colaboração foi fácil ou difícil de implementar? Porquê? Que estruturas existem no âmbito dessa colaboração? Como é que funciona (ao nível operacional)?

[*NÃO LER: esta parte é para a consulta*]

- *Elementos de colaboração que funcionam bem e elementos que podiam ser melhorados;*
- *Percepção que leva o entrevistado a considerar alguns aspectos de colaboração como sendo positivos e outros não. Razões para essa visão;*
- *Opinião relativa: positiva/negativa*

[LER]

9. Para além de acções de colaboração, ou, mesmo se não há colaboração suportada por um acordo oficial, existe alguma actividade informal, baseada na boa vontade dos funcionários? Baseada em quê? [*NÃO LER, esta parte é para a consulta: actividade adicional que vai por além das responsabilidades formalizadas: baseada na vontade de ajudar e na confiança mútua, por exemplo*].
10. Existe na sua organização um método de avaliação da colaboração tendo em conta a relação custo/benefício?
11. No seu entender, quais é que podem ser os benefícios de uma colaboração?
12. O que é que uma organização pode perder se fizer parte de uma colaboração?
13. Quando várias entidades participam no cuidado ou apoio a um doente, acha que deve existir alguém a coordenar a actividade? Se sim, deve pertencer ao grupo ou deve ser alguém externo? Em qualquer dos casos, quem? Deve ser um individual ou um grupo? Nesse grupo de entidades deve haver algumas regras comuns ou cada um desempenhar e controlar a sua própria parte das actividades?
14. Quando um doente chega, a sua instituição tem acesso a informação prévia acerca do estado de saúde dele de que precise para poder fazer o seu trabalho? Existe algum sistema informático que lhe permita consultar a informação do doente?
15. No caso da sua organização, recebe informação acerca do doente de outras entidades que prestam cuidado ou apoio a esse doente? Se sim, em que formato e por que meio? Essa informação é suficiente?
16. A sua organização disponibiliza aos doentes informação sobre outros serviços úteis aos seus casos? Se sim, alguém os ajuda a estabelecer contacto com essas entidades externas?
17. Acha que pessoas que tiveram um AVC têm conhecimento de tratamentos e ajudas disponíveis? Considera suficiente a informação que existe sobre os serviços e apoio existentes para esses doentes? É fácil encontrar essa informação?
18. Como é que a sua organização garante o nível de conhecimentos adequado à boa prestação de serviços para doentes após um AVC? A organização possui alguns critérios específicos de admissão de funcionários? Existem programas de formação contínua dos funcionários? Como decorrem? Como selecionam funcionários que os frequentam?

19. Acha que os funcionários da sua organização têm conhecimentos suficientes ao bom desempenho das suas tarefas?

20. Quando se trata dos casos de doentes com necessidades específicas, fora do perfil típico de um doente após um AVC, acha que os funcionários têm capacidades para lidar com essas situações?

21. Qual é a sua posição face à partilha de dados do doente?

22. Até que ponto dados dos doentes são tratados de forma confidencial na sua organização?

23. Há algum processo interno de controlo da qualidade do serviço prestado? Que instrumentos usam para isso? Que meios? Quem intervém no processo?

24. Acha que os funcionários sentem vantagens, para eles e a sua organização, resultante da colaboração com outras entidades?

25. Como é que avalia a capacidade de mudar, eventualmente, os métodos de trabalho na sua organização? Qual é o nível de flexibilidade dos funcionários?

26. Qual é o nível de desenvolvimento de relações interpessoais na sua organização: que tipo de relações entre os funcionários predomina, formais ou informais?

27. Como é que funciona a comunicação no dia-a-dia na sua organização?

28. No caso da sua organização, qual a importância dada ao trabalho em equipa?

29. Os funcionários da sua organização mantêm contactos também fora do âmbito profissional?

30. Como é que está organizado o sistema que suporta casos após o acidente vascular cerebral?

31. Quais orientações formais existem neste momento para um acidente vascular cerebral?

32. O que é que está disponível na rede de suporte para doentes após um AVC?

33. Qual é o percurso para os doentes após um AVC depois da alta hospitalar?

34. Como é que considera o apoio que a comunidade dá, neste momento, a casos como os dos doentes após o AVC?

Muito mau	Mau	Nem bom nem mau	Bom	Muito bom	NS/NR
☐1	☐2	☐3	☐4	☐5	☐99

APPENDICE 11: Complete codification system of the interviews with patients

Complete codification system of the interviews with patients

Topic	Category	Sub-category
Support in Provision of First Aid	Contact with Fire Department/the INEM	Family (n=45) Neighbors (n=2) Boss (n=1) Patient (n=3)
	Service Quality of Fire Department/the INEM	Practices developed by the fire department contributing to service quality (n=63)
Assessment of Situation and Care Provision after Discharge	Perception of Physical Condition	Positive (n=52)
		Negative (n=39)
	Advantages of Recovery at Home	At-will/freedom of movement (n=52)
		Relatives (n=35)
	Disadvantages of Recovery at Home	Lack of health care on place (n=18)
	Information on Rehabilitation and Support Services	Difficulties of access (n=51)
	Monitoring by Health Professionals	Family doctor supervision (n=49)
	Community Support	Appreciation of community support (n=32)
	Service Quality	Perception of the recovery after treatments (n=54)
		Service quality of entities with which patients interacted: Rehabilitation unit (n=50) Firemen (n=100) IPSS (n=27) Social Security (n=17)

		Church (n=5) *Misericórdia* (n=3) Parish council (n=2) City council (n=1)
Perceived Social Support	Family Support	Appreciation of family support (n=82)
	Neighbors Support	Appreciation of neighbors support (n=75)
	Friends Support	Appreciation of friends support (n=70)
Assessment of Current Health Status	Health Status	Positive (n=55)
		Negative (n=15)
		Variable (n=23)

APPENDICE 12: Health and social care systems in Portugal

Health and social care systems in Portugal

Portugal is a country located in the Iberian Peninsula in the south-west of Europe and comprises the continental part and two archipelagos, Azores and Madeira, the autonomous regions. The continental part is agglomerated into 18 districts: Aveiro, Beja, Braga, Bragança, Castelo Branco, Coimbra, Évora, Faro, Guarda, Leiria, Lisbon, Portalegre, Porto, Santarém, Setúbal, Viana do Castelo, Vila Real and Viseu. Madeira and Azores are governed autonomously. Districts are divided into 308 municipalities (*municípios* or *concelhos*) further subdivided into 3091 parishes (*freguesias*) (the number was decreased in 2013 from 4260). Municipalities and parishes together with the national governmental structure are the only officially legally standing local administrative units for the governance purpose. The Portuguese population reached 10.6 million people (INE, 2011) and has been steadily increasing.

A district serves as a basis for administrative decisions and regional division of public services. It is used as an area of jurisdiction for local offices of ministries and governmental agencies. The district of Aveiro is located in the central region of the country, at the coastal part, between the districts of Porto, Coimbra and Viseu. It covers the area of 2808 km2 and has population of over 750 000 people. The district is constituted of 19 municipalities. The capital of the district is the city of Aveiro.

The district of Aveiro comprises 19 municipalities: Águeda, Albergaria-a-Velha, Anadia, Arouca, Aveiro, Castelo de Paiva, Espinho, Estarreja, Ílhavo, Mealhada, Murtosa, Oliveira de Azeméis, Oliveira do Bairro, Ovar, Santa Maria da Feira, São João da Madeira, Sever do Vouga, Vagos and Vale da Cambra, giving origin to 208 further parishes.

The responsibility for health care provision is of the Ministry of Health, and for social care is of responsibility of the Ministry of Labor and Social Solidarity, which is also liable for social benefits such as pensions, unemployment and incapacity benefits. Structures of care provision exist under both systems, which, ideally, should be complementary and contributing for the best outcome of the citizen in need. In this spirit, the National Network of Integrated Continuous Care was brought to life. Its mission is to provide support in continuity of care by means of diverse and accordingly chosen levels of integrated care unceasingly contributing to its development. For that purpose, different entities of the network were created with different targets and purposes, making frequent use of already existing structures. In this moment, the network is constituted from three levels of integrated care: convalescence (short-term) units, medium-term and rehabilitation units and long-term and maintenance units; and palliative care units, supporting situations of dependency and incapacity, with a strong focus on home care.

The network of care for patients who underwent cerebrovascular accident may therefore consist of a range of entities, some of them operating within the National Network of Integrated Continuous Care, hospitals, a typology of rehabilitation units, Private Institutions of Social Solidarity, *Misericórdias*, health centers, city councils, parish councils, the Social Security, fire departments offering transportation services, religious entities (providing spiritual, material and often financial support), physiotherapy clinics, and other private service providers whose services may be beneficial to a patient (a gym, a swimming pool).

Health centers are primary care public sector establishments delivering care through public funds. They are an entry point to the health system, with GPs and primary care nurses and, in some cases, specialists and have gone in recent years through a deep reform. Primary care centers provide a wide range of services, including, in addition to general medical care for the population, prenatal care, family planning, home visits, preventive services such as screening for breast or cervical cancer or some preventable diseases (Barros et al., 2011). Besides health centers, primary care can also be provided by private sector providers, and professionals contracted or collaborating with the NHS (Simões, 2012).

Hospital services are provided mostly according to the integrated model, directly run by the NHS. Hospitals are classified according to the services they deliver (Barros & Simões, 2007):

a) central hospitals – these dispose advanced technology and specialist human resources and are able to provide highly specialized services;

b) specialized hospitals – these provide a wide range of specialized services;

c) district hospitals – these are located in main administrative districts and provide a range of specialized services; and

d) district first-level hospitals – these type of hospitals provide only internal medicine services, surgery and one or a few other basic specialties.

The network of integrated care is coordinated at the central, regional and local level, allowing for adopting measures sometimes palpable only in the field. More specifically, the network promotes coordination between different institutions of care, with early referrals and what requires monitoring the patient's situation and eventual adaptation of the condition to current needs to enhance improvement. Collaboration between the health and the social sectors together with the society, more or less related to a given case is crucial for a long-term success of the network.

According to the law, a convalescence unit is an independent inpatient unit, integrated within an acute care hospital or another entity in articulation with an acute care hospital that provides treatment and intense, continued clinical supervision and rehabilitation care for cases that originated in a hospitalization event (Decree Law no. 101/2006, article 13). Convalesce units have at their disposal a range of health specialists, whose objective is functional and clinical stabilization of health condition of a patient not who does not require acute care and finds themselves in a transitory phase of a loss of autonomy. As the RNCCI refers, a convalesce unit has at its disposal at least (a) permanent medical and nursery care; (b) daily observation and revision of the recovery plan; (c) availability of rehabilitation care with specialized professionals; (d) support with a daily life activities with which a patient may still present difficulties.

According to the law, a medium-term and rehabilitation unit is an inpatient unit for providing rehabilitation care and psychosocial support with articulation with an acute care hospital for clinical situations for a recovery from an acute process or a pathologic chronic disease, and is destined to persons with potentially recoverable autonomy (Decree Law no. 101/2006, article 13). The hospitalization period in a medium-term unit is predicted for at least 30 to maximum 90 days, referring these limits into each admission. The services provided in such units include daily medical care, permanent nursery care, physiotherapy and occupational therapy care, psychosocial support, and leisure. Consequently, the professional team is a multidisciplinary group from the health and social care fields, involving professionals such as doctor, nurse, physiotherapist, occupational therapist, psychologist, nutritionist, social workers, health care auxiliaries, other employees guaranteeing smooth functioning of the unit, and others, whose professional profiles suit the current needs of the unit. Additionally, a unit may sub-contract services (outsourcing) if it finds that beneficial.

According to the law, a long-term and maintenance unit is an inpatient temporary or permanent institution, providing health services and social support to persons with chronic conditions, with different levels of dependency or not fulfilling conditions for self-care in domicile (Decree Law no. 101/2006, article 13). Its principal objective is to prevent degenerating of the situation of dependency (confirmed), increasing quality of life and providing comfort a patient may not count for on a daily basis. The hospitalization period in a long-term duration unit exceeds 90 days, although may be shorter in case of situation arising from difficulties in providing family support to the patient or excessive burden handled by the primary caregiver; in such case the hospitalization period of a patient may take up to 90 days per year (Barros & Simões, 2007). Patients from long-term units represent a different profile that those from convalescence units. Due to their situation of dependency they require integrated continuous care. Services provided by a unit include permanent nursery service that constitute a basis of care, regular medical visits, rehabilitation care, support in development occupational and leisure activities, support in the interaction between the relatives and the patient. Long-term care and maintenance units have been for long neglected in terms of public sector involvement. Traditionally, their services were provided by *Misericórdias* and other non-governmental institutions. The current status of long-term care in the country context, except of cases comprised by the RNCCI, strongly relies on informal networks and privately funded care.

Misericórdias have a long tradition in the Portuguese history and were first organized in Florence in the 13th century to be later brought to Portugal in the 15th century. They are organized in order to meet social needs while performing the Catholic worship, in harmony with their spirit and quintessence, and based on the Catholic principles and morals. Over centuries charitable organizations played an important role in providing social (and until very late, health) assistance to the community; nowadays, they continue to do so, yet, not exclusively. In fact, services provided by *Misericórdias* are very similar to those offered by IPSS. These charitable organizations may be associated to the National Union of *Misericórdias*, however, the membership is not obligatory. Following the latest data for the country, from those affiliated to the Union, there are 398 *Misericórdias* and other 80 remain inactive, although with some equity residues. In the district of Aveiro there are currently 21 *Misericórdias*, located in Anadia, Mealhada, Murtosa, Águeda, Albergaria-a-Velha, Arouca, Castelo de Paiva, Espinho, Ílhavo, Estarreja, Oliveira de Azeméis, Ovar, Oliveira do Bairro, São João da Madeira, Santa Maria da Feira, Sangalhos, Sever do Vouga, Vagos, Vale de Cambra, Vila de Cucujães and Aveiro. The estimates are more uncertain concerning other charitable entities as no formal registries exist.

Private Institutions of Social Solidarity are non-profit organizations that sprang from a private initiative, based at goodwill and availability of the community, and with the purpose of providing organized care. Their beneficiaries may be children and youth, whole families, and elderly. Services aim at solving living problems of the population; protecting the citizens temporarily or permanently disabled, elder and in all situations of subsistence; promoting healthy lifestyle and health education; providing preventive medical, curative and rehabilitative care. In practice, it is translated into existence of nurseries, kindergartens, social offices, after school activities centers, domiciliary care, day centers for adults and nursing homes. IPSS are financed through agreements with the State that supports their activity and functioning recognizing its meaning and value for public interest even in the Portuguese Constitution (1976, revision of 2005, art. 63). Payment for services is a result of the household income as a fraction of the price practicing by a given IPSS; the remaining part is co-financed by the State on a basis of the norms of the Ministry of Labor and Social Solidarity.

City councils and parish councils may play an important role in the network of care as they have legal, organizational and financial and means to establish a scheme of technical support for patients after stroke. In practice, this refers to technical aids, a spider or an articulated bed that can constitute a great help for a patient and improve his quality of life. Depending on a decision, the entity support may be financial (co-financing an equipment, co-financing the house adaptation to the patient current physical limitations) or borrowing the equipment from the entity possessions.

City councils and parish councils can also turn to those on who lays the hardest responsibility for the well-being of the patients, that is, the caregivers. Support can encompass from one side, organizing special sessions on education and information on how to care the best a post-stroke patient and what to expect, measures of care, informing on existing community resources, and creating support groups with regular meetings, sessions on dealing with stress and hidden rage that may appear as a consequence of a huge and unstoppable tension, teaching relaxation techniques, on the other.

Firemen in Portugal are a branch of civil protection and, depending on a unit, a combination of firemen by profession, mixed and volunteers. Their primary activity is the public welfare in the country, comprising prevention, combating fire which has already been detected and public order. The operational service of the fire department is the activity of an internal or external nature that in developed accordance to the mission of the respective department. Interestingly, and what differs Portugal from other countries, a part of the operational service of fire departments contributes in high level to the functioning of the care system, on a basis of the cooperation agreement between the Portuguese League of the Firemen and the Ministry of Health. The specific norms are regulated further by the law, as the transportation rules and the co-payments depend on a patient health condition and the type of the transporting entity (the general agreement with the Ministry of Health specifies also details of the cooperation with other potential transportation entities). The district of Aveiro possesses the following fire departments: Albergaria-a-Velha, Anadia, Arouca, Bombeiros Novos de Aveiro, Bombeiros Velhos de Aveiro, Arrifana, B.P.Portucel, B.P.Nestlé, B. Caetano, B.Alegre, Castelo de Paiva, Esmoriz, Espinho, Fajões, Espinhenses, Estarreja, Feira, Mealhada, Murtosa, Lourosa, Oliveira de Azeméis, Oliveira do Bairro, Pampilhosa, Sever do Vouga, Ovar, Vagos, São João da Madeira, Vale de Cambra, Águeda and Ílhavo.

The Social Security is the central service of the administration of the State. It creates, coordinates and supports the social regimes. The Social Security is a very relevant source of information in what financial support for stroke patients and caregivers concerns. The district of Aveiro holds 24 local units of the Social Security, some of them temporary (situation for the day 5 February 2014).

Physiotherapy clinics are private entities developing their activities often through a model of service contracting with the State. Typically, the State regulates, delivers and finances services, however, this classic model has been fading away with insufficient means to both, investing in equipment and providing services (Barros & Gomes, 2002). At the same time, and in order to be effective, the contracting parties need to create a control system of the patient flow with supporting information system, and guarantee qualified human resources to gain competitive advantage (Barros & Gomes, 2002). The payment system is predominantly retrospective.

Religious entities, independently of the faith, are recognized as for their power to bring support and spiritual carefulness. There is also evidence they can provide material and financial support for persons in need.