Universidade de Aveiro Secção Autónoma de Ciências da Saúde
2015

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INSTITUTO DE CIÊNCIAS BIOMÉDICAS ABEL SALAZAR
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ANA LUÍSA BALONAS BARBOSA

APOIO A CUIDADORES FORMAIS DE PESSOAS COM DEMÊNCIA: OS EFEITOS DE UMA INTERVENÇÃO PSICO-EDUCATIVA

SUPPORTING DIRECT CARE WORKERS CARING FOR PEOPLE WITH DEMENTIA: EXPLORING THE EFFECTS OF A PSYCHO-EDUCATIONAL INTERVENTION

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Tese apresentada à Universidade de Aveiro para cumprimento dos requisitos necessários à obtenção do grau de Doutor em Gerontologia e Geriatria, realizada sob a orientação científica da Doutora Daniela Maria Pias Figueiredo, Professora Adjunta na Escola Superior de Saúde da Universidade de Aveiro, e coorientação da Doutora Liliana Xavier Marques de Sousa, Professora Auxiliar com Agregação no Departamento de Educação da Universidade de Aveiro e do Professor Michael Robert Nolan, Professor Catedrático na Universidade de Sheffield.

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Dedico este trabalho aos meus pais.

o júri

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agradecimentos

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palavras-chave

ajudantes de ação direta, cuidado centrado na pessoa, demência, estruturas residenciais, intervenção psicoeducativa

resumo

A necessidade de prestar cuidados mais centrados na pessoa a um crescente número de pessoas com demência admitidas em estruturas residenciais tem sido amplamente reconhecida. Os cuidados nestas estruturas tendem a ser prestados por ajudantes de ação direta que apresentam elevados níveis de *stress*, exaustão e insatisfação profissional. A insuficiente formação na demência, a sobrecarga de trabalho ou ausência de uma liderança suportiva, representam alguns dos fatores com impacto no seu bem-estar emocional, podendo comprometer a prestação de cuidados centrados na pessoa.

As intervenções psico-educativas, ao integrar informação acerca da doença e apoio emocional, podem ter efeitos benéficos no bem-estar dos ajudantes de ação direta e na prestação de cuidados, todavia, esta abordagem tem sido pouco estudada junto de cuidadores formais. Assim, o presente trabalho teve como objetivo desenhar, implementar e avaliar uma intervenção psico-educativa, baseada no cuidado centrado na pessoa, para ajudantes de ação direta que cuidam de pessoas com demência em estruturas residenciais. Especificamente, este estudo experimental visou avaliar a eficácia da intervenção: (i) no *stress* percebido, exaustão e satisfação profissional dos ajudantes de ação direta; (ii) nos comportamentos comunicacionais dos ajudantes de ação direta; (iii) na qualidade das interações dos ajudantes de ação direta com as pessoas com demência. Adicionalmente, foram analisados os efeitos a médio prazo da intervenção e realizado um estudo qualitativo acerca dos fatores relevantes para o seu (in)sucesso.

O presente estudo envolveu um desenho do tipo pré-teste pós-teste com grupo de controlo. Quatro estruturas residenciais foram aleatoriamente alocadas ao grupo experimental (intervenção psico-educativa) ou de controlo (intervenção educativa). Os dados foram recolhidos antes, duas semanas e seis meses após a intervenção através de instrumentos de autopreenchimento, vídeo-gravação dos cuidados manhã e entrevistas semiestruturadas.

Os resultados sugerem um impacto limitado mas promissor da intervenção junto dos ajudantes de ação direta. Observou-se uma redução dos níveis de exaustão e resultados modestos mas positivos em vários comportamentos comunicacionais (por exemplo, envolvimento e riso). No entanto, não se observaram resultados significativos ao nível do *stress* percebido e satisfação profissional, verificando-se um declínio aos seis meses em ambas as variáveis. Vários fatores foram apontados como inibidores ou facilitadores do impacto e sustentabilidade da intervenção, incluindo: a natureza da própria intervenção; o contexto organizacional; as atitudes e comportamentos dos ajudantes de ação direta e da liderança; e o nível de dependência das pessoas com demência.

Os resultados deste estudo oferecem dados preliminares acerca da eficácia das intervenções psico-educativas junto de ajudantes de ação direta e informação relevante para o seu desenvolvimento futuro. Destacam a importância de ver estas iniciativas como um importante estímulo para a mudança, sugerindo a necessidade de ampliar o seu foco às pessoas com demência, seus familiares, organização e sociedade de forma a alcançar mudanças mais consistentes e positivas na qualidade dos cuidados.

keywords

direct care workers, person-centred care, dementia, aged-care facilities, psychoeducational intervention

abstract

There is widespread recognition of the need to provide more person-centred care to the increasing number of people with dementia being cared for in aged-care facilities. The bulk of this care is provided by direct care workers who experience high levels of stress, burnout and job dissatisfaction. Inadequate training in dementia care, high workload or a non-supportive leadership, have been shown to negatively impact these workers' emotional wellbeing and to compromise the provision of person-centred care. Psycho-educational interventions, by including both illness-specific information and support for stress-reduction, can benefit care workers and care provision, yet, there has been little attempt to examine the effects of such interventions in the context of formal caregiving. Thus, the purpose of this study was to design, implement, and evaluate a person-centred care-based psycho-educational intervention for direct care workers caring for people with dementia in aged-care facilities. Specifically, this experimental study aimed to assess the effects of the intervention on direct care workers: (i) perceived stress, burnout, and job satisfaction; (ii) person-centred communicative behaviours; (iii) and quality of interactions with residents with dementia. Also, the medium-term efficacy of the intervention was assessed, and a qualitative study of the factors that were relevant to the success or failure of the intervention was undertaken.

A pretest-posttest control group design was used. Four aged-care facilities were randomly assigned to an experimental group (psycho-educational intervention) or control group (education-only intervention). Data were gathered at baseline, two weeks and six months after the intervention, through self-administered instruments, video-recordings of morning care routines and semi- structured interviews.

Results suggested limited although promising support for the impact of a psycho-educational intervention on direct care workers. There was evidence that the intervention could assist in reducing these workers' burnout and modest positive findings were found on several person-centred communicative behaviours (e.g., involvement and laugh). However, the study did not confirm the efficacy of the intervention on perceived stress and job satisfaction, with a decline in six month follow-up being noticed for both variables. Several factors were reported to inhibit or facilitate the impact and sustainability of the intervention, including the: nature of the intervention itself; the organisational context; care workers and managers' attitudes and behaviours; and residents' level of disability.

The results of this study provide preliminary evidence of the effectiveness of psycho-educational interventions on direct care workers and provide indications of how these might be developed in the future. Findings highlight the importance of seeing these initiatives as an important stimulus for change but are also suggestive of the need to broaden their focus to include residents, residents' family, organisational and societal factors in order to achieve more positive and long-lasting changes in the quality of care.

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List of Abbreviations

AD - Alzheimer’s disease
BPSD - Behavioural and psychological symptoms of dementia
DCW - Direct care worker
DGS - Global Deterioration Scale
DSM - Diagnostic and Statistical Manual of Mental Disorders
FAST - Functional Assessment Staging
GBS – Global Behaviour Scale
MBI - Maslach Burnout Inventory
MMSE - Mini-Mental Status Examination
MSP- Malignant Social Psychology
MSQ - Minnesota Satisfaction Questionnaire
PCC - Person-centred care
PE - Psycho-educational
PPW – Positive Person Work
PSS - Perceived Stress Scale
RCT – Randomised controlled trial

General introduction

Introduction[1]

The impetus to improve the quality of care for an increasing number of older people with dementia is challenging care facilities to move beyond the deep-rooted biomedical model and embrace a person-centred approach to care.

The relationship between the person with dementia and the direct care worker (DCW) - responsible for the majority of paid care in aged-care facilities - is pivotal to the experience of person-centred care (PCC). However, DCWs face significant stress, burnout and job dissatisfaction, which are known to create a disruption in the worker-resident relationship and hinder the delivery of quality care (Edvardsson, Fetherstonhaugh, McAuliffe, Nay, & Chenco, 2011; Gray-Stanley & Muramatsu, 2011)[2].

Educational interventions for DCWs are often suggested as key to raising standards of care and so they have been widely promoted (Fossey et al., 2014). Whilst the improvement of DCWs' technical expertise has been confirmed (Edvardsson, Winblad, & Sandman, 2008; Fossey et al., 2014), education-alone has shown to be insufficient to minimize their levels of stress, burnout and job dissatisfaction (Barbosa, Sousa, Nolan, & Figueiredo, 2014; van den Pol-Grevelink, Jukema, & Smits, 2012). The philosophy of PCC emphasizes that if workers are to deliver such care they need to have their own needs acknowledged and addressed (Brooker, 2007; Kitwood, 1997), however there has been little attempt to respond to their emotional and psychological needs.

This thesis seeks to address this gap. Supported by a grant from the Portuguese Foundation for Science and Technology, it aims to develop, implement, and evaluate a psycho-educational (PE) intervention for DCWs caring for people with dementia in aged-care facilities. PE - a distinct type of intervention that integrates both education and emotional support aiming to relieve participants' stress and prevent burnout (Lukens & McFarlane, 2004) - has evidenced efficacy with informal carers of people with dementia (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003; Gallagher-Thompson & Coon, 2007; Guerra, Mendes, Figueiredo, & Sousa, 2012; Losada, Montorio, Izal, Marquez, & Perez, 2004), but remains largely underdeveloped within the formal care context. By preparing DCWs to deal with their emotionally demanding job, PE holds

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[1] The present thesis is written in British English. However, in some chapters the American English has been used to meet the journals' recommendations.

[2] Cited publications are referred in this thesis according to the 6th edition of the American Psychological Association style (APA). However, the reader can notice inconsistencies along the text, as in the papers comprising this work the referencing style has to meet the journals' recommendations.

promise as a means of driving forward benefits for DCWs and care provision. It is therefore expected that this study will have both important research and practice implications.

This general introduction provides a broad background to the research that was conducted throughout the course of this study. It presents an overview of dementia, looking at what dementia is, the differential diagnoses and describing its main causes and available treatments. Then, it discusses the changes that are occurring in the provision of long-term care to people with dementia, and provides a description, particularly focused on the Portuguese context, of the aged-care facilities and the DCWs' profile. This is followed by a detailed consideration of the theoretical framework upon which this thesis is based – the person-centred care (Kitwood, 1997). Using this framework the importance of a supportive social environment for the person with dementia is highlighted. The main findings and limitations of the existing PCC-based educational interventions are summarised and the significance of PE interventions addressed. It ends by stating the objectives and main structure of the thesis.

1. Dementia: significance, definition and epidemiology

1.1. A world in transition

Over the last century the world has been undergoing profound shifts in its population age structure (*demographic transition*). Given the falling birth rates and rising life expectancy, population ageing is the most predictable of all the major changes that society will experience in the first half of the twenty-first century (World Health Organization, 2011). By 2030, and for the first time in human history, there will be more people over 65 years than children (aged 0–14 years) worldwide (World Health Organization, 2011). The rising life expectancy within the older population itself is increasing the number and proportion of the *oldest old* (people aged 85 or older) which already accounts for eight percent of the world's 65-and-over population (World Health Organization, 2011).

This global *demographic transition* has been accompanied by an *epidemiological transition*, with a shift from the predominance of infectious, acute diseases to non-communicable or chronic diseases (Harris, 2013). Dementia is one of the most daunting chronic conditions and numbers are likely to increase significantly due to ever-longer life expectancies. Globally, it was estimated that 35.6 million people suffered from dementia in 2010 and this is projected to nearly double every twenty years, to 65.7 million in 2030 and 115.4 million in 2050 (World Health Organization, 2012). Despite different inclusion criteria, several meta-analyses and nationwide surveys have yielded similar age-specific prevalence of dementia (Prince et al., 2013). Prevalence of dementia rises sharply with age; it doubles approximately every 5 years after the age of 65 (Prince et al., 2013). Nearly two-thirds of all dementia cases in the world live in low- and middle-income countries (Figure 1). Among developed nations, approximately 1 in 10 older people are affected by some degree of dementia, whereas more than one third of the oldest old may have dementia-related symptoms and signs. Although it mainly affects older people, it is estimated that between 2% and 10% of all cases of dementia start before the age of 65 years (World Health Organization, 2012).

While there have been no comprehensive prevalence studies on dementia conducted in Portugal, the EuroCoDe study, based on 2006 Census of Population in Portugal, suggests that there are currently close to 153.000 people with dementia in the country (Reynish et al., 2006).

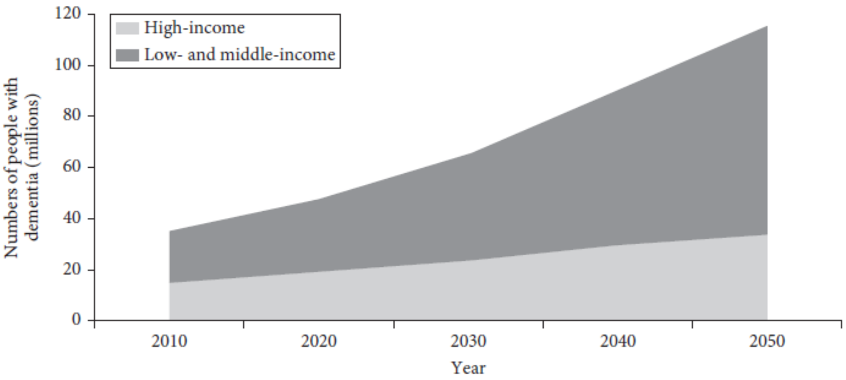


Figure 1. Numbers of persons with dementia in high-income and low and middle-income countries. Reprinted from “Dementia: A Public Health Priority” by World Health Organization & Alzheimer’s Disease International, 2012, World Health Organization

1.2. Defining dementia, its causes and symptoms

Clinicians often refer to the Diagnostic and Statistical Manual of Mental Disorders (DSM) to guide them in determining if an individual has dementia and, if so, the condition causing it.

The fourth edition of DSM (DSM-IV) (American Psychiatric Association, 1994) described dementia as a syndrome characterized by impairment in memory and one other cognitive domain (aphasia, apraxia, agnosia or disturbance in executive functioning). These deficits represent decline from a previous functional level and are sufficiently severe to compromise activities of daily living. This definition, published in 1994, became internationally influential in defining dementia and its subtypes. However, two main limitations have been recently acknowledged, providing an impetus to re-examine the terminology and the criteria: (i) the term 'dementia' has become equated with Alzheimer's disease (AD) in the minds of lay people and policymakers; in the case of cognitive impairment due to another cause (e.g., human immunodeficiency virus infection), the term dementia is considered pejorative and stigmatizing; and (ii) the inclusion of memory impairment as a necessary criterion in the definition of dementia is considered as an *Alzheimerization*; memory impairment is not necessarily a feature of other causes of dementia (e.g., Frontotemporal dementia) (Dening & Thomas, 2013).

In the latest edition of the DSM-5 (American Psychiatric Association, 2013) dementia is subsumed under the newly named entity *major neurocognitive disorder*. To meet criteria for a *major neurocognitive disorder,* an individual must present significant cognitive decline in one or more cognitive domains (attention, executive abilities, learning and memory, language, visuo-constructional and perceptual motor ability, and social cognition) and the decline must interfere with independence in everyday activities (e.g., assistance may be needed with complex activities, such as managing medications) (American Psychiatric Association, 2013). To acknowledge continuity in cognitive dysfunction, DSM-5 recognises a less severe level of cognitive impairment, *mild neurocognitive disorder.* To meet the criteria for *mild neurocognitive disorder* (frequently reported as *mild cognitive impairment*), an individual must present modest cognitive decline in one or more cognitive domains, but the decline does not interfere with activities of daily living (American Psychiatric Association, 2013). This can be considered an intermediate stage and research has shown that individuals who fit this profile have an increased risk of developing dementias in subsequent years (Petersen, 2004). However, given the historical legacy and wide recognition, the term 'dementia' has been used in the present thesis.

Cognitive decline may not be sufficient to explain the functional disability in people with dementia. "Behavioural and psychological symptoms of dementia" (BPSD), as designated by the International Psychogeriatrics Association (Finkel, 2000), are common, affecting 90% of people with dementia at some time during the course of their illness. The most common symptoms are affective syndromes (depression, anxiety, and irritability), apathy, agitation, aggression, psychosis (delusions and hallucinations) and disorders of sleep (McKeith & Cummings, 2005; Petrovic et al., 2007; Finkel, 2000). BPSD can result in suffering, premature institutionalization, increased costs of care, and significant loss of quality of life for patients and their families and caregivers (McKeith & Cummings, 2005; Finkel, 2000). However, despite their significance, neither DSM-5 nor any other diagnostic nomenclature provides a structured approach to identifying the degree or type of BPSD.

The specific symptoms experienced by the person are dependent on the brain pathology that is causing dementia. The reported frequency of dementia due to potentially reversible causes varies from 0 to 23% (Tripathi & Vibha, 2010); the remaining are degenerative and progressive. The most common irreversible cause of dementia is AD, accounting for 50 to 75% of all cases (World Health Organization, 2012). Other common causes include vascular dementia, frontotemporal dementia, dementia with Lewy bodies and Parkinson’s disease. Each of these diseases is briefly described in Table 1. Increasing evidence from long-term observational and autopsy studies indicates that many people with dementia have mixed dementia, i.e., brain abnormalities associated with more than one cause of dementia (World Health Organization, 2012).

Table 1. Main causes and characteristics of Dementia (Alzheimer's Disease International, 2013; World Health Organization, 2012)

Causes	Early symptoms	Neuropathology	Proportion of dementia cases
Alzheimer’s disease	Difficulty remembering recent conversations, names or events Apathy Depression Gradual onset	Accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons, accompanied by the damage and death of neurons	50-75%
Vascular dementia	Impaired judgment or impaired ability to make decisions, plan or organize Physical frailty Stepwise onset	Blood vessel blockage or damage leading to infarcts (strokes) or bleeding in the brain	20-30%
Frontotemporal dementia	Marked changes in personality and behaviour Difficulty with producing or comprehending language Most people develop symptoms at age of 60	Nerve cells in the frontal and temporal lobes of the brain are especially affected, and these regions become markedly atrophied (shrunken)	5-10%
Dementia with Lewy bodies	Marked fluctuation in cognitive ability Visual hallucinations Parkinsonism (tremor and rigidity)	Accumulation of Lewy bodies (abnormal aggregations, or clumps, of the protein alpha-synuclein) that accumulate in the neurons from the cortex	<5%
Parkinson’s disease	Problems with movement (slowness, rigidity, tremor and changes in gait).	Alpha-synuclein aggregates are thought to cause degeneration of the nerve cells that produce dopamine	10%

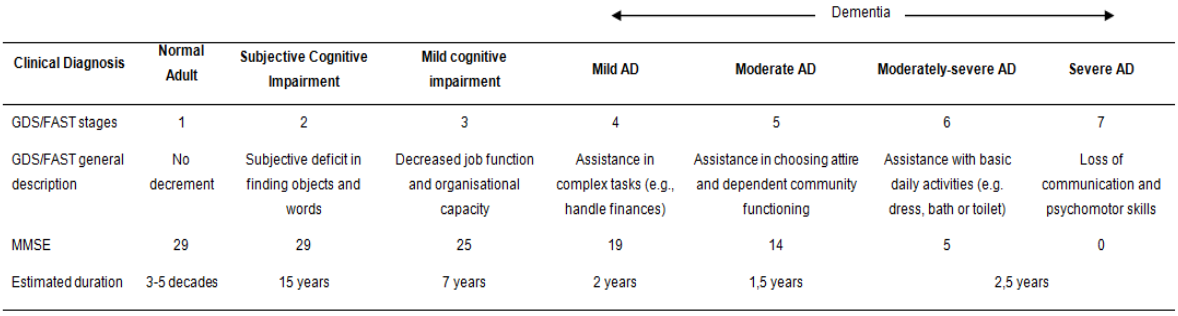
An early diagnosis of dementia and its subtype should be supported by a careful neuropsychological assessment, a history from the patient (subjective impairment in memory and other cognitive functions) and from a key informant (objective signs suggestive of cognitive decline, and evidence of impact on social and/or occupational functioning) (American Psychiatric Association, 2013). Neuroimaging is used to exclude other organic causes of cognitive impairment and to provide information supporting definition of subtype. Also, laboratory tests may be done to eliminate other causes of cognitive changes, such as thyroid disease, vitamin deficiencies or infection. Dementia diagnosis provides access to a pathway of evidence-based treatment, care and support across the disease course; however, research shows that most people currently living with dementia have yet to receive a formal diagnosis (Alzheimer's Disease International, 2011).

1.3. Time course and stages of dementia

The typical time course attributed to dementia has been originally elaborated for AD. However, it is increasingly apparent that several non-AD dementias might present similar clinical stages (Burns & Winblad, 2006).

AD features are often classified into three main stages or phases – mild, moderate or severe - based on scores of global rating scales including, the Global Deterioration Scale (DGS) (Reisberg, Ferris, & de Leon, 1982), the Functional Assessment Staging (FAST) (Reisberg, 1988) and the Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975). The mild stage is characterised by very minor changes in the person's abilities or behaviour, which are often mistakenly attributed to the normal process of ageing (e.g., becoming forgetful, especially regarding things that just happened; becoming lost in familiar places or having difficulty carrying out complex household tasks). In the moderate stage, limitations become clearer and more restrictive; the person is likely to become increasingly forgetful, to need help with personal care, to have increasing difficulty with communication and to display escalated behaviour changes, such as wandering or hallucinations. The last stage is one of nearly total dependence and inactivity; all cognitive functions are severely impaired and the person loses the ability to perform basic activities of daily living (World Health Organization, 2012). Studies indicate that older people survive an average of 4 to 8 years after a diagnosis of AD, yet some live as long as 20 years with the disease (World Health Organization, 2012). On average, a person with AD will spend more years (40 % of the total number of years with AD) in the most severe stage of the disease than in any other stage (Figure 2).

Although the use of stages might be a useful way of understanding the changes that occur over time, it must be noted that they only provide a rough guide to the course of the disease; symptoms may be sporadic or persistent, may not be present, or may manifest earlier or later than indicated.



Dementia

Clinical Diagnosis	Normal Adult	Subjective Cognitive Impairment	Mild cognitive impairment	Mild AD	Moderate AD	Moderately-severe AD	Severe AD
GDS/FAST stages	1	2	3	4	5	6	7
GDS/FAST general description	No decrement	Subjective deficit in finding objects and words	Decreased job function and organisational capacity	Assistance in complex tasks (e.g., handle finances)	Assistance in choosing attire and dependent community functioning	Assistance with basic daily activities (e.g. dress, bath or toilet)	Loss of communication and psychomotor skills
MMSE	29	29	25	19	14	5	0
Estimated duration	3-5 decades	15 years	7 years	2 years	1,5 years	2,5 years	

Figure 2. Typical time course of functional loss in normal ageing and Alzheimer's disease. Adapted from "Severe Dementia" by A. Burns & B. Winblad, 2006

1.4. Management of dementia

There is currently no cure for the majority of types of dementia. Yet, pharmacological management aimed at slowing the progression of the symptoms and the provision of health and social care can improve the lives of people with dementia and their caregivers. The type of care required depends on the severity of the dementia, with health and social care ideally moving through the various stages as a seamless process (Moïse, Schwarzinger, & Um, 2004) (Figure 3).

At the early stages of dementia the emphasis is placed on managing and living well with the diagnosis (Moïse et al., 2004). This includes assisting people and caregivers, when available, to become more knowledgeable about and to develop basic skills in managing the condition. Clinical management for early-stage dementia follows general healthcare strategies for age-based norms: encourage physical activity, a well-rounded diet, adequate sleep, and management of co-morbid chronic conditions, such as cardiovascular diseases. As the condition progresses past the early to the middle stage, clinical management focuses on maintaining dignity and as much independence as possible (Moïse et al., 2004). Worsening symptoms and behaviours render the role of the caregiver particularly difficult; thus, the clinical management aims at relieving or eliminating BPSD. It is widely recognised that treatment approaches to BPSD need to reflect the range of possible causes of these symptoms - physical, social, environmental or psychological. While good practice recommendations, such as the NICE-SCIE Dementia Guideline (National Institute for Health and Clinical Excellence (NICE), 2007), urge non-pharmacological management as a first-line intervention, in practice, this is rarely attempted. The use of pharmacotherapy tends to be the first clinician’s choice of treatment, despite the modest evidence of its efficacy and significant side effects such as Parkinsonism, falls, accelerated cognitive decline or increased cerebrovascular events (Ballard & Waite, 2006). Once dementia has progressed beyond the middle stage, social care aspect becomes the dominant feature of dementia care. People require full support with activities of daily living, requiring more professional caregiving and, for the majority, admission to a long-term care institution (Moïse et al., 2004).

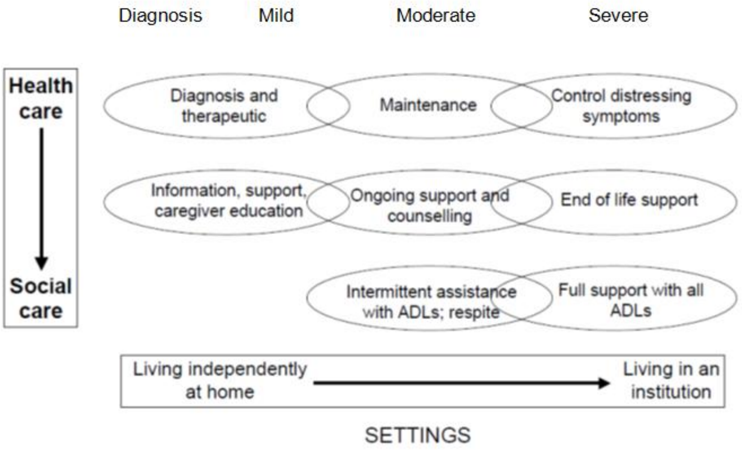


Figure 3. Care continuum for people with dementia. Adapted from “Dementia Care in 9 OECD Countries: A Comparative Analysis” by P.Moïse, M. Schwarzinger, & M. Um, 2004. Notes: ADLs = Activities of Daily Living.

A range of non-pharmacological strategies are available for each stage of dementia (Cooper et al., 2012; Testad et al., 2014). In the early stages, these interventions focus on training in cognitive skills to enhance current function, with the goal of delaying or preventing future cognitive decline. For people with moderate to severe dementia, the goals are to optimize and extend cognitive and functional skills for the longest possible period. Four major types of non-pharmacological interventions can be found in the literature: behaviour-oriented, stimulation-oriented (e.g., multisensory stimulation), emotion-oriented (e.g., validation and reminiscence therapies) and cognitive-oriented (e.g., cognitive, training or rehabilitation stimulation) (American Psychiatric Association, 2007). Although the evidence for these is mixed, the emergence of such interventions denotes a move towards more person and relationship-centred forms of care (Kitwood, 1997; Nolan, Davies, Brown, Keady, & Nolan, 2004). Within these approaches, greater attempts are made to understand the individual's experience of dementia and to employ strategies to improve the person's quality of life and that of their carer.

2. Dementia and aged-care facilities

2.1. The changing picture of long-term care

As the population ages and more people live longer with chronic conditions, the demand for long-term care services (i.e., types of assistance provided to people with functional or cognitive limitations to help them perform routine daily activities) will rise dramatically (World Health Organization, 2011).

Long-term care may be provided in several different forms and venues. The largest percentages of older persons needing long-term care services still rely on informal care (i.e., care provided by unpaid caregivers, usually family members, friends, neighbours or volunteers) (Moïse et al., 2004; Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000; Stone & Wiener, 2001). *Ageing in place* is often preferable (and less expensive) than being uprooted from one's home and placed in a care facility. Thereby, supports (such as in-home care) to extend community living are widely promoted (World Health Organization, 2011).

However, there is increasing recognition that recent social trends are challenging the availability of informal caregivers to care (Moïse et al., 2004; Pickard, et al., 2000; Stone & Wiener, 2001). Declining family size, higher divorce rates, rising female participation in the formal labour market, rising childlessness and changing living arrangements, with decreased co-residence of elderly with their families, are likely to have an effect on informal care provision, contributing to its uncertainty (Moïse et al., 2004; Pickard et al., 2000). With the potential decline in informal care, it is expected that the demand for formal care services, particularly aged-care facilities, will markedly increase (Moïse et al., 2004).

Dementia is the leading chronic disease contributing to disability and dependence among older people worldwide (affecting around one half of all care dependent older people) (Alzheimer's Disease International, 2013) and the strongest predictor of admission to aged-care facilities (Argimon, Limon, Vila, & Cabezas, 2005; Luppa, Luck, Brahler, Konig, & Riedel-Heller, 2008; Matthews & Dening, 2002; Verbeek et al., 2015). The severity of dementia, the presence of BPSD, including agitation, depression and hallucinations, and the informal caregivers' burden are the most important determinants for moving into these long-term care facilities (Luppa et al., 2008; Verbeek et al., 2015). According to the Alzheimer's Disease International (Alzheimer's Disease International, 2013), the mean proportion of people with dementia from high income countries living in institutions is 34%. Studies have indicated that up to 90% of the occupants of aged-care facilities in OECD countries have dementia, two-thirds of which have moderate or severe dementia (Alzheimer's Disease International, 2013). During these stages, informal caregivers' burden is amplified and this jeopardizes the viability of continued home care (Hebert, Dubois, Wolfson, Chambers, & Cohen, 2001).

With most signs pointing to a diminishing pool of informal caregivers, the pressure to admit people with dementia into aged-care facilities is expected to increase. Providing care to people with dementia must be the primary concern of the care home sector.

2.2. An overview of Portuguese aged-care facilities

In Portugal, the extended family plays a key role in the care of older and dependent people (Sousa & Figueiredo, 2007). However, given the above-mentioned societal trends this situation is changing, with formal care services assuming a critical role in care provision.

The large majority of support services for older and dependent people exist within the Social Security system. The number of for-profit actors in the market is increasing, but the main providers so far have been the Private Non-profit Institutions of Social Solidarity (IPSS – *Instituições Particulares de Solidariedade Social*), mostly in conjunction with protocols established with the Social Security (Moïse et al., 2004). IPSS offer a number of social care services, including care home, day care and home support. As there are few facilities specifically developed to support people with dementia, these individuals tend to be cared for in aged-care facilities that provide collective housing for temporary or permanent use, meals, health care and leisure activities (Ministério da Solidariedade, Emprego e Solidariedade Social, 2013).

Out of 7.400 social care services for older people, almost 2.500 consist of aged-care facilities (Ministério da Solidariedade, 2013). Their size varies considerably, but the average number of available beds is 40. At the head of each IPSS is the administrator (the person or company responsible for management and administrative operations). Typically below the administrator is the care-home or middle manager (a qualified professional who supervises direct care workers, oversees residents' care and performs administrative functions, such as record keeping and budgeting). The frontline workers, the vast majority of which are direct care workers (DCWs)[3], are supported by a small number of part-time nurses, doctors, physical or occupational therapists.

Of all people living in aged-care facilities, 71% are more than 80 years old, 47% of which are 85 years or more (Ministério da Solidariedade, 2013). While no formal data exist, anecdotal accounts suggest that the numbers of people with dementia may be similar to those reported in the international literature.

2.3. Direct care workers – the key to quality

Direct care workers (DCWs) represent the largest component of the long-term care workforce, being often referred to as the "eyes and the ears" of the care system (Stone, 2012). Among other tasks, these workers are responsible for helping frail and disabled older adults perform the most basic activities of daily life, such as bathing, dressing, toileting, and eating. As residents spend the majority of their time with the DCWs, these workers are also their primary source for communicative interaction, and are therefore essential to achieving quality of care and to preserving care recipient's quality of life (Stone, 2012).

It is recognised that DCWs around the world share common characteristics (Fujisawa & Colombo, 2009; Harris-Kojetin, Lipson, Fielding, Kiefer, & Stone, 2004; Stone, 2012). The overwhelming majority are middle-aged women, have low levels of educational attainment and experience low-job quality as a result of a physically and mentally demanding occupation (Fujisawa & Colombo, 2009; Harris-Kojetin et al., 2004; Stone, 2012).

They have a low-wage job, being among the lowest paid in the service industry and making little more than the minimum wage. Even though DCWs provide most of the hands-on care, they lack opportunity for meaningful input into residents' care planning,

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[3] DCWs may be called under different names in different countries, for example, nursing aides or care assistants.

and they often receive inadequate recognition and appreciation by families, residents, or employers. They often have to work with less than the scheduled number of DCWs for a given shift, and working hours are frequently long and irregular. Adding to this, available evidence suggests that DCWs lack the understanding, education and training that is needed to work in this complex and rapidly changing environment, particularly with the increased number of people with dementia (Fujisawa & Colombo, 2009; Harris-Kojetin et al., 2004; Stone, 2012). Overall, these work-related demands can be divided into three groups (Cohen-Mansfield, 1995): (i) the *institutional level*, relating to the functioning of the workplace as a whole and to all employees; (ii) the *unit level*, relating to the interaction between the individual worker and immediate co-workers in his or her unit; and (iii) the *resident level*, relating to the interaction between the worker and the individual residents (and their families) and the specific types of work done (Table 2).

Many scholars contend that the interaction of all these factors is related to high rates of DCWs' perceived stress, burnout and job dissatisfaction (Cohen-Mansfield, 1995; Edberg et al., 2008; Gray-Stanley & Muramatsu, 2011; Zimmerman et al., 2005). This is a major problem that accounts for DCWs' turnover, absenteeism, low morale and an overall lower quality of care (Cohen-Mansfield, 1995; Edberg et al., 2008; Gray-Stanley & Muramatsu, 2011; Moniz-Cook, Woods, & Gardiner, 2000; Zimmerman et al., 2005).

Table 2. Work-related demands for DCWs

Stressors
Institutional factors (Baillon, Scothern, Neville, & Boyle, 1996; Cohen-Mansfield, 1995; Hasson & Arnetz, 2008; Redfern, Hannan, Norman, & Martin, 2002)
• Policies (inadequate salary; infrequent positive reinforcement; few benefits and promotional opportunities; lack of training to work with people with dementia)
• Communication patterns (lack of participation in policy decisions)
• Staffing (inadequate staff cover; workload)
Unit factors (Cohen-Mansfield, 1995; Gray-Stanley & Muramatsu, 2011; Redfern et al., 2002)
• Physical environment
• Social climate (poor interpersonal relations with staff)
• Role definition (role ambiguity)
• Leadership style (lack of emotional support; inadequate supervisory competence)
Resident factors (Baillon et al., 1996; Cohen-Mansfield, 1995; Miyamoto, Tachimori, & Ito, 2010)
• Disability (type of disability; BPSD; death)
• Relationship with resident and the family
• Specific work (heavy lifting)

Direct care workers' perceived stress, burnout and job dissatisfaction

Stress is commonly defined as a physiological and psychological response to a demand or challenge leading to arousal and mobilisation of an individual's capacity for coping (Selye, 1976). Specifically, job-related stress is the condition in which some factor or combination of factors (Table 2) at the workplace interacts with the worker to disrupt his or her psychological or physiological homeostasis (Cohen-Mansfield, 1995). In terms of its impact on the individual, several domains are often affected: physiological (fatigue, frequent headaches or sleep disturbances), emotional (e.g., fear, frustration, depression), cognitive (difficulty in concentrate or feeling of losing control) and behavioural (impulsiveness or isolation) (Cohen-Mansfield, 1995). For the workplace, the impact of stress is manifested by deteriorated quality of care, greater absenteeism, tardiness, and higher turnover, which in themselves affect morale and constitute sources of stress to other workers and residents (Cohen-Mansfield, 1995; Edberg et al., 2008; Gray-Stanley & Muramatsu, 2011; Moniz-Cook et al., 2000; Zimmerman et al., 2005).

Burnout is a concept commonly used to describe the workers' response to chronic stress. The most widely accepted conceptualization originates from the work of Maslach and Jackson (1986), who consider burnout as an ongoing emotional state, characterized by the three dimensions of emotional exhaustion, depersonalization and reduced personal accomplishment. Emotional exhaustion refers to feelings of being emotionally overwhelmed at work and having depleted energy levels. Depersonalization is believed to be related with feelings of cynicism and detachment from the job. The third dimension of reduced personal accomplishment refers to a sense of ineffectiveness and lack of accomplishment (Maslach & Kackson, 1986). These dimensions also comprise the three subscales of the Maslach Burnout Inventory (MBI) (Maslach, Schaufeli, & Leiter, 2001), which is the most frequently used instrument to assess burnout.

Job satisfaction is the affective orientation that an employee has towards his or her work (Spector, 1997). Job satisfaction has been conceptualised and operationalised as both a global and a multifaceted construct. The global approach is used when the overall attitude is of interest, while the multifaceted approach is used to explore which parts of the job produce (dis)satisfaction. The two-factor theory of job satisfaction postulates that satisfaction and dissatisfaction are two separate and sometimes even unrelated phenomena (Herzberg, Mausner, & Snyderman, 2011). Intrinsic factors, named 'motivators' (i.e., factors intrinsic to the nature and experience of doing work), were found to be job 'satisfiers' and included: achievement, recognition, work itself and responsibility.

Extrinsic factors, named hygiene factors, were found to be job *dissatisfiers* and included: company policy, administration, supervision, salary, interpersonal relations and working conditions (Herzberg et al., 2011). Motivation-Hygiene formed a basis for the development of job satisfaction assessment (e.g., the Minnesota Satisfaction Questionnaire).

In general, stress, burnout and job satisfaction have been treated as distinct yet related constructs, strongly associated with the DCWs' behaviour towards residents and the quality of care (Jenkins & Allen, 1998; Moniz-Cook et al., 2000; Todd & Watts, 2005). For instance, Jenkins and Allen (1998) found that DCWs with a higher sense of personal accomplishment were observed to interact more with residents. In the studies conducted by Moniz-Cook, Woods and Gardiner (2000) and Rose and Rose (2005) workers who had higher levels of stress reported greater difficulty in managing residents' challenging behaviour. Todd and Watts (2005) reported that DCWs' burnout was associated with less willingness to help, low optimism and negative emotional responses to residents' behaviour. Although DCWs' wellbeing and satisfaction seem to have a pivotal role in predicting quality of care, it is also plausible that these variables reinforce each other through a mutual feedback system: high quality of care may lead to high DCWs' job wellbeing which may lead to higher quality of care. Considering this, Zimmerman et al. (2005) reported that DCWs who perceived themselves to provide quality of care reported more job satisfaction.

The ageing of the population and increased prevalence of people with dementia in aged-care facilities demands a competent workforce to deliver care. Person-Centred Care (PCC) is now considered synonymous with good quality care and is advocated in good practice guidelines for dementia care (American Psychiatric Association, 2007; National Institute for Health and Care Excellence [NICE] guidelines, 2006), particularly in care home facilities where it can be learned through DCWs' education and support. As the relationship between DCWs and people with dementia is central to PCC, insight is needed into how to create a satisfied and sustainable workforce.

3. Person-centred care: broadening the vision of dementia care

3.1. The evolution of the understanding of dementia

For the past 30 years the understanding of dementia evolved through three distinct moments (Bartlett & O'Connor, 2010). In the first moment, dementia was considered a predictable sign of normal ageing, being largely neglected by services and professionals. In the second moment, which had emerged by the early 1980s, the acceptance of deteriorating cognitive functioning as a sign of normal ageing was increasingly criticised and dementia began to be considered a biomedical condition. This understanding of dementia as a neurodegenerative disorder, assumed a trajectory of irreversible decline related to neuropathological changes. The biomedicalisation of dementia has had important benefits: it has generated scientific research, which has led to more accurate diagnostic practices; and it has endorsed the development of medications for slowing the progression of some of the dementia symptoms (Bartlett & O'Connor, 2010; George, Qualls, Camp, & Whitehouse, 2012). However, using the biomedical model for understanding dementia has also had significant negative consequences: (i) with the focus on the ‘disease’ the tendency is to negate the person behind it; (ii) although changes in the brain do matter, considering neuropathology the only relevant factor to explain the trajectory of the dementia path is increasingly recognised as overly simplistic; and (iii) given its focus on deficits, the person with dementia is defined only by loss and incapability (Bartlett & O'Connor, 2010). Responding to the limitations associated with the biomedical model, a third moment began to emerge in the early 1990s based on a more humanistic or psychosocial approach. This understanding of dementia has been defined by attention to personhood (Kitwood, 1997) .

Tom Kitwood (Kitwood, 1997), one of the most recognised pioneers of this new approach, informed by the work of Martin Buber (1958) and Carl Rogers (1961), defined personhood as: “a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements” (Kitwood, 1997: 7). With this definition, Kitwood stressed the influence of interpersonal relations as an essential aspect for understanding the dementia experience. Rather than assuming a trajectory of irrevocable decline related to neurodegenerative changes, this perspective recognises that performance, behaviour and quality of life are not solely determined by neuropathology but also by psycho-social factors. The interplay of the elements that affect the individual’s response to dementia was expressed by Kitwood (1997) with the following equation:

Dementia = NI (neurological impairment) + H (health) + B (biography) + P (personality) + SP (social psychology)[4]

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[4] Social psychology encompasses the sense that individuals make in their daily interactions.

This understanding of dementia called for a shift toward providing personalised, individualised, and self-deterministic care with an emphasis on the person with dementia. Much of this change in care practice is captured in the term *person-centred care* (PCC)[5].

3.2. Person-centred care in context

For decades, the care provided for people with dementia in aged-care facilities has been largely dominated by a biomedical model (or the "standard paradigm" as defined by Kitwood (1997)). Within this model, residents receive care based on standardized protocols, which overlook their individual needs, preferences, and values; they are often excluded from decision making processes about their lives; and live in an under-stimulated environment, with little emphasis on restorative interactions (Brooker, 2005; Kelly, 2010; Kitwood, 1997).

PCC involves stepping away from this standard care practice applied on a 'one size fits all' basis which is task-centred around physical care and support with activities of daily living, in favour of a broader understanding of dementia, more focused on the individual (Brooker, 2004, 2007; Kitwood, 1997). As an approach to care, PCC does not represent any one technique or therapeutic intervention. Rather, it is a philosophy of care (Brooker, 2004, 2007; Kitwood, 1997), espousing a group of core values focused on the promotion of quality of life and the recognition of the essential humanity of all people.

A number of authors have made an attempt to define the core values of person-centeredness (Brooker, 2004, 2007; McCormack, 2004). Based on an extensive review of the literature, and using the definition of personhood provided by Kitwood, McCormack (2004) argues that there are four main concepts at the heart of PCC: being in relation; being in a social world; being in place; and being with self. Table 3 describes the link made by McCormack (2004) between the four concepts derived from the literature and the components of Kitwood's definition.

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[5] The term has been used alongside others, such as resident/client/patient-centred care. However, according to the author, the later imply a consumer orientation rather than a focus on the uniqueness of the person.

Table 3. Relationship between Kitwood's definition and concepts of person-centeredness made by McCormack (2004)

Concept	Link with Kitwood's definition
Being in relation	Persons exist in relationships with other persons
Being in a social world	Persons are social beings
Being in place	Persons have a context through which their personhood is articulated
Being with self	Being recognised, respected and trusted as a person impacts on a persons' sense of self

Also, Brooker (Brooker, 2004, 2007) breakdowns PCC into four elements, providing what must be the most contemporary understanding of this philosophy of care: (i) affirms the value of the person and of those who care for them; (ii) treats everyone as an individual; (iii) adopts the perspective of the person with dementia; and (iv) provides a supportive social environment. Continuing with the style that Tom Kitwood had for representing information in the form of equations, Brooker (2004, 2007) used the acronym VIPS to abbreviate the above four elements, defining PCC as:

$$PCC= V+ I + P + S$$

Element one is about **v**aluing people throughout the care organisation (Brooker, 2004, 2007). Firstly, PCC seeks to affirm the person as a living human, being focused on the person's strengths, abilities and possibilities rather than on the degree of impairment or illness. This has particular salience for those with moderate to severe dementia; people whose cognitive capacities are severely compromised and functional capacities have diminished, are at higher risk of being prejudice. Hence, an 'inverse-care law' (Watt, 2002) is likely to occur, with people with the most significant degree of cognitive impairment receiving the lowest levels of input in terms of emotional and social support. Also, adopting PCC means to apply the same set of principles to care workers. If the personhood of an individual member of staff is not respected, then she or he in turn will find it difficult to sustain valuing and caring relationships with people with dementia over a sustained period (Brooker, 2004, 2007).

According to the second element, providing PCC requires an **i**ndividualised approach, i.e., the recognition that each person with dementia is a unique individual with his/her own biography, personality, (dis)likes, and social and economic resources (Brooker, 2004, 2007). Each individual‘s uniqueness is promoted through knowledge of the individual‘s needs and preferences, which are incorporated into care so that current ways of living are congruent with past patterns of living (Talerico, O'Brien, & Swafford, 2003). Emphasis is on empowering residents, even those with cognitive impairments, to make their own decisions about their care and activities (White, Newton-Curtis, & Lyons, 2008).

Element three of PCC is about recognising that each person's experience has its own psychological validity, that people with dementia act from this **p**erspective, and that empathy with this perspective has its own therapeutic potential (Brooker, 2004, 2007). It means attending to both mental health and psychological needs. Carrying out structured observations - such as those involved in Dementia Care Mapping (Kitwood, 1997) - can assist in the development of an understanding of the subjective reality of being a person with dementia.

A key contribution of PCC emerges from the fourth element: the recognition that all human life is grounded in relationships and that people with dementia need an enriched **s**ocial environment which both compensates for their impairment and fosters opportunities for personal growth (Brooker, 2004, 2007). In providing PCC, a supportive and nurturing social environment is the means to maintain the personhood of the person with dementia on a daily basis (Kitwood, 1997).

Dementia, relationships and communication

Much of the Kitwood's work was focused on the description of the interpersonal processes involved in care facilities and their impact on the person with dementia (Kitwood, 1997). With his work, Kitwood emphasises the primacy of the DCWs – the residents' primary source for interaction – and their ability to offer more than a mechanistic care.

The author described a variety of ways in which DCWs' interactions with people with dementia may inhibit or promote their personhood. "Malignant social psychology" was the term used to describe a range of careless and thoughtless interactions (or personal detractions) that create negative experiences for the person with dementia (Kitwood, 1997). These are thought to undermine the ability of the person to maintain personhood, leading to emotional distress and increased BPSD (Kitwood, 1997) (Table 4). Conversely, "Positive person work" describes aspects of interaction which are therapeutic and helpful in maintaining the residents' personhood (Kitwood, 1997) (Table 5). The literature shows that although rarely done with malicious intent but rather as part of a cultural inheritance (Kitwood, 1997), episodes of malignant social psychology occur with surprising regularity. Hence, according to previous research, people with dementia, particularly with severe cognitive impairment, are more likely to be disengaged and isolated than their less cognitively impaired counterparts in care facilities, because of their perceived inability to communicate (Hubbard, Cook, Tester, & Downs, 2002; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Crucial opportunities for interaction occur mainly during personal care provision; unfortunately such encounters are often spent in silence and when verbal interactions are present these are predominantly focused on care tasks rather than on person-centred topics (Ward et al., 2008).

Table 4. Malignant Social Psychology by Professor Tom Kitwood (Brooker, 2007; Kitwood, 1997)

Malignant Social Psychology

Accusation: Blaming the person for their actions or inactions when they lack understanding

Banishment: Excluding the person with dementia psychologically, socially and/or physically

Disempowerment: Taking away what powers still remain to the person with dementia

Disparagement: Damaging the self-esteem of the person with dementia

Disruption: Interrupting the person’s concentration as they are engaged in a task or conversation

Ignoring: Having conversations with others in the presence of the person without including them

Imposition: Forcing someone else’s values on the person with dementia

Infantilisation: Patronising or treating and talking to the person as though they were a child

Intimidation: Threatening or physically manipulating the person with dementia to induce fear or anxiety in them

Invalidation: Not giving credibility to the reality of the experience of the person

Labelling: Identification of a person by naming them through their behaviour or condition

Mockery: Making fun of the person with dementia as if they were unaware of what is being spoken about

Objectification: Not treating the person as a sentient being who thinks and feels but rather treating them as though they were an object

Outpacing: Applying pressure for actions faster than the person is capable of doing

Stigmatisation: Labelling the person with dementia as though they were an object or outcast

Treachery: Using deception to distract or manipulate a person with dementia

Withholding: Refusing to meet the needs of the person with dementia

Table 5. Positive Person Work by Professor Tom Kitwood (Brooker, 2007; Kitwood, 1997)

Positive Person Work

Celebration: Celebrating anything the individual finds enjoyable

Collaboration: Care worker aligns him/herself with care recipient to engage in a task

Creation: Allowing creativity to flourish for the person with dementia without seeking control

Facilitation: Enabling the person to use their remaining abilities

Giving: Accepting the person’s concerns, gratitude and affections

Holding: Remaining fully present, especially in stressful times, providing both physical and psychological support

Negotiation: The person is consulted about preferences, choices and needs

Play: Encouraging expressions of spontaneity and of self

Recognition: Using an open and unprejudiced attitude to the person with dementia (e.g., maintain eye contact)

Relaxation: Providing close personal comfort

Timalation: Interacting in a way that is directly pleasurable to the person with dementia (e.g., using senses).

Validation: Acknowledging person’s emotions and feelings and responding to them

Since Kitwood, a growing body of research have been focused on the relational nature of PCC. Anchored in the key contribution of relationships to create excellence in dementia care, Nolan and colleagues (Nolan et al., 2004; Nolan, Davies, Ryan, & Keady, 2008; Nolan, Keady, & Aveyard, 2001) called for a new philosophy of care based on a *relationship-centred approach*. Whilst recognising that each person is unique and has intrinsic worth, relationship-centred care sees people as being primarily interdependent, a value base that recognises the reciprocity that is inherent in relationships (Nolan et al., 2004; Nolan et al., 2008; Nolan et al., 2001). In their “Senses Framework”, the authors suggest that to create and sustain an enriched environment of care, both people with dementia and care workers should experience the following *senses*: (i) security (to feel safe physically, psychologically, and existentially); (ii) belonging (to maintain important relationships and to feel part of a valued group or community); (iii) continuity (to be able to create links between the past, the present, and the future); (iv) purpose (to be able to engage in valued activities, to have something to ensure the meaningful passage of time); (v) achievement (to be able to achieve valued goals, to feel that efforts are valued); and (vi) significance (to feel that who we are and what we do is important to others) (Nolan et al., 2004; Nolan et al., 2008; Nolan et al., 2001).

Underpinning both person and relationship-centred care is the belief that if negative interactions can be identified, appraised, and overcome, then care can be improved and the person with dementia will achieve a greater sense of wellbeing.

3.3. Person-centred education and training interventions

With the emergence of the above-cited frameworks, interest has been geared towards the development of training and educational interventions aiming to encourage and ease communication between DCWs and residents with dementia (Eggenberger, Heimerl, & Bennett, 2013; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010).

In most of these interventions, attention is drawn to the ways in which DCWs can use verbal and non-verbal behaviour to establish relationships with people with dementia (Eggenberger et al., 2013; Vasse et al., 2010). The factors considered important include verbal content and how it should be delivered (e.g., speak clearly and slowly, with short, simple sentences), means of conveying information nonverbally to support verbal expression and reflect empathy with the resident (e.g., maintain eye contact or use touch), and specific non-pharmacological interventions that can be used to sustain communication (e.g., validation or multisensory therapies) (Eggenberger et al., 2013; Vasse et al., 2010).

Much of the published research suggests that PCC-based education and training for DCWs is likely to benefit people with dementia. Lowered agitation and aggression, increased engagement in daily activities, and improved wellbeing have been described (Chenoweth et al., 2009; Fossey, 2006; Sidani, Streiner, & Leclerc, 2012; Sloane et al., 2004). At the same time, research suggests that DCWs' relationship skills can improve, particularly in responding to calls for help, incorporating residents' life stories into the caregiving interaction, and encouraging residents to participate more in personal care activities (Edvardsson et al., 2008; Fossey et al., 2014).

Nevertheless, the impact of PCC-based education and training on DCWs' stress, burnout and job satisfaction is typically overlooked and, when considered, findings have been mixed, neither significant nor long-lasting (Barbosa et al., 2014; van den Pol-Grevelink et al., 2012). Detailed information about the studies exploring this association can be found in the literature review conducted for this study and presented in the next chapter.

From the existing evidence it is clear that education alone is unlikely to be an effective strategy to reduce DCWs' stress, burnout and job dissatisfaction. The addition of stress management tools into existing educational interventions, including strategies to enhance positive self-care behaviours, to manage workload and interpersonal conflicts or to improve team work, might have the potential to better prepare DCWs to deal with their multifaceted role (Edvardsson et al., 2011; Figueiredo, Barbosa, Cruz, Marques, & Sousa, 2013).

The roots and characteristic of psycho-education

Psycho-education (PE) is a distinct type of intervention that integrates and synergises psychotherapeutic and educational interventions (Lukens & McFarlane, 2004). PE has been widely used with family carers of older people with chronic diseases, aiming to reduce their stress and burden, and improve the quality of life and care for the person with the illness (Gallagher-Thompson & Coon, 2007; Guerra et al., 2012; Lukens & McFarlane, 2004; McFarlane, Dixon, Lukens, & Lucksted, 2003). The seminal work in this area began in the late 1970s, with the growing realization that conventional family therapy, in which family dysfunction is assumed and becomes the target of intervention, was ineffective and damaging to patient and carers' wellbeing.

The theoretical support for PE is found in several complementary theories and models: (i) cognitive-behavioural theory, as cognitive-behavioural techniques such as problem solving and role-play are used to enhance the presentation of didactic material and allow participants to acquire new information and skills in a safe setting; (ii) stress and coping models, given that specific attention is placed on the development of stress management and coping strategies to deal with stressful situations; (iii) social learning model, as participants may, for example, be taught to monitor and then increase their level of engagement in pleasant activities or to challenge and modify unhelpful negative thoughts; (iv) and narrative approaches, as participants are encouraged to recount their own stories, which help them to recognize personal strengths (Lukens & McFarlane, 2004).

Usually, PE is carried out in a group format so that within-group dialogue, social learning, expansion of support and cooperation, and network building can occur (Brown, 2011; Lukens & McFarlane, 2004). PE groups are characterised by the brevity of their sessions (8 to 10 weekly sessions) over a short time period (Brown, 2011; Gallagher-Thompson & Coon, 2007; Lukens & McFarlane, 2004). The leaders are not just presenters of information. They are also facilitators, who are responsible for providing opportunities for emotional expression in a safe place, for valuing participants' contributions and encourage them to recognise the importance of their own work and feelings (Brown, 2011).

The efficacy of PE is well established for informal carers of people with dementia, with the existing research suggesting that such interventions have the capacity to reduce carers' burden, decrease levels of depression and anxiety, enhance emotional wellbeing and quality of life, and improve attitudes towards caregiving (Coon et al., 2003; Gallagher-Thompson & Coon, 2007; Guerra et al., 2012; Losada et al., 2004). Although there has been little attempt to examine the effects of such intervention in the context of formal caregiving, the commonalities and intersections of formal and informal care (e.g., both formal and informal caregiving can be equally stressful or overwhelming), suggest that adapting the PE intervention for DCWs holds promise as a means of driving forward benefits for workers and care provision.

4. Objectives and outline of the thesis

4.1. Objectives

The overall aim of this thesis was to develop, implement, and evaluate a PCC-based PE intervention for DCWs caring for people with dementia in aged-care facilities.

First, a systematic literature review was conducted to assess the impact of PCC approaches on stress, burnout and job satisfaction among DCWs providing care for people with dementia in aged-care facilities. A tendency towards their effectiveness was apparent, however, due to the methodological weaknesses and heterogeneity of studies, it was not possible to draw firm conclusions about the efficacy of PCC approaches for DCWs. This review was critical to inform many aspects of the experimental research.

Thus, an experimental study with a pre-posttest control group design was conducted in four Portuguese aged-care facilities, in which the implementation of the PCC-based PE intervention was compared to an educational-only intervention. Specifically, this study aimed to:

(i) Analyse the effects of a PCC-based PE intervention on DCWs' perceived stress, burnout, and job satisfaction;

(ii) Assess the effects of a PCC-based PE intervention on DCWs' verbal and non-verbal communicative behaviours with residents with dementia during morning care;

(iii) Assess the effects of a PCC-based PE intervention on the quality of DCWs' interactions with residents with dementia;

(iv) Assess the medium-term efficacy of the intervention on DCWs' outcomes;

(v) Identify DCWs and managers' perceptions about the factors that were relevant to the success or failure of the intervention.

The four facilities were randomly allocated to the experimental group (PE intervention) and control group (educational-only intervention), after being grouped into clusters of similar staff/resident ratio and proportion of residents with dementia. A total of 58 DCWs entered the study at baseline – 27 in the experimental group and 31 in the control group. Measurements were performed in both groups at baseline, two weeks after the intervention and at six months follow-up.

The design and content of the PCC-based PE intervention was informed by the above-mentioned literature review, findings from a pilot-study conducted in one aged-care facility with six DCWs (Figueiredo et al., 2013), and pre-test interviews with different grades of staff about training and emotional needs and the topics they would like to see included in the intervention[6]. Overall, the intervention consisted of eight 90 minute weekly sessions containing two key-components: educative (aiming to provide DCWs with information concerning dementia and PCC-based interaction strategies) and supportive (aiming to provide DCWs with strategies to cope with work-related stress). Each session followed the same sequence and structure: (i) discussion of the prior session's 'homework' assignment; (ii) overview of the content of the current session; (iii) educative component; (iv) supportive component; and (v) homework assignment to be completed prior to the next session. The sessions were facilitated by a gerontologist (the author) and a physical therapist experienced in leading groups. In the three days following each session, the same professionals assisted each DCW individually during morning care to support the delivery of PCC-based interaction strategies.

It was the absence of the supportive component that distinguished the control from the experimental group. The coordination, length, order and content of the sessions were the same of the educational component of the PE intervention. More detailed description of the interventions can be found in the subsequent chapters of this thesis.

4.2. Outline of the thesis

The main body of this thesis is structured into 6 chapters, reporting on the studies (published or submitted to international indexed journals) that have been conducted throughout the project to accomplish the above objectives (Table 6).

Chapter 1 presents a systematic literature review on the impact of PCC approaches on stress, burnout and job satisfaction among DCWs providing care for people with dementia in care homes. The small number of existing studies, their heterogeneity and methodological weaknesses emphasized the future development of this research area.

Chapter 2 describes the results of a pretest-posttest control group study into DCWs' stress, burnout and job satisfaction. In total, 56 DCWs were included and assessed at baseline and immediately after the intervention through self-administrated instruments and focus-group interviews.

Chapters 3 and 4 present the results of the study on DCWs' person-centred communicative behaviours. Fifty-six DCWs were included and video-recorded during morning care before and two weeks after the intervention. Chapter 4 is concerned with the

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[6] Two qualitative studies concerning this data have been published in conference proceedings and can be find in appendix 1 and 2.

efficacy of the PE intervention on the frequency and duration of DCWs' verbal and non-verbal communicative behaviours; Chapter 5 presents the effects of the intervention on the quality of DCWs' interactions with residents with dementia.

Chapter 5 reports on the medium-term effects of the PE intervention on DCWs' outcomes. In this quantitative study data was gathered from 53 DCWs at baseline, immediately and six months after the intervention, through self-administrated instruments and video-recorded morning care sessions.

Chapter 6 describes the results of an additional qualitative study conducted to obtain more insight into the implementation process of the PE intervention on care facilities.

The thesis ends with the General conclusion where theoretical and methodological considerations are discussed and future directions for research and practice addressed.

Table 6. General description of the studies that comprises the main body of the thesis

	Design	Sample	Data collection	Chapter
Paper I	Systematic literature review	7 studies	Experimental and quasi-experimental studies published in scientific journals indexed in PubMed, Web of Knowledge, Scopus and EBSCO	1
Paper II	Pretest-posttest control group, mixed methodology	n= 56 DCWs	(1) Self-rated instruments: Stress Perceived Scale; Maslach Burnout Inventory; Minnesota Satisfaction Questionnaire (2) Focus-group interviews	2
Papers III, IV	Pretest-posttest control group, quantitative	n= 56 DCWs	Video-recordings of morning care	3,4
Paper V	Pretest-posttest control group, quantitative (six month follow-up)	n= 53 DCWs	(1) Self-rated instruments: Stress Perceived Scale; Maslach Burnout Inventory; Minnesota Satisfaction Questionnaire (2) Video-recordings of morning care	5
Paper VI	Post-intervention, qualitative	n= 21 DCWs; 2 managers	Focus-group and individual interviews	6

5. References

Alzheimer's Disease International. (2013). World Alzheimer Report 2013: An analysis of long-term care for dementia. London: Alzheimer's Disease International.

Alzheimer’s Disease International. (2011). The benefits of early diagnosis and intervention. London.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders: Diagnostic criteria from DSM-IV*: American Psychiatric Association.

American Psychiatric Association. (2007). Practice guideline for the treatment of patients with Alzheimer’s disease and other dementias. Arlington (VA): American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, (DSM-5®)*: American Psychiatric Pub.

Argimon, J. M., Limon, E., Vila, J., & Cabezas, C. (2005). Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. *Alzheimer Disease and Associated Disorders, 19*(1), 41-44.

Baillon, S., Scothern, G., Neville, P. G., & Boyle, A. (1996). Factors that contribute to stress in care staff in residential homes for the elderly. *International Journal of Geriatric Psychiatry, 11*(3), 219-226. doi: 10.1002/(Sici)1099-1166(199603)11:3<219::Aid-Gps342>3.3.Co;2-C

Ballard, C., & Waite, J. (2006). The effectiveness of atypical antipsychotics for the treatment of aggression and psychosis in Alzheimer's disease. *The Cochrane database of systematic reviews*(1), CD003476. doi: 10.1002/14651858.CD003476.pub2

Barbosa, A., Sousa, L., Nolan, M., & Figueiredo, D. (2015). Effects of person-centered care approaches to dementia care on staff: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias, 30*(8), 713-722. doi: 10.1177/1533317513520213

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Bristol: The Police Press.

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology, 13*(3), 215-222. doi: http://dx.doi.org/10.1017/S095925980400108X

Brooker, D. (2005). Dementia Care Mapping: A review of the research literature. *Gerontologist, 45*(suppl 1), 11-18. doi: 10.1093/geront/45.suppl_1.11

Brooker, D. (2007). *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers.

Brown, N. (2011). *Psychoeducational groups: Process and practice* (3rd ed.). New York, USA: Taylor & Francis.

Buber, M. (1958). The I-thou theme, contemporary psychotherapy, and psychodrama. *Pastoral Psychology, 9*(5), 57-58.

Burns, A., & Winblad, B. (2006). *Severe dementia*. West Sussex, UK: John Wiley & Sons.

Chenoweth, L., King, M. T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology, 8*(4), 317-325. doi: 10.1016/S1474-4422(09)70045-6

Cohen-Mansfield, J. (1995). Stress in nursing home staff: A review and a theoretical model. *Journal of Applied Gerontology, 14*(4), 444-466. doi: 10.1177/073346489501400406

Coon, D. W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *Gerontologist, 43*(5), 678-689. doi: 10.1093/geront/43.5.678

Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., . . . Teri, L. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics, 24*(06), 856-870. doi: 10.1017/S1041610211002614

Dening, T., & Thomas, A. (2013). *Oxford Textbook of Old Age Psychiatry* (2nd ed.). Oxford: Oxford University Press.

Edberg, A.-K., Bird, M., Richards, D. A., Woods, R., Keeley, P., & Davis-Quarrell, V. (2008). Strain in nursing care of people with dementia: Nurses' experience in Australia, Sweden and United Kingdom. *Aging & Mental Health, 12*(2), 236-243. doi: 10.1080/13607860701616374

Edvardsson, D., Fetherstonhaugh, D., McAuliffe, L., Nay, R., & Chenco, C. (2011). Job satisfaction amongst aged care staff: exploring the influence of person-centered care provision. *International Psychogeriatrics, 23*(8), 1205-1212. doi: 10.1017/S1041610211000159

Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology, 7*(4), 362-367. doi: 10.1016/s1474-4422(08)70063-2

Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics, 25*(3), 345-358. doi: 10.1017/S1041610212001664

Figueiredo, D., Barbosa, A., Cruz, J., Marques, A., & Sousa, L. (2013). Empowering staff in dementia long-term care: Towards a more supportive approach to interventions. *Educational Gerontology, 39*(6), 413-427. doi: 10.1080/03601277.2012.701105

Finkel, S. (2000). Introduction to Behavioural and Psychological Symptoms of Dementia (BPSD). *International Journal of Geriatric Psychiatry, 15*, S2-S4. doi: 10.1002/(SICI)1099-1166(200004)

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189-198.

Fossey, J. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ, 332*(7544), 756-761. doi: 10.1136/bmj.38782.575868.7C

Fossey, J., Masson, S., Stafford, J., Lawrence, V., Corbett, A., & Ballard, C. (2014). The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia. *International Journal of Geriatric Psychiatry, 29*(8), 797-807. doi: 10.1002/gps.4072

Fujisawa, R., & Colombo, F. (2009). The long-term care workforce: Overview and strategies to adapt supply to a growing demand. France: OECD.

Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22*(1), 37-51. doi: 10.1037/0882-7974.22.1.37

George, D. R., Qualls, S. H., Camp, C. J., & Whitehouse, P. J. (2012). Renovating Alzheimer’s: “Constructive” Reflections on the New Clinical and Research Diagnostic Guidelines. *The Gerontologist*. doi: 10.1093/geront/gns096

Gray-Stanley, J. A., & Muramatsu, N. (2011). Work stress, burnout, and social and personal resources among direct care workers. *Research in Developmental Disabilities, 32*(3), 1065-1074. doi: 10.1016/j.ridd.2011.01.025

Guerra, S. R., Mendes, Á. F., Figueiredo, D. M., & Sousa, L. X. (2012). ProFamilies-dementia: A programme for elderly people with dementia and their families. *Dementia, 11*(5), 589-596. doi: 10.1177/1471301211421061

Harris-Kojetin, L., Lipson, D., Fielding, J., Kiefer, K., & Stone, R. (2004). Recent findings on frontline long-term care workers: A research synthesis 1999-2003. USA: Institute for the Future of Aging Services Association of Homes and Services for the Aged.

Harris, R. E. (2013). *Epidemiology of chronic disease: Global perspectives*. Burlington, MA: Jones & Bartlett Publishers.

Hasson, H., & Arnetz, J. E. (2008). Nursing staff competence, work strain, stress and satisfaction in elderly care: a comparison of home-based care and nursing homes. *Journal of Clinical Nursing, 17*(4), 468-481. doi: 10.1111/j.1365-2702.2006.01803.x

Hebert, R., Dubois, M. F., Wolfson, C., Chambers, L., & Cohen, C. (2001). Factors associated with long-term institutionalization of older people with dementia: data from the Canadian Study of Health and Aging. *The journals of gerontology. Series A, Biological sciences and medical sciences 56*(11), M693-699.

Herzberg, F., Mausner, B., & Snyderman, B. B. (2011). *The motivation to work* (Vol. 1): Transaction Publishers.

Hubbard, G., Cook, A., Tester, S., & Downs, M. (2002). Beyond words. Older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies, 16*, 155-167. doi:10.1016/S0890-4065(02)00041-5

Jenkins, H., & Allen, C. (1998). The relationship between staff burnout/distress and interactions with residents in two residential homes for older people. *Int J Geriatr Psychiatry, 13*(7), 466-472.

Kelly, F. (2010). Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society, 30*(01), 103-124. doi: http://dx.doi.org/10.1017/S0144686X09008708

Kitwood, T. (1997). *Dementia Reconsidered: The person comes first* Buckingham: Open University Press.

Losada, A., Montorio, I., Izal, M., Marquez, O., & Perez, G. (2004). Psychoeducational interventions efficacy on dementia caregivers' distress: Different outcomes for different contents. *International Journal of Psychology, 39*(5-6), 589-589.

Lukens, E. P., & McFarlane, W. R. (2004). Psychoeducation as evidence-based practice: Considerations for practice, research, and policy. *Brief Treatment and Crisis Intervention, 4*(3), 205-225. doi: 10.1093/brief-treatment/mhh019

Luppa, M., Luck, T., Brahler, E., Konig, H. H., & Riedel-Heller, S. G. (2008). Prediction of institutionalisation in dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders, 26*(1), 65-78. doi: 10.1159/000144027

Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job burnout. *Annual Review of Psychology, 52*, 397-422. doi: 10.1146/annurev.psych.52.1.397

Matthews, F. E., & Dening, T. (2002). Prevalence of dementia in institutional care. *The Lancet, 360*(9328), 225-226. doi: 10.1016/S0140-6736(02)09461-8

McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing, 13*, 31-38. doi: 10.1111/j.1365-2702.2004.00924.x

McFarlane, W. R., Dixon, L., Lukens, E., & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy, 29*(2), 223-245. doi: 10.1111/j.1752-0606.2003.tb01202.x

McKeith, I., & Cummings, J. (2005). Behavioural changes and psychological symptoms in dementia disorders. *The Lancet Neurology, 4*(11), 735-742. doi: 10.1016/s1474-4422(05)70219-2

Ministério da Solidariedade, Emprego e Solidariedade Social (2013). Carta social - Rede de serviços e equipamentos 2013. Lisboa: Centro de Informação e Documentação

Miyamoto, Y., Tachimori, H., & Ito, H. (2010). Formal caregiver burden in dementia: impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing, 31*(4), 246-253. doi: 10.1016/j.gerinurse.2010.01.002

Moïse, P., Schwarzinger, M., & Um, M. (2004). Dementia care in 9 OECD countries: A comparative analysis. France: OECD

Moniz-Cook, E., Woods, R., & Gardiner, E. (2000). Staff factors associated with perception of behaviour as 'challenging' in residential and nursing homes. *Aging and Mental Health, 4*(1), 48-55. doi: 10.1080/13607860055973

National Institute for Health and Care Excellence [NICE] guidelines. (2006). Dementia: Supporting people with dementia and their carers in health and social care. UK: Social Care Institute for Excellence (SCIE).

National Institute for Health and Clinical Excellence [NICE]. (2007). Dementia: A NICE-SCIE Guideline on supporting people with dementia and their careers in health and social care. London: The British Psychological Society & The Royal College of Psychiatrist.

Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: a new vision for gerontological nursing. *Journal of Clinical Nursing, 13*(3a), 45-53. doi: 10.1111/j.1365-2702.2004.00926.xJCN926 [pii]

Nolan, M., Davies, S., Ryan, T., & Keady, J. (2008). Relationship-centred care and the 'Senses' framework. *Journal of Dementia Care, 16*(1), 26-28. doi: http://dx.doi.org/10.1108/14717794200600015

Nolan, M., Keady, J., & Aveyard, B. (2001). Relationship-centred care is the next logical step. *British Journal of Nursing, 10*(12), 757. doi: 10.12968/bjon.2001.10.12.12336

Petersen, R. C. (2004). Mild cognitive impairment. *CONTINUUM: Lifelong Learning in Neurology, 10*(1), 9-28. doi: 10.1212/01.CON.0000293545.39683.cc

Petrovic, M., Hurt, C., Collins, D., Burns, A., Camus, V., Liperoti, R., . . . Byrne, E. J. (2007). Clustering of behavioural and psychological symptoms in dementia (BPSD): a European Alzheimer's disease consortium (EADC) study. *Acta Clinica Belgica, 62*(6), 426-432. doi: 10.1179/acb.2007.062

Pickard, L., Wittenberg, R., Comas-Herrera, A., Davies, B., & Darton, R. (2000). Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing and Society, 20*(6), 745-772. doi: 10.1017/S0144686x01007978

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers & Dementia, 9*(1), 63-75. doi: 10.1016/j.jalz.2012.11.007

Redfern, S., Hannan, S., Norman, I., & Martin, F. (2002). Work satisfaction, stress, quality of care and morale of older people in a nursing home. *Health and Social Care in the Community, 10*(6), 512-517. doi: 10.1046/j.1365-2524.2002.00396.x

Reisberg, B. (1988). Functional Assessment Staging. *Psychopharmacology Bulletin, 24*(4), 653-659.

Reisberg, B., Ferris, S. H., & de Leon, M. J. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry, 139*(9), 1136-1139.

Reynish, E., Fratiglioni, L., Prince, M., Bickel, H., Kiejna, A., & Georges, J. (2006). EUROCODE: Report of WP7 2006. Prevalence of Dementia in Europe: Alzheimer Europe.

Rogers, C. (1961). *On becoming a person*. Boston: Houghton Mifflin.

Rose, D., & Rose, J. (2005). Staff in services for people with intellectual disabilities: the impact of stress on attributions of challenging behaviour. *Journal of Intellectual Disability Research, 49*(11), 827-838. Doi: 10.1111/j.1365-2788.2005.00758.x

Selye, H. (1976). The stress concept. *Canadian Medical Association Journal, 115*(8), 718.

Sidani, S., Streiner, D., & Leclerc, C. (2012). Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. *International journal of older people nursing, 7*(1), 37-45. doi: 10.1111/j.1748-3743.2011.00273.x

Sloane, P. D., Hoeffer, B., Mitchell, C. M., McKenzie, D. A., Barrick, A. L., Rader, J., . . . Koch, G. G. (2004). Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *Journal of the American Geriatrics Society, 52*(11), 1795-1804. doi: 10.1111/j.1532-5415.2004.52501.x

Sousa, L., & Figueiredo, D. (2007). *Supporting family carers of older people in Europe-The national background report for Portugal* (Vol. 5): LIT Verlag Münster.

Spector, P. E. (1997). *Job satisfaction: Application, assessment, causes, and consequences*. London, UK: Sage.

Stone, R. (2012). The long-term care workforce: From accidental to valued profession. In D. Wolf & N. Folbre (Eds.), *Universal coverage of long-term aare in the United States: Can we get there from here?* United States: Russell Sage Foundation.

Stone, R., & Wiener, J. (2001). Who will care for us? Addressing the long-term care workforce crisis. United States of America: The Urban Institute and the American Association of Homes andServices for the Aging.

Talerico, K. A., O'Brien, J. A., & Swafford, K. L. (2003). Person-centered care. An important approach for 21st century health care. *J Psychosoc Nurs Ment Health Serv, 41*(11), 12-16.

Testad, I., Corbett, A., Aarsland, D., Lexow, K., Fossey, J., Woods, B., & Ballard, C. (2014). The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: a systematic review. *International Psychogeriatrics, 26*(07), 1083-1098. doi: 10.1017/S1041610214000131

Todd, S. J., & Watts, S. C. (2005). Staff responses to challenging behaviour shown by people with dementia: an application of an attributional-emotional model of helping behaviour. *Aging and Mental Health, 9*(1), 71-81. doi: 10.1080/13607860412331310254

Tripathi, M., & Vibha, D. (2010). An approach to and the rationale for the pharmacological management of behavioral and psychological symptoms of dementia. *Ann Indian Acad Neurol, 13*(Suppl 2), 0972-2327. doi: 10.4103/74252

van den Pol-Grevelink, A., Jukema, J. S., & Smits, C. H. (2012). Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry, 27*(3), 219-229. doi: 10.1002/gps.2719

Vasse, E., Vernooij-Dassen, M., Spijker, A., Rikkert, M. O., & Koopmans, R. (2010). A systematic review of communication strategies for people with dementia in residential and nursing homes. *International Psychogeriatrics, 22*(2), 189-200. doi: 10.1017/S1041610209990615

Verbeek, H., Meyer, G., Challis, D., Zabalegui, A., Soto, M. E., Saks, K., . . . Hamers, J. P. (2015). Inter-country exploration of factors associated with admission to long-term institutional dementia care: evidence from the RightTimePlaceCare study. *Journal of Advanced Nursing, 71*(6), 1338-1350. doi: 10.1111/jan.12663

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2008). A different story: exploring patterns of communication in residential dementia care. *Ageing & Society, 28*(05). doi: 10.1017/s0144686x07006927

Watt, G. (2002). The inverse care law today. *The Lancet, 360*(9328), 252-254. doi: 10.1016/S0140-6736(02)09466-7

White, D. L., Newton-Curtis, L., & Lyons, K. S. (2008). Development and initial testing of a measure of person-directed care. *Gerontologist, 48 Spec No 1*, 114-123.

World Health Organization. (2011). Global Health and Aging. Geneva: World Health Organization.

World Health Organization. (2012). Dementia: a public health priority. Geneva: World Health Organization.

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *Gerontologist, 45 Spec No 1*(1), 96-105. doi: 10.1093/geront/45.suppl_1.96

Chapter 1

Effects of person-centred care approaches to dementia care on staff: A systematic review

This chapter was published as:

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Abstract

Person-centered care (PCC) has been the subject of several intervention studies, reporting positive effects on people with dementia. However, its impact on staff remains unclear. The purpose of this systematic review was to assess the impact of PCC approaches on stress, burnout and job satisfaction of staff caring for people with dementia in residential aged care facilities. Research articles published up to 2013 were searched on PubMed, Web of Knowledge, Scopus and EBSCO and reference lists from relevant publications. The review was limited to experimental and quasi-experimental studies, published in English and involving direct care workers (DCWs). Seven studies were included, addressing different PCC approaches: dementia care mapping (n=1); stimulation-oriented approaches (n=2); emotion-oriented approaches (n=2) and behavioral-oriented approaches (n=2). Methodological weaknesses and heterogeneity among studies make it difficult to draw firm conclusions. However, five studies reported benefits on DCWs, suggesting a tendency towards the effectiveness of PCC on staff.

Keywords: residential aged care facilities; dementia; direct care workers; person-centered care; systematic review.

1. Introduction

Dementia affects nearly 35.6 million of people worldwide and this number is projected to rise as the population ages[1]. Behavioral and psychological symptoms of dementia (BPSD), such as agitation and wandering, emerge in a significant number of cases, with almost 90% of people with dementia developing at least one BPSD[2]. These symptoms are often distressing for informal caregivers and greatly increase the likelihood of care recipients' admission to residential aged care facilities (i.e., homes for the aged, assisted living facilities or nursing homes)[3]. Also, BPSD are one of the main causes of stress, burnout and job dissatisfaction amongst direct care workers (DCWs), who provide the bulk of care to people with dementia in residential aged care facilities[4,5].

Between one-half and two-thirds of care home residents have some form of dementia and these numbers will escalate rapidly in coming years[6-8]. The increasing prevalence of dementia has challenged residential aged care facilities to recognize the need to go beyond the medical and supervisory care that has traditionally provided the rationale for their existence and in recent years, growing attention has been paid to the concept of Person-Centred Care (PCC) as a key approach to creating a more positive psychosocial environment for residents with dementia[9]. The term PCC had its origins in the work of Carl Rogers and client-centred therapy[10]. His approach was an evolution from the medical model of the practitioner as an expert figure, to one that validates the individual with the illness and recognizes their strengths and needs[10]. Rogers advocated a change to the traditional therapeutic relationships, with more emphasis on the person and less on the care task[11].

Later, it was Tom Kitwood who encouraged PCC approach in dementia care. Kitwood (1997) argued that BPSD were not just the result of changes in the brain, but a consequence of a complex interaction between neuropathology and the person's psychosocial environment. Within this conceptualization, many of the difficulties people with dementia experience are not just a consequence of the disease itself but are the result of threats to one's personhood, brought about by negative interactions with others. Kitwood (1997) termed this 'malignant social psychology'. Examples of a 'malignant social psychology' include infantilization, disempowerment or objectification and are often seen as a product of the DCW's limited skills in communicating adequately with the person with dementia[12,13]. Thus, Kitwood (1997) emphasizes the relational nature of PCC and the need to value carers, i.e., the provision of PCC is not possible unless carers themselves:

have communication skills; their own emotional strains are recognized; and they experience feelings of being respected and valued.

His framework provided an important theoretical rationale for the development of different forms of approaches to dementia care[14], such as: behavior oriented approaches (e.g., simplify tasks and provide one-step instructions); emotion oriented approaches (e.g., reminiscence and validation therapy); cognition oriented approaches (e.g., reality orientation); and stimulation oriented approaches (e.g., recreational therapies and multisensory stimulation) (Table 7).

Providing DCWs with education and training to deliver PCC approaches have typically been used as the means to improve quality of care for people with dementia. Studies have showed positive effects of PCC on different outcomes among residents, including: a decrease in the use of chemical restraints[15]; less resident agitation and aggression[16]; fewer falls[17]; and an increase in residents' participation during care routines[18]. However, the relationship between PCC and DCWs' outcomes, including stress, burnout and job satisfaction remains understudied[19]. Considering the relational nature of PCC, one might assume that this approach has benefits not only for the care receiver, but also for the DCWs.

A recent systematic literature review conducted by van Pol-Grevelink et al.[20] concluded that there are limited indications that PCC has a positive effect on DCWs' job satisfaction. Despite its valuable contribution to the current state of knowledge in this field, this review was not specifically focused on DCWs providing care for residents with dementia, but targeted to all care home residents, and it only included studies conducted in Dutch nursing homes. Furthermore, the authors overextended the construct of job satisfaction by considering the job stress and burnout as components of the former. Such conceptualization seems to disregard the significance and independence of each one of these variables.

The increasing demand for more and higher quality services highlights the need to address the psychological pressure experienced by care staff, as this can also affect the process of caring for people with dementia[13]. Stress, burnout and job dissatisfaction among DCWs have been recognized in a number of studies as the most important threats to the care provision, as well as to the well-being of the worker and the resident[5,21,22].

The aim of the present systematic review was therefore to assess the impact of PCC approaches on stress, burnout and job satisfaction among DCWs providing care for residents with dementia in residential aged care facilities, in order to add to knowledge about the impact of PCC on DCWs and to determine if specific interventions are of benefit.

Table 7. Approaches based on PCC[14]

Approaches	General description
Behavioral-oriented approaches	Manage disabilities and problem behaviors using principles of learning (e.g., scheduled toileting).
Emotion-oriented approaches	
• Reminiscence therapy and life story	• Stimulate memory and mood in the context of the resident's life history.
• Validation therapy	• Restore self-worth and reduce stress by validating emotional ties to the past.
• Simulated presence therapy	• Alleviate problem behaviors by playing an audio or videotape to a person with dementia that has been personalized by his or her caregiver.
Cognition-oriented approaches	
• Reality orientation	• Manage disorientation and confusion through regular stimulation and repetition of basic orientation (e.g., calendars, clocks).
• Skills training	• Restore specific cognitive deficits through structured activities.
Stimulation-oriented approaches	
• Multisensory stimulation/*snoezelen*	• Stimulate the senses using lighting effects, color, sounds, music or scents in order to obtain maximum pleasure from the activity in which people are involved.
• Art therapies	• Provide meaningful stimulation and improve social interaction through dancing, drawing, painting, etc.
• Recreational activities/therapies	• Engage in pleasant activities such as crafts or games as a way of facilitating the individual's need for communication, self-esteem, sense of identity and productivity.
• Aromatherapy	• Use of natural oils to enhance psychological and physical wellbeing.
Exercise	• Engage in sport activities to improve psychomotor function and social interaction.

2. Methods

2.1. Eligibility criteria

Types of studies

Since the present review is one of the first attempts to study the association between PCC approaches and outcomes for staff, and it is anticipated that the effects of interventions are unlikely to be studied only in randomized trials, both randomized and non-randomized studies were considered. Concerning the latter, the following designs were eligible: controlled before-after studies; uncontrolled before-and-after studies and post-test studies. Studies had to be written in English and published in a scholarly peer-reviewed journal. Non-experimental studies (e.g., observational studies), reviews, letters, notes, case reports or qualitative studies were not considered.

Types of participants

Studies were eligible if they included mainly DCWs providing care to people with dementia in residential aged care facilities as participants. A number of designations for DCWs were included: Nursing Assistant/Aid; Personal Care Attendant, Attendant Care Worker, Personal Assistant or Frontline Staff. Given the lack of research in this area, Certified Nursing Assistants/Aids (CNAs) were also considered eligible in order to obtain a large number of studies. As DCWs, CNAs are responsible to assist residents with activities of daily living, such as bathing, dressing, grooming and eating, however, they are required to be certified after complete a specialized training.

Types of interventions

The interventions of interest consisted of interventions in dementia care distinguished by American Psychiatric Association (APA)[14] as reflecting a person-centered philosophy of care, i.e., in which an understanding of the individual is emphasized, and strategies are employed to improve the person’s quality of life and maximize function in the context of existing deficits: behavior-oriented approaches; emotion-oriented approaches; cognition-oriented approaches and stimulation-oriented approaches. Dementia Care Mapping (DCM) utilizes systematic observations to evaluate the quality of care and well-being of people with dementia in formal care settings[23]. As DCM can be used to help staff understand the experience of people of dementia and change practices, it was also considered in this review. In order to ensure that studies actually reflected a PCC, they should explicitly mention to be focused on PCC, i.e., employ the terms person/patient/client/relationship-centered care or emphasize that the choice of the approach was based on the resident’s characteristics and preference.

Interventions were assigned to only one category even if more than one would have been appropriate in some cases. When this happened, two authors (AB and DF) met to reach an agreement.

Types of outcomes

Broad variables that are considered important threats to the care provision and that may offer an initial picture of the impact of PCC on staff wellbeing were selected. Therefore, the primary outcomes that were considered for review were DCWs' stress, burnout and job satisfaction. Studies were not required to address all these outcomes to be eligible for inclusion. Stress has been defined as a physiological and psychological response experienced when the demands of a situation tax or exceed a person's resources and some type of harm or loss is anticipated[23]. Long-term exposure to stress may result in burnout, a state of emotional exhaustion (feelings of being emotionally overextended and exhausted); depersonalization (cynicism or callous attitude towards others); and lack of personal accomplishment (negative assessment of one's competence and work achievements)[24]. Job satisfaction reflects how people feel about the different dimensions of their jobs[25].

2.2. Search strategy

Research articles published from the inception of the database up to 2013 were searched on the electronic databases PubMed, Web of Knowledge, Academic Search Complete - EBSCO and Scopus, between December 2012 and March 2013. The following strategy created for PubMed was adopted for each one of the other databases:

Dementia [MESH] AND residential facilities [MESH] AND (behavior therapy OR emotion-oriented OR validation therapy OR reminiscence OR simulated presence OR cognitive-oriented OR reality orientation OR skills training OR stimulation-oriented OR multi-sensory stimulation OR aromatherapy OR sensory stimulation OR snoezelen OR recreational therapy OR art therapy OR activity therapy OR person cent OR patient cent* OR client cent* OR relationship cent* OR dementia care mapping)*

The bibliography of all potential relevant papers was also used to identify additional articles.

2.3. Selection of studies

Search results obtained from the databases were combined using the software Endnote version X5 and duplicate records were removed. Afterwards, the titles and abstracts of the identified references were screened for relevance by the first author (AB), considering the established eligibility criteria. The full text of the potentially relevant papers was obtained and screened to determine its inclusion in the review. If information about the study was lacking or unclear, the corresponding authors were contacted to request further details. The final decision about the studies to be included was confirmed by the last author (DF).

2.4. Data extraction and quality assessment

The following details of the included studies were extracted and summarized by the first author (AB): authors and year of publication, country, study design, type and description of the intervention, sample, outcomes and main results. A second researcher (DF) independently checked the data extraction for accuracy and detail. Disagreements were resolved by consensus between the two authors. Each study was independently reviewed for methodological quality by two authors (AB and DF), using the assessment tool recommended by Cochrane[26]. The following criteria were considered: selection bias (method of randomization, allocation concealment), performance bias (blinding of participants, personnel and outcome assessors), attrition bias (incomplete outcome data), and reporting bias (selective outcome reporting). The decision whether the criteria were fulfilled ("yes") or not ("no") was based on the information provided in the article, and if this information was inadequate, the decision was labelled "unknown" ("?").

2.5. Data synthesis

Given the variability among studies regarding study design, interventions and measuring outcomes, instead of a meta-analysis qualitative analysis was employed to synthesize the findings. This relies primarily on the use of text to summarize and explain the findings of multiple studies[27].

3. Results

3.1. Overview of results

A total of 678 references were initially identified.

Based on their titles and abstracts, a total of 16 references were acknowledged as potentially eligible, while 662 were excluded. Non-experimental studies, interventions implemented in settings other than residential aged care facilities and studies not focused on dementia were identified as the main reasons for exclusion. The full papers of the 16 potentially relevant studies were obtained. After a complete reading, nine references were excluded from the review[29-37]. Reasons for exclusion included: participants or outcomes were not in accordance with those established in the inclusion criteria[30,32,35-37]; study design did not meet defined criteria[33,34]; or there was dearth of information about the intervention[29,31]. Although these two studies were possibly relevant, no response was obtained from the authors in order to clarify the intervention, thus, they were excluded from the review. A total of seven studies met the inclusion criteria (Figure 4).

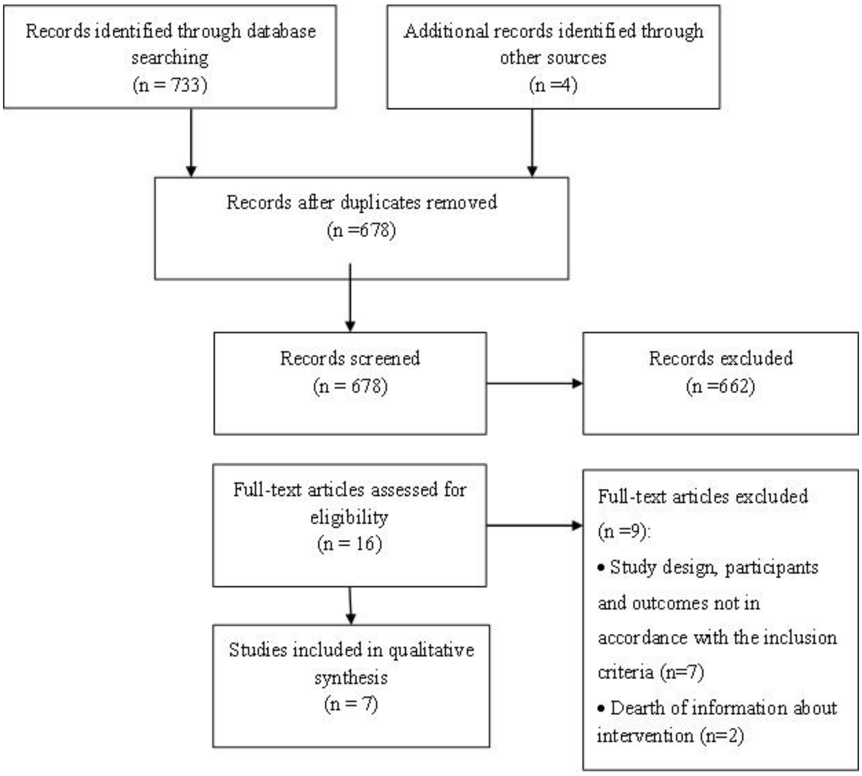

Figure 4. Selection of studies procedure

3.2. Characteristics of included studies

The seven included studies addressed different PCC approaches, including: dementia care mapping (DCM)[38]; stimulation-oriented approaches, such as recreational therapy (storytelling) or multisensory stimulation (*snoezelen)*[39]; emotion-oriented[40,41] and behavioral-oriented approaches[38,42,43].

Three studies originated from the Netherlands[39-41], two from the United States[42,44], one from Canada[43] and one from Australia[38]. The number of participants ranged from 26 to 300 (Table 8).

None of the seven studies met all the quality criteria (Table 9). Four out seven studies were randomized controlled trials (RCTs)[38,40,41,44]. Residential aged care facilities were selected as the units of randomization, yet information about the method for the allocation concealment was unclear. It was not possible to blind residents due to the nature of the interventions; however, an effort to blind outcome assessors was made in Wells et al. (2000). Most studies (n = 5) lacked follow up assessments. For those which had[38,41], time-periods varied from four months[38] to one year[41]. Only Schrichnemaekers et al. (2003) stated that they used intention-to-treat analysis. In the remaining studies data were collected only from the ‘completers’. For the studies of Passalacqua & Harwood (2012) and Fritsch et al. (2009) selective reporting was apparent as one or more outcomes were not reported. In the study of Passalacqua & Harwood (2012) it was stated in the methodology that MBI was used to assess burnout, however the authors have only reported the results obtained for one subscale - “depersonalization”. In the study of Fritsh et al. (2009) job satisfaction and burnout were reported in the methodology but insufficient detail about their findings were present in the results section. There was a risk of other bias in van Weert et al. (2005) as the dropouts during the study were replaced by new staff members. Therefore, the treatment duration periods were unequal for subjects in the original group and the replacement group, which does not allow intention-to-treat analysis.

3.3. Outcome measures

Five out 7 studies assessed burnout[37,38,40,41,43], four studies measured staff’s stress[37-39,42], and 3measured job satisfaction[38,40,43]. The Maslach Burnout Inventory (MBI) was the instrument used across all studies to measure burnout. The Maastricht Work Satisfaction Scale for Healthcare (MAS-GZ) was selected in two studies to assess job satisfaction[38,40]. In one study, this outcome was assessed using an adaptation of the scale of Montgomery[43]. The General Health Questionnaire (GHQ) was used in three studies to assess levels of stress[37-39]. There was little consistency in the use of the outcome measures. Finnema et al. (2005) used the full-version of GHQ (28 items), while Jeon et al. (2012) and van Weert et al. (2005) administered the short version of the scale (12 items). van Weert et al. (2005) selected four of the seven subscales of MAS (satisfaction with quality of care, opportunities for self-actualization, contact with colleagues and contact with residents) while Schrijnemaekers et al. (2003) selected five subscales (satisfaction with the head of the ward, quality of care, opportunities for self-actualization/growth, contact with colleagues and residents). Of the three subscales of MBI “emotional exhaustion,” “depersonalization” and “personal accomplishment,” van Weert et al. (2005) excluded the depersonalization subscale from the analysis (Table 8).

3.4. Effects of PCC approaches on DCWs’ outcomes

Stimulation-oriented interventions

Two different studies fell into this group. Van Weert et al. (2005), through a quasi-experimental pre post-test design, investigated the effectiveness of integrated *snoezelen* on work-related outcomes of staff in nursing homes. The intervention consisted of a four day in-house training programme, three follow-up meetings and two general meetings to support the implementation of *snoezelen* in daily care. Data collected at baseline and after 18 months indicated that the implementation of *snoezelen* was significantly associated with a reduction of stress (*intervention group*: before intervention (t0)Mean (M)=1.46, Standard Deviation (SD)=0.4; after intervention (t1) M=0.77, SD=0.4; *control group*: t0 M=1.24, SD=0.4; t1 M=1.93, SD=0.4), job dissatisfaction (*intervention group*: t0 M=53.36, SD=0.97; t1 M=56.41, SD=1.6; *control group*: t0 M=54.33, SD=1.6; t1 M=52.87, SD=1.6) and emotional exhaustion on staff (*intervention group*: t0 M=10.75, SD=0.8; t1 M=8.31, SD=0.9; *control group*: t0 M=10.35, SD=0.8; t1 M=10.77, SD=0.9).

Fritsch et al. (2009) evaluated the impact of a group storytelling approach on people with dementia and care assistants. A post-test only study with a group control was conducted. Staff (n=192) received 10-week on-site training on how to implement storytelling. Outcomes were assessed two weeks after the intervention. No effects on staff’s burnout or job satisfaction among either the intervention or control group were observed (Table 8).

Emotion-oriented interventions

Two studies fell into this group. Finnema et al. (2005) used a pre post- test control group design to examine the effect of integrated emotion-oriented care (an approach that applies validation in combination with other interventions such as reminiscence and sensory stimulation) on both nursing home residents with dementia and staff. Staff in the intervention group received training and supervision in emotion-oriented care, over nine months. The following courses were offered: (i) basic training on emotion-oriented care for all staff members involved in care; (ii) advanced course “emotion-oriented care worker” for five staff members; (iii) a training course “adviser emotion-oriented care” for one staff member. Data were gathered at baseline and after seven months. Findings indicated a significant decrease in stress in those who perceived improvements in their emotion-oriented care competences (*intervention group*: t0 M=15.14, SD=7.9; t1 M=14.77, SD=6.8; *control group*: t0 M=16.92, SD=12.2; t1 M=19.25, SD=9.8).

Also, Schrijnemaekers et al. (2003) studied the effect of emotion-oriented care on staff through a pre-post randomized controlled trial. The eight facilities at the experimental group received: (i) clinical lessons to all employees; (ii) six-day training programme for 8 workers in each facility; (iii) 3 supervision meetings (half-a-day each) held over four months after training. Data were gathered at baseline, three, six and 12 months follow-up. Based on a sample of 300 care assistants, the authors observed significantly positive effects in favor of the intervention groups on burnout (subscale of ‘personal accomplishment’) and some aspects of staff’s job satisfaction (‘opportunities for self-actualization’ – *intervention group*: t0 M=7.3, SD=2.3; *control group*: t0 M=8.0, SD=1.8). Though, findings were not consistent over time (Table 8).

Behavioral-oriented approaches

Two different studies fell into this group. Passalacqua & Harwood (2012) assessed the effects of a communication skills training for 26 DCWs through a quasi-experimental pre- and post-intervention without control group. The intervention was offered in four 1-hour workshops over a period of 4 weeks, with each workshop devoted to one of the four elements of Brooker’s (2004) VIPS model (**V**aluing people and those who care for them; treating people as **I**ndividuals; looking at the world from the **P**erspective of the person with dementia; create a positive **S**ocial environment) and to communication skills training. Findings suggested a significant reduction in one aspect of burnout – depersonalization (t0 M=1.71, SD=1.36; t1 M=1.16, SD=0.43).

Wells et al. (2000) implemented a behavioral approach consisting of training staff through five educational sessions to use an abilities focused morning care routine with residents. Specifically, staff were taught to give residents verbal prompts before carrying out care tasks and to help them to carry out care tasks as independently as possible. Data were gathered at baseline and at three and six months post-intervention. Findings suggested an absence of impact on staff's stress levels (Table 8).

Dementia- care mapping

Jeon et al. (2012) through a RCT conducted in 15 aged-care facilities assessed the efficacy of DCM and PCC on staff stress and burnout. The DCM intervention consisted of training for 45 staff members (42.2% nurse assistants) on DCM and skills to implement PCC based care practices. The intervention required intensive six to eight hours of systematic observations of individual residents and their interactions with staff. Burnout and stress were assessed at three moments: prior to the intervention, immediately post intervention and at four months' follow-up. Significant decreases for emotional exhaustion, a subscale of MBI, were only obtained at post intervention among staff of DCM group (*DCM*: t0 M=17.3, SD=1.7; t1 M=14.8, SD=1.8; *PCC*: t0 M=14.3, SD=1.5; t1 M=16.0, SD=1.7; *control* t0 M=12.4, SD=2.3; t1 M=14.5, SD=2.5).This outcome also declined significantly with time only in the DCM group (*DCM* F [2.82] = 5.49, p = 0.006; *PCC* F [2.102]= 0.28, p=0.76; *control* F[2.40]= 0.96, p=0.39). MBI personal accomplishment rose significantly over time for all groups, but differences were not found between them. Although not significant, results for the measures of depersonalization tended to drop from baseline to follow-up only for intervention groups. For all groups there was a significant time effect for stress, which increased at post-intervention but declined at follow-up. Yet, time effect did not differ between clusters. Findings need to be interpreted with caution given that the values are not specific for DCWs but rather to the whole group of staff (Table 8).

Table 8. Characteristics of selected studies

Source	Methods	Approach	Participants	Outcomes	Results
Finnema et al. (2005)	Design: RCT Measurement: one month before and seven months after the intervention.	Emotion-oriented	Sample: 99 nursing assistants (46 intervention group; 53 control group) Setting: 16 psychogeriatric wards in 14 nursing homes Country: Netherlands	Stress: GHQ-28	Positive significant differences in favor of the intervention group for stress (p<0.05).
Fritsch et al. (2009)	Design: Post-only study with a group control Measurement: two weeks after the intervention.	Stimulation-oriented	Sample: 192, including 67% of nursing assistants Setting: 20 nursing homes Country: United States	Burnout: MBI Job satisfaction: 5 indicators adapted from Montgomery (1993)	No significant differences were observed for job satisfaction and burnout.
Jeon et al (2012)	Design: RCT Measurement: before, after and 4 months after the intervention.	Dementia Care Mapping	Sample: 124 (43,5% nursing assistants) Setting: 15 residential aged care sites Country: Australia	Burnout: MBI Stress: GHQ-12	Significant decreases in emotional exhaustion (MBI) (p<0.05). No significant decrease in depersonalization (MBI) in both intervention groups. Significant time effect for stress, which increased at post-intervention, but declined at follow-up.
Passalacqua & Harwood (2012)	Design: Quasi-experimental, pre and post without control group Duration: 14 weeks Measurement: four weeks before and six weeks after the intervention.	Behavior-oriented	Sample: 26 DCWs Setting: 1 home for the aged Country: United States	Burnout: MBI (emotional exhaustion and depersonalization subscales)	Positive significant differences for depersonalization (p<0.05).
Schrijnemaekers et al. (2003)	Study: Randomized controlled trial Duration: 16 months Measurement: pre, three, six and 12 months post intervention.	Emotion-oriented	Sample: 300 caregivers (155 intervention group;145 control group) Setting: 16 homes for the aged Country: Netherlands	Job satisfaction: 5 of 7 subscales of Maastricht Work Satisfaction Scale for Healthcare (MAS) Burnout: MBI	Short-term differences in favor of the intervention group. Differences were statistically significant for two subscales of job satisfaction - "opportunities for self-actualization" and "contact with residents" - and one subscale of burnout - "personal accomplishment" (p<0.05). Findings were not consistent over time.

Source	Methods	Approach	Participants	Outcomes	Results
van Weert et al. (2005)	Design: Quasi-experimental, pre- and post-test control group Duration: 19 months Measurement: before and 18 months post intervention.	Stimulation-oriented	Sample: 127 certified nursing assistants (64 intervention group; 63 control group) Setting: 6 nursing homes Country: Netherlands	Job satisfaction: 4 of 7 subscales of MAS Stress- GHQ-12 Burnout - MBI	Job satisfaction: positive significant differences in favor of the intervention group for satisfaction with quality of care ($p<0.001$), contact with residents ($p<0.01$) and total satisfaction ($p<0.01$). Stress: positive significant differences in favor of the intervention group ($p<0.05$). Burnout: positive significant differences in favor of the intervention group for emotional exhaustion ($p<0.05$).
Wells et al. (2002)	Design: Quasi-intervention, repeated measures design. Duration: 12 months Measurement: baseline, three and six months post intervention.	Behavior-oriented	Sample: 44 nursing staff (16 – 7 care assistants -on the intervention group and 28 – 13 care assistants - on the control groups) Setting: 4 nursing home units Country: Canada	Stress: Hassless subscale of the Nurses Hassless and Uplifts Scale (41-item)	No effect on staff level of stress.

Table 9. Methodological quality of the included studies based on Higgins & Green (2011)

	Randomization?	Allocation concealment?	Blinding of participants and personnel	Blinding of outcome assessors?	Incomplete outcome data addressed?	Free of selective reporting?	Free of other bias?
Fritsch et al. (2009)	+	?	?	?	-	+	-
Finnema et al. (2005)	+	?	-	-	-	+	+
Jeon et al. (2012)	+	?	-	?	-	+	+
Passalacqua & Harwood (2012)	-	-	?	?	-	-	+
van Weert et al. (2005)	-	-	-	-	-	+	-
Schrijnemaekers et al. (2003)	+	?	-	-	+	+	+
Wells et al. (2000)	-	-	?	+	-	+	+

Note: + yes (low risk of bias); − no (high risk of bias); ? unclear

4. Discussion

This study aimed to explore the impact of PCC approaches to dementia care on DCWs' stress, burnout or job satisfaction.

A total of seven studies were included which assessed a range of PCC approaches: emotion-oriented approaches (n=2); stimulation-oriented approaches (n=2); behavioral-oriented approaches (n=2); and DCM (n=1). Differences in the type of design, outcomes, number of participants and duration of intervention hindered study comparisons and generalizations. Moreover, a range of methodological weaknesses make it difficult to provide any conclusive indication of the effectiveness of these approaches.

Nonetheless, findings point to a potentially important benefit of such approaches for staff, as most studies (n=5) reported significant positive changes in the outcome domains. Each of the two RCTs that assessed emotion-oriented approaches were successful in reducing DCWs' stress[40], burnout and job dissatisfaction[41]. However, emotion-oriented approaches comprise multiple components (e.g., validation and reminiscence), making it difficult to understand which one was the most effective. An additional RCT found that DCM positively affected DCWs' stress and burnout[38]. A non-randomized controlled study based on multisensory stimulation[39] showed immediate significant positive impacts on the three outcomes of interest. Lastly, one out two behavioral-oriented approaches that adopted a non-randomized design reduced DCWs' burnout[42]. The remaining two studies reported no effects on staff's psychological outcomes[43,44]. As a group, these studies provide valuable insights about the different types of PCC approaches that impact on DCWs. In line with previous literature, PCC can offer a better preparation for the challenging task of providing dementia care, enabling DCWs to respond to residents' BPSD more effectively and with less personal impact on themselves. Such approaches are also more likely to reflect the type of care that DCWs would wish to provide, a care that is focused on the residents and on their needs, habits, interests and wishes[19,45].

As identified in a previous review[20], this one demonstrates that studies in this area still lack sufficient rigor. Nevertheless, it must be acknowledge that implementing interventions within residential care facilities is hampered by several inherent methodological concerns.

Conducting RCTs to assess non-pharmacological interventions represents a challenge especially with respect to the blinding of participants. Yet, more could be done to blind outcomes assessors, something that was only noted in one of the included studies[43]. Better quality reporting of the method of allocation would also be a methodological advance.

The long-term effects of the interventions were only assessed in two studies[38,41] and in the future follow-up data are required to demonstrate the extent to which the effects of interventions are maintained. This is particularly important given that several previous studies have indicated that positive outcomes are not maintained over extended periods of time[46]. Another weakness concerns the possible existence of bias in samples. Only one study reported intention-to-treat analysis[41], highlighting the necessity for future studies to undertake a ‘‘complete cases’’ analysis.

There was a great variability in the outcome measures used, further compromising comparability. Except for burnout, which was universally assessed with the MBI, stress and job satisfaction were measured using different tools. And even when the same tool was used, its application was inconstant across studies (i.e. studies selected different subscales or items).

Given the lack of widely accepted instruments to measure occupational stress and job satisfaction, future studies should use the most responsive and precise instruments relevant to their study aims and justify their use.

Finally, despite all approaches being focused on PCC, they have a different emphasis. For example, while some studies were focused on training staff to promote residents' independence[43], others were more focused on enhancing staff-resident communication[39]. This demonstrates the complexity of the term PCC and indicates that there is still a lack of conceptual clarity as to it meaning. In order to be able to compare the benefits of these different approaches, there is a need for further exploration of the concept and features of PCC.

4.1. Strengths and limitations

A few limitations have to be considered within this review. Potential reporting bias may exist, as only studies published in scholarly peer-reviewed journals and in English language were included. There may have been other studies describing suitable interventions that were not included. Obtaining and including data from grey literature would probably reduce such bias. As well, the number of included studies could have been superior if other psychological variables were considered, namely self-efficacy or confidence. Moreover, the small number of studies and their methodological limitations reduces the inferences that can be legitimately drawn. Finally, post-only studies were eligible to be included in the review despite its recognized weaknesses.

Despite the limitations, this is the first review to date that focuses specifically on interventions addressing staff caring for people with dementia. This work is instructive and makes available important insights for the future development of this research area.

5. Conclusions

Based on the available evidence and considering the methodological weaknesses and heterogeneity of studies, it is not possible to draw firm conclusions about the efficacy of PCC approaches for DCWs. Yet, a tendency towards their effectiveness was apparent.

This review highlights the need for more well-design research and higher quality reporting of study methodology. Specifically, reporting should include the method of randomization and treatment allocation concealment, information about blinding of participants or outcome assessors and an intention-to-treat analysis should be performed. Future studies should careful consider the use of more responsive and precise instruments relevant to their study aims and justify their use and follow-up assessments in order to determine any lasting effects. In order to compare the benefits of the different approaches, further exploration of the features of PCC are required.

References

1. World Health Organization. *Dementia: a public health priority.* Geneva: WHO;2012.
2. Ballard CG, Gauthier S, Cummings JL, et al. Management of agitation and aggression associated with Alzheimer disease. *Nat Rev.* 2009;5(5):245-255.
3. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *J. Am. Med. Assoc.* 2002;287(16):2090-2097.
4. Miyamoto Y, Tachimori H, Ito H. Formal caregiver burden in dementia: impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatr Nurs.* 2010;31(4):246-253.
5. Brodaty H, Draper B, Low BL. Nursing home staff attitudes towards residents with dementia strain and satisfaction with work. *J Adv Nurs.* 2003;44(6):583-590.
6. Magaziner J, German P, Zimmerman SI, et al. The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: diagnosis by expert panel. Epidemiology of Dementia in Nursing Homes Research Group. *Gerontologist.* 2000;40(6):663-672.
7. Matthews FE, Dening T. Prevalence of dementia in institutional care. *The Lancet.* 2002;360(9328):225-226.
8. Mongil R, Trigo JA, Sanz FJ, Gómez S, Colombo T. Prevalencia de demencia en pacientes institucionalizados: estudio RESYDEM. *Rev Esp Geriatr Gerontol.* 2009;44(1):5-11.
9. Edvardsson D, Winblad B, Sandman P. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol.* 2008;7(4):362-367.
10. Rogers C. *On becoming a person*. Boston: Houghton Mifflin; 1961.
11. McCormack B, McCance TV. Development of a framework for person-centred nursing. *J Adv Nurs.* 2006;56(5):472-479.
12. Woods RT. Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging Ment Health.* 2001;5 Suppl 1:S7-16.
13. Kitwood T. *Dementia Reconsidered: The Person Comes First* Buckingham: Open University Press; 1997.
14. American Psychiatric Association. *Practice Guideline for the Treatment of Patients With Alzheimer's Disease and Other Dementias.* Arlington (VA): American Psychiatric Association;2007.

15. Fossey J. Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ.* 2006;332(7544):756-761.

16. Sloane PD, Hoeffer B, Mitchell CM, et al. Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *J Am Geriatr Soc.* 2004;52(11):1795-1804.

17. Chenoweth L, King MT, Jeon YH, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol.* 2009;8(4):317-325.

18. Sidani S, Streiner D, Leclerc C. Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. *Int J Older People Nurs.* 2012;7(1):37-45.

19. Edvardsson D, Fetherstonhaugh D, McAuliffe L, Nay R, Chenco C. Job satisfaction amongst aged care staff: exploring the influence of person-centered care provision. *Int Psychogeriatr.* 2011;23(8):1205-1212.

20. van den Pol-Grevelink A, Jukema JS, Smits CH. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *nt J Geriatr Psychiatry.* 2012;27(3):219-229.

21. Evans S, Huxley P, Gately C, et al. Mental health, burnout and job satisfaction among mental health social workers in England and Wales. *Br J Psychiatry.* 2006;188:75-80.

22. Gray-Stanley JA, Muramatsu N. Work stress, burnout, and social and personal resources among direct care workers. *Res Dev Disabil.* 2011;32(3):1065-1074.

23. Brooker D. Dementia Care Mapping: A Review of the Research Literature. *Gerontologist.* 2005;45(suppl 1):11-18.

24. Lazarus RS, Folkman S. *Psychological stress and the coping process*. New York: Springer; 1984.

25. Maslach C, Schaufeli WB. Historical and conceptual development of burnout. In: Schaufeli W, Maslach C, Marek T, eds. *Professional burnout:recent developments in theory and research*. London: Taylor & Francis; 1993.

26. Spector PE. *Job satisfaction: Application, assessment, causes, and consequences*. London: Sage; 1997.

27. Higgins J, Green S. *Cochrane Handbook for Systematic Reviews of Interventions - Version 5.1.0*: The Cochrane Collaboration; 2011.

28. Popay J, Roberts H, Sowden A, et al. *Guidance on the conduct of narrative synthesis in systematic reviews.* UK: Lancaster University;2006.

29. Bird M, Llewellyn-Jones RH, Korten A. An evaluation of the effectiveness of a case-specific approach to challenging behaviour associated with dementia. *Aging Ment Health.* 2009;13(1):73-83.

30. Berkhout A, Boumans NPG, Nijhuis FJN, Van Breukelen GPJ, Huijer Abu-saad H. Effects of resident-oriented care on job characteristics of nursing caregivers. *Work Stress.* 2003;17(4):337-353.

31. Davison TE, Hudgson C, McCabe MP, George K, Buchanan G. An individualized psychosocial approach for "treatment resistant” behavioral symptoms of dementia among aged care residents. *Int Psychogeriatr.* 2006;19(05):859.

32. McGilton KS, O'Brien-Pallas LL, Darlington G, Evans M, Wynn F, Pringle DM. Effects of a relationship-enhancing program of care on outcomes. *J Nurs Scholarship.* 2003;35(2):151-156.

33. Wilson B, Swarbrick C, Pilling M, Keady J. The senses in practice: Enhancing the quality of care for residents with dementia in care homes. *J Adv Nurs.* 2013;69(1):77-90.

34. McKeown J, Clarke A, Ingleton C, Ryan T, Repper J. The use of life story work with people with dementia to enhance person-centred care. *Int J Older People Nurs.* 2010;5(2):148-158.

35. Hoeffer B, Talerico KA, Rasin J, et al. Assisting cognitively impaired nursing home residents with bathing: Effects of two bathing interventions on caregiving. *Gerontologist.* 2006;46(4):524-532.

36. Buron B. Life history collages: Effects on nursing home staff caring for residents with dementia. *J Gerontol Nurs* 2010;36(12):38-48.

37. McCallion P, Toseland RW, Lacey D, Banks S. Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *Gerontologist.* 1999;39(5):546-558.

38. Jeon YH, Luscombe G, Chenoweth L, et al. Staff outcomes from the Caring for Aged Dementia Care REsident Study (CADRES): A cluster randomised trial. *Int J Nurs Stud* 2012;49(5):508-518.

39. van Weert JCM, van Dulmen AM, Spreeuwenberg PMM, Bensing JM, Ribbe MW. The effects of the implementation of snoezelen on the quality of working life in psychogeriatric care. *Int Psychogeriatr.* 2005;17(03):407.

40. Finnema E, Drões R-M, Ettema T, et al. The effect of integrated emotion-oriented care versus usual care on elderly persons with dementia in the nursing home and on nursing assistants: a randomized clinical trial. *Int. J. Geriatr. Psychiatry.* 2005;20(4):330-343.

41. Schrijnemaekers VJJ, van Rossum E, Candel MJJM, et al. Effects of emotion-oriented care on work-related outcomes of professional caregivers in homes for elderly persons. *J Gerontol B-Psychol.* 2003;58(1):S50-S57.

42. Passalacqua SA, Harwood J. VIPS Communication Skills Training for Paraprofessional Dementia Caregivers: An Intervention to Increase Person-Centered Dementia Care. *Clin Gerontologist.* 2012;35(5):425-445.

43. Wells D, Dawson P, Sidani S, Craig D, Pringle D. Effects of an abilities-focused program of morning care on residents who have dementia and on caregivers. *J Am Geriatr Soc.* 2000;48(4):442-449.

44. Fritsch T, Kwak J, Grant S, Lang J, Montgomery RR, Basting AD. Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *Gerontologist.* 2009;49(1):117-127.

45. Zimmerman S, Williams CS, Reed PS, et al. Attitudes, stress, and satisfaction of staff who care for residents with dementia. *Gerontologist.* 2005;45 Spec No 1(1):96-105.

46. Livingston G, Johnston K, Katona C, Paton J, Lyketsos CG. Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *Am. J. Psych.* 2005;162(11):1996-2021.

Chapter 2

Supporting direct care workers in dementia care: effects of a psycho-educational intervention

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Abstract

An experimental study using a pre-posttest control group design was conducted to assess the effects of a person-centered care based psycho-educational intervention on direct care workers' stress, burnout and job satisfaction. The intervention aimed to develop person-centered care competences and tools for stress management. Four aged-care facilities were randomly assigned to a psycho-educational or an education-only intervention (control). Data were collected from fifty-six direct care workers (female, mean age 44.72±9.02) through measurements of burnout (Maslach Burnout Inventory), job satisfaction (Minnesota Satisfaction Questionnaire-short form) and stress (Perceived Stress Scale) and focus-group interviews. Results showed significant positive effects in emotional exhaustion ($p=0.029$) and positive but no significant effects in stress and job satisfaction. According to qualitative data, the experimental group perceived enhanced group cohesion, emotional management and self-care awareness. Psycho-educational interventions may contribute to reduce direct care workers' burnout. Further work is needed to determine the extent of its benefits.

Keywords: burnout, dementia, direct care workers, job satisfaction, stress, person-centered care

1. Introduction

The number of older adults living with dementia worldwide has been increasing and will continue to do so over the coming years[1]. Currently, around one-third to one-half of people with dementia in high income countries are cared for in aged-care facilities (i.e., places of collective living that provide health, personal care and supportive services)[2].

Direct care workers (DCWs) represent the largest component of the workforce in aged-care facilities[3]. They provide the most basic activities of daily life and have the most frequent contact with the residents, being more likely to influence the quality of life and quality of care provided to people with dementia[3]. However, dementia-related behaviors (e.g., agitation) along with an inadequate education and training in dementia care, a high workload, interpersonal conflicts or a non-supportive leadership contribute to high levels of DCWs' stress, burnout and job dissatisfaction and compromise the quality of care and residents' wellbeing[4,5].

Until recently, the development and implementation of educational interventions to foster DCWs' dementia care skills has been the main researchers' concern. Emerging philosophies, such as person-centered care (PCC), are increasingly used to describe high-quality care and have become the cornerstone of such interventions. Education on PCC aim to help DCWs to provide a care that asserts: the human value of people with dementia and those who care for them; the individuality of people with dementia; the importance of relationships and interactions and their potential for promoting residents' wellbeing[6,7]. The latter emphasizes the importance of considering the needs of those who care and ways of supporting and enhancing their response to the person with dementia. Although PCC places the resident's experience at the centre of quality care, it recognizes that if DCWs are to deliver such care they need to have their own emotional strains acknowledged[6,7].

The literature has been focused on the benefits of PCC education for residents. Lowered agitation and aggression[8,9,10], increased engagement in daily activities[11] and improved wellbeing[10,12] have been described. Considering the relational nature of PCC, one might to expect that DCWs would benefit from PCC education, however, the effects of PCC interventions on workers' stress, burnout or job satisfaction are not always detectable nor significant[13,14]. This suggests that interventions need to extend beyond DCWs' educational needs to also address emotional and relational skills, which, despite the rhetoric of PCC are still undervalued.

Adding to an educational component a supportive one, aiming to provide DCWs with tools for stress and emotional management, holds promise as a means of driving forward benefits for DCWs and care provision[15]. Thus, this study aimed to analyze the effects of a PCC-based psycho-educational (PE) intervention on DCWs' work-related stress, burnout and job satisfaction. It is hypothesized that, compared to education-only, an intervention offering both educational and emotional support is more effective in reducing DCWs' stress, burnout and job dissatisfaction.

2. Design and methods

2.1. Design and settings

An experimental study, using a pre-posttest control group design was conducted in four aged care residential facilities of the central region of Portugal, between November 2011 and March 2013.

After having been grouped into clusters of similar staff/resident ratio and residents with dementia/total of residents' ratio, two pairs of facilities of the same cluster were selected. The managers of each facility were then contacted to present the aims of the study and to address their availability to participate. All accepted to participate and guaranteed no simultaneous participation in similar studies or significant organizational changes during the intervention. After recruitment, the facilities within each pair were randomly assigned to the experimental group - PE intervention - or control group - education-only intervention - using a random number generator. This decision was supported by the fact that education has become the most widely used approach with DCWs. Randomization occurred at the facility level because of possible contamination.

Study facilities were private, non-profit institutions of collective accommodation with more than 30 licensed beds, with a staff/resident ratio between 1:2 and 1:3 and a residents with dementia/total of residents' ratio between 1:3 and 1:4.

The study received approval from the Health Sciences Research Unit: Nursing (UICISA: E), Portugal (Ref. 5-11/2010).

2.2. Participants

The service managers of each facility were asked to identify all DCWs that provided morning personal care (i.e., period of time between 07am and 12am when DCWs are involved on activities related to bathing, grooming, dressing and toileting) to people with dementia in a regular basis; and were employed for at least 2 months. Temporary DCWs and trainees were excluded as it was not possible to ensure their participation until the end of the study. A meeting with eligible DCWs was then scheduled to elucidate the study and invite them to participate. They were informed about the voluntary nature of their participation and their anonymity and confidentiality were assured. Written informed consent was obtained prior to any data collection.

All eligible DCWs (n=58) agreed to participate and entered the study at baseline – 27 in the experimental group and 31 in the control group. Of these, 56 completed the post-test questionnaires (dropouts occurred in the control group and were due to sick leave) and 50 participated in the post-test interviews. Eight workers were unable to attend the interviews due to to sick leave (n=2) or incompatible schedules (n=6). Dropouts occurred mainly in the control group (n=6).

2.3. Interventions

Psycho-educational intervention

The experimental group received a PCC-based PE intervention consisting of 8 weekly sessions of approximately 90 minutes.

The intervention design was informed by: relevant literature on psycho-educational approaches, PCC and dementia; findings from a pilot-study conducted by authors' team[15,16]; interviews with DCWs and managers about training and emotional needs[17]. The latter suggested the need for: information and skills to manage dementia-related behaviors and interact with residents; knowledge about residents' biographies; practical guidance; and support to improve teamwork, workload and time management[17].

Each session comprised two components - educative and supportive (Table 10) - coordinated by a gerontologist and a physical therapist with previous experience in facilitating PE interventions. These facilitators adopted an active and empathetic posture, reinforced DCWs' competencies and resources and mediated the interaction between group participants.

The educative component lasted approximately 60 minutes and aimed to provide DCWs with: principles of PCC (e.g., interpret behavior from the person's viewpoint and recognition of residents' life histories); basic information about dementia; verbal and non-verbal communication strategies to interact with residents (e.g., maintain eye contact and use short, simple sentences); and PCC-based interaction strategies including, motor stimulation (e.g., encourage the person to perform one task or a part of it) and multisensory stimulation (e.g., provide a massage while washing resident's hair). In the 3 days following each session, the same professionals assisted each DCW individually during morning care, clarifying doubts and making suggestions to implement more PCC. Supportive skills were not addressed during individual assistance.

Morning care is considered the period where more interaction between DCWs and residents occurs and dementia-related behaviors are more frequent[18].

At the supportive component participants were taught coping strategies to manage work-related stress and prevent burnout (e.g., time-management and teamwork). At the end of each supportive component, relaxation techniques (e.g., abdominal breathing and guided imagery), stretching and strengthening exercises were practiced.

All participants were given hand-outs with relevant information. Active-learning methods were used during sessions, including: group discussions, role-playings or brainstorming.

Education-only intervention

The control group received an education-only intervention entailing 8 weekly sessions. It was the absence of the supportive component (including the final stretching and strengthening exercises) that distinguished both interventions. The coordination, length, order and content of the sessions were the same as the educational component of the PE intervention. Participants were individually assisted during morning care by the same professionals, which helped DCWs to deliver more PCC and clarified doubts that emerged from sessions.

2.4. Data collection

Quantitative and qualitative methods were applied to enhance the understanding of the results[19]. Quantitative data included standardized outcome measures of perceived stress, burnout and job satisfaction that were applied two weeks before and two weeks after the intervention; qualitative data was collected through focus-group interviews with participants two weeks after the intervention.

Table 10. Content of the interventions

Session	Component	Experimental Group	Control Group
1	Educative	*Information about PCC and dementia:* Information about the concept and principles of PCC. Basic information on dementia, its causes, symptoms and evolution.	
	Supportive	*Emotional impact of caregiving:* The positive and negative impacts of the caregiving experience on personal and professional life; Abdominal breathing.	-
2	Educative	*Communication in dementia:* Communicative behavioral strategies to interact with residents with dementia. (e.g., give simple choices; use validation; allows time to respond; use individual's name and eye contact).	
	Supportive	*Conflict management:* Improving assertiveness through the DESC technique (Describe; Explain; Specify; Conclude) technique (Bower & Bower, 2004). Stretching and strengthening exercises.	-
3	Educative	*Challenging behaviors:* Information about challenging behaviors and strategies to deal with them.	
	Supportive	*Teamwork:* The importance, benefits and constraints to teamwork; strategies to enhance cooperation between DCWs (e.g., active listen, positive feedback). Cognitive relaxation technique.	-
4	Educative	*The environment and dementia*: Strategies to enhance the physical and social environment for the person with dementia (e.g., decrease background noise; post signs as reminders); information about the risk factors and strategies to prevent falls.	
	Supportive	*Deal with emotions:* Improving emotion-management strategies through the activity "six colors to think" (based on Bono, 1985); Stretching and strengthening exercises.	-
5	Educative	*Motor stimulation:* Information about motor stimulation; strategies to enhance residents' involvement in daily care (e.g.,, break the small steps of an activity); and techniques for the moving and handling of residents.	
	Supportive	*Time management:* The impact of poor time management on personal and professional life and tools for better time management (e.g., set priorities; use a planning tool). Mental body-scan.	-
6	Educative	*Multisensory stimulation - olfaction:* Information about multisensory stimulation; dementia-related olfactory changes and strategies to stimulate the olfaction during the daily care (e.g., use shower gel of different fragrances; place aroma diffusers in the bedroom)	
	Supportive	*Problem-solving:* Using the problem-solving technique: (a) identify the problem; (b) explain the problem; (c) create solutions; (d) choose one solution; (e) plan the implementation of the solution; (f) evaluate the efficacy. Stretching and strengthening exercises	-
7	Educative	*Multi-sensory stimulation – vision and tactile stimulation:* The importance of vision and touch for people with dementia, dementia-related visual and tactile changes; strategies to stimulate the vision (e.g., reality orientation) and touch (e.g., hand massage during bath)	
	Supportive	*Relaxation*: Yoga	-
8	Educative	*Multi-sensory stimulation – audition and taste:* The importance of audition and taste for people with dementia; dementia-related audition and taste changes; strategies to stimulate the audition (e.g., listen to residents' favorite song) and taste (e.g., brush the person's teeth with toothpastes of different flavors).	
		Celebration and finalization	

Quantitative data

Socio-demographic data. A socio-demographic questionnaire, including variables such as gender, age, education, marital status and length of time at the facility, was designed to collect DCWs' background data at baseline.

Perceived stress. The Portuguese version of the Perceived Stress Scale (PSS)[20] was used to assess DCWs' perception of life stress in the past month. The PSS consists of 13 items (item 12 was excluded from the original version[21] given its weak psychometric properties) rated on a 5-point Likert-type scale ranging from "never" (0) to "very often" (4). Higher scores correspond to higher degrees of perceived stress. The PSS has been used in previous studies in this field, reporting high levels of reliability[22]. The used version demonstrated high internal consistency (α=0.76).

Burnout. The Portuguese version of the Maslach Burnout Inventory (MBI) - Human Services Survey was used to assess DCWs' experience of burnout[23]. The MBI has been the most widely used measure of DCWs' burnout[24,25,26]. It consists of 22 items divided into three subscales: emotional exhaustion (EE), depersonalisation (DP) and personal accomplishment (PA). The EE subscale (8 items) assesses feelings of being emotionally exhausted by one's work. The DP subscale (5 items) measures the negative attitudes toward recipients' care. The PA subscale (8 items) assesses feelings of competence and successful achievement in work. The MBI is a 7-point Likert-type scale, ranging from "never" (0) to "every day" (6). For EE and DP subscales, higher mean scores correspond to higher degrees of burnout. Lower mean scores on PA subscale mean higher degrees of burnout. The Portuguese version demonstrated high internal consistency (α=0.75). Reliability coefficients of 0.80, 0.71 and 0.70 were found for EE, DP and PA, respectively[23].

Job satisfaction. The Portuguese version of the short-form Minnesota Satisfaction Questionnaire (MSQ)[27] was used to assess DCWs' job satisfaction. It includes 20 items rated on a 5-point Likert-type scale ranging from "extremely dissatisfied" (1) to "extremely satisfied" (5). Item responses are summed or averaged to create a total score – the lower the score, the lower the level of job satisfaction.

Besides a total score, the short-form MSQ can also be scored for intrinsic and extrinsic satisfaction. The intrinsic subscale includes 6 items with scores ranging between 1 and 30 and refers to how people feel about the nature of the job tasks themselves. The extrinsic satisfaction subscale contains 8 items ranging from 8 to 40 and refers to how people feel about aspects of the work situation that are external to the job tasks or work itself[27]. The MSQ has been widely used, with previous researches reporting high levels of reliability[28,29]. The used version had excellent internal consistency (α=0.93).

Qualitative data

Qualitative data was collected through 8 focus-groups interviews (two in each facility) with 5-12 participants. They were conducted by the first author in a private and quiet room of each facility. A semi-structured interview guide with open-ended questions was used. The interview aimed to collect DCWs' perceptions about the intervention and its impact on their working life. The moderator's role was to encourage participants' reflection and discussion, using probes to elaborate their responses (e.g., 'can you explain further?') while keeping a non-judgmental attitude. Each interview lasted approximately 45 minutes. Focus-groups were recorded with the interviewees' consent and transcribed *verbatim*.

2.5. Data analysis

Socio-demographic characteristics of the groups at baseline were defined using descriptive statistics and compared with independent *t* tests or χ^2 tests as appropriate.

Independent sample *t* tests were performed to examine differences between the groups at baseline. After running normality and homogeneity of variance tests, the repeated measures analysis of variance (RM-ANOVA) was used to assess group×time intervention effects for each outcome measure. *Partial eta squared* was interpreted as small (≤0.05), medium (0.05-0.25), large (0.25-0.50) and very large (≥0.50)[29]. The established level of significance was $p<.05$. Statistical analyses were performed using SPSS v20.0 (IBM Corp., Armonk, NY).

Data from the focus-groups was submitted to thematic analysis by two independent judges (first and last authors), as follows: the text was read several times to construct a sense of the text as a whole; preliminary codes were created, reflecting the interview questions; codes were organized into categories and then integrated into major themes; the categorization was discussed between the two judges until they reached a consensus; the other authors were individually asked to review the final categorization and make suggestions of improvement; both agree with the categorization and no suggestions were made. A qualitative data analysis software - webQDA (Portugal) - was used to manage data. All names were coded to protect participants' anonymity.

3. Results

3.1. Quantitative data

Demographic information

There were no significant differences between the groups in terms of socio-demographic data. Participants were all female with a mean age of 44.72±9.02 years. The majority were married (67.2%), 46.4% had the primary and middle school and 41.4% the high school. The average length of service was 9.61±3.72 years (Table 11).

Table 11. Baseline characteristics of DCWs (n=58)

Outcome	Total (n=58) N (%)	Experimental group (n=27) N (%)	Control Group (n=31) N (%)	χ^2	*df*	p-value
Gender						
Female	58 (100.0)	27 (100.0)	31 (100.0)	No statistical analysis possible		
Age in years						
M (SD)	44.72 (9.02)	43.37 (10.00)	45.90 (8.04)	1.069[a]	56	0.290
Marital Status						
Married	39 (67.2)	17 (63.0)	22 (71.0)			
Widowed	3 (5.2)	1 (3.7)	2 (6.5)			
Single	4 (6.9)	2 (7.4)	2 (6.5)	1.148	4	0.887
Divorced/separated	9 (15.5)	5 (15.5)	4 (12.9)			
Other	3 (5.2)	2 (7.4)	1 (3.2)			
Education						
Primary school[b]	15 (25.9)	4 (14.8)	11 (35.5)			
Middle school[c]	12 (20.7)	6 (22.2)	6 (19.4)			
High school[d]	24 (41.4)	11 (40.7)	13 (41.9)	6.857	4	0.144
College degree	1 (1.7)	1 (3.7)	0 (0.0)			
Other	6 (10.3)	5 (18.5)	1 (3.2)			
Length of service (years)						
M (SD)	9.61 (3.72)	9.84 (4.86)	9.42 (2.51)	-0.418[a]	56	0.678

Abbreviations: M= mean; SD= standard deviation; *df*= degrees of freedom

[a] t-test student

[b]1–4 years of education;[c]5–9 years of education; [d]10–12 years of education.

DCWs' perceived stress, burnout and job satisfaction

Data concerning DCWs' outcomes is presented in Table 12. At baseline there were no significant differences between the groups in perceived stress, burnout or job satisfaction.

Within both groups there was a positive change from pre to post-test on the DCWs' perceived stress. However, the differences were not significant (p=0.826) and the effect size was irrelevant (η^2partial=0.001).

Analyses revealed a significant group×time interaction effect on the emotional exhaustion scores. DCWs in the experimental group had reduced emotional exhaustion scores, whereas the scores in the control group increased immediately after the intervention (p=0.029). Effect sizes were moderate (η^2partial=0.095). No differences were found for the remaining MBI subscales.

Both groups showed moderate levels of job satisfaction. The experimental group showed a positive change from pre to post-test on this outcome, whereas in the control group change was minimal. Yet, no significant differences (p=0.618) or effect sizes (η^2partial=0.005) were obtained. Also, no differences were detected for both intrinsic (p=0.388) and extrinsic (p=0.133) subscales.

Table 12. Results of the repeated measures ANOVA

Outcome	Experimental group (n=27)		Control group (n=31)		Group x Time effect	ES
	Pre-test	Post-test	Pre-test	Post-test		
	Mean (SD)		Mean (SD)			
PSS	19.74 (6.16)	18.93 (6.60)	20.55 (6.31)	20.10 (4.79)	F=0049, *df*(1) p=0.826	0.001
MBI						
EE	16.08 (11.15)	14.88 (8.62)	12.67 (10.59)	15.42 (9.72)	F=0.251, *df*(1) p=0.029	0.095
DP	5.93 (5.67)	6.70 (6.05)	6.07 (5.71)	5.52 (4.01)	F=0.732, *df*(1) p=0.396	0.013
PA	38.89 (6.84)	36.59 (9.74)	40.69 (6.20)	37.31 (8.02)	F=5.058, *df*(1) p=0.618	0.005
MSQ						
MSQ intrinsic	24.18 (2.20)	23.89 (2.14)	22.55 (4.19)	21.55 (3.53)	F=0.757, *df*(1) p=0.388	0.014
MSQ extrinsic	26.85 (4.57)	26.40 (3.54)	24.62 (4.84)	25.59 (4.15)	F=2.232, *df*(1) p=0.133	0.041
Total	72.74 (6.04)	73.7 (8.18)	68.14 (9.06)	68.55 (10.13)	F=0.101, *df*(1) p=0.618	0.005

Abbreviations: PSS= Perceived Stress Scale; MBI= Maslach Burnout Inventory; EE=Emotional Exhaustion; DP= Depersonalization; PA= Personal Accomplishment; MSQ= Minnesota Satisfaction Questionnaire; ES= Effect Size

3.2. Qualitative data

Seven major themes were identified concerning the DCWs' perceptions about the intervention and its impact on their working life. Three themes emerged only within the experimental group: group cohesion; better emotional management and; self-care awareness.

According to participants, the PE intervention encouraged the sharing of personal experiences and a sense of closeness between peers, giving an opportunity for participants to get to know each other. DCWs reported becoming more aware of the other members' emotions, which increased mutual understanding:

> *"The way we interact has improved. We had the opportunity to learn things of each other that we otherwise would not know."* [DCW2, experimental group]
> *"It made us realize that we must try to understand our colleagues' perspective."* [DCW3, experimental group]

The PE intervention helped participants to deal with emotions more effectively, with DCWs feeling more thoughtful and experiencing increased self-control toward residents' behaviors:

> *I'm calmer. I no longer work with the same anxiety. Now we reflect, we breathe before doing things."* [DCW4, experimental group]

DCWs also reported becoming more aware of the importance of self-care and realized that their wellbeing is closely related to residents' wellbeing:

> *"I've been thinking a little more about me. We tend to forget ourselves, we are always more concerned with our work or our family. Now I'm aware that if we don´t feel healthy we will not be able to support others."* [DCW3, experimental group]

Four themes were shared between the groups: self-worth feelings; increased knowledge about dementia; increased knowledge about the person; and PCC awareness.

Participants reported feeling valued, as their skills and efforts were appreciated and recognized as adequate by facilitators. The recognition of their worth allowed them to improve care practice and enhance job enthusiasm:

> *"We never had such an appreciation! The facilitators have told us 'good work, congratulations'. I think this motivate us to carry on and improve."* [DCW2, experimental group]
> *"We have been valued. During the individual assistance the facilitators told us "you are doing well" which is essential for us.*" [DCW5, control group]

Receiving information helped DCWs from both groups to understand the syndrome better, particularly how to interpret and manage residents' behaviors. The acquisition of new information enhanced their attitude and commitment to work:

> *"We had no knowledge about dementia or why those behaviors occurred and your intervention helped us to understand and manage those behaviors".* [DCW1, experimental group]
> *"Now we know that their behavior might be explained by several reasons. (…) and we fell more committed to work*." [DCW6, control group]

Both interventions allowed participants to better understand the residents. Being aware of the person's background and preferences helped DCWs to interact with the resident and improved the quality of care provision:

> *"We are more familiar with the residents´ past history which helps us to understand certain behaviors."* [DCW2, experimental group]
> *"Now we know how to start a conversation with them. When we consider their past history they interact more with us."* [DCW7, control group]

Also, interventions improved DCWs' competences on PCC. Participants reported being more aware of the importance of fostering the residents' independence, communicating and promoting their active participation during care routines:

> *"Now during care practice I stop to ask them 'help me' and I interact a little more. The small details as 'comb up, get up or wear your shoes' helped them to be more active."* [DCW8, experimental group]
> *"Now, we communicate more frequently with residents or let them cooperate during care practices."* [DCW9, control group]

When asked about hindering factors, *workload,* as a result of the *lack of time and the shortage of staff*, was highly emphasized. According to several participants, this constrained DCWs' ability to communicate and foster the residents' active participation during morning care routines:

> *"We would like to have more possibilities to let them [residents] participate, but we can't"* [DCW10, experimental group]

Participants missed collaboration from their managers and reported feeling unappreciated as they obtain no recognition for their physically and emotionally labor-intensive care. This lack of recognition was stated to discourage practice change and to enhance dissatisfaction:

> *"There is a lack of collaboration from managers, a lack of interest to hear us and a lack of support and recognition of our work. If we had it, we probably were more motivated to improve practice."* [DCW5, control group]

Also, DCWs considered that many of their skills were developed from practice, often through years of experience, which is associated with some resistance to change. Change, according to participants, is harder given *the short duration of the intervention.*

4. Discussion

This study sought to assess the effects of a PCC based psycho-educational (PE) on DCWs' work-related stress, burnout and job satisfaction.

Significant differences were found for emotional exhaustion (MBI): the experimental group score for this variable was significantly reduced after the intervention whereas in the control group it increased significantly. This suggests that providing emotional support along with knowledge and skills for PCC can be effective in reducing DCWs' burnout.

Data obtained from the focus-group interviews provided information that may have contributed to this result. According to qualitative data, both interventions improved participants' feelings of worth, awareness of PCC and knowledge about dementia and about the person. Yet, participants from the experimental group also reported enhanced group cohesion, emotional management and self-care awareness, which have been considered important determinants of emotional exhaustion[31]. These findings suggest that education - common to both groups - can provide DCWs with useful knowledge and skills relevant for quality dementia care. However, adding a supportive component to educational interventions might be a key ingredient to lessen DCWs' burnout as it enables them to nurture positive relationships at work, to better regulate their emotions and to effectively cope with distress. Without emotional support, workers can possess fewer abilities to cope with their emotions when faced with challenging situations.

No significant effects were obtained for depersonalization and personal accomplishment. Nevertheless, burnout is believed to be a process that begins with emotional exhaustion and develops over time[32]. The reduction in the exhaustion level predicts changes over time in the two other components. Besides, depersonalization and personal accomplishment are highly resistant to change[32].

The experimental group showed a positive but non-significant change from pre to post-test on perceived stress and job satisfaction. Three factors could account for these findings. The first has to do with the possible lack of responsiveness of the outcome measures to changes over time. The PSS asked participants to rate how they have been feeling over the last month, which can be a short period of time to capture meaningful changes on stress levels. The MSQ is based on the conceptualization of job satisfaction as a multidimensional construct, including several aspects that were not covered by the intervention (e.g., managers' support and organization conditions).

The second relates to organizational characteristics. From qualitative data it was possible to discern that DCWs' outcomes can be affected by perceptions of workload and poor leaderships' support. This is consistent with findings from previous studies[33,34,35]. Efforts to intervene at the organizational level could be a determinant to engendering more positive impact on DCWs' stress and job satisfaction. This could be accomplished by extending the focus of interventions to service and top-level managers so that they could provide DCWs with constructive feedback and supervision or make the necessary modifications in the organizational structures for DCWs use the new skills[36].

Lastly, participants from both groups were assisted during morning care routines, which might have reduced the differences between them. Individual assistance is considered a key complementary factor to educational sessions that helps to endorse practice change[37]. Still, by allowing workers to have immediate guidance and support to handle challenging situations, it can have an independent effect on DCWs' stress and job satisfaction. The impact of individual assistance on DCWs' outcomes is worthy of further consideration.

Some limitations should be acknowledged. First, the relatively small sample size could have reduced the statistical power to detect more significant changes. Second, results may have been influenced by the short implementation period. A small study period has been selected given the risk that the intervention could create an additional burden for DCWs. However, according to the qualitative data, this burden was inexistent as participants stressed the need for a longer intervention to attain greatest effects. Third, although participants were blinded to the experimental or the control group, it was not possible to blind the researchers to the intervention or assessments. Therefore, studies with larger samples, longer implementation periods and a double-blind design should be conducted to clarify these findings. At last, participants were recruited after the clusters have been randomly allocated which could have led to selection bias. It is possible that significantly different levels of residents' challenging behavior or other important confounding variables could have accounted for the modest post-test effects but further research is needed to clarify this.

Despite the limitations, the results of this study provide preliminary evidence of the effectiveness of a PCC-based PE intervention on DCWs. The findings are encouraging and highlight the importance of interventions to go beyond DCWs' knowledge and instrumental skills to also address emotional and relational competences, including interpersonal and self-care skills, which have been considered important determinants of DCW's strain[4,5].The importance of this has been acknowledged within the 'relationship-centered care' (RCC)[38]. RCC is an approach that captures the important dimensions of interdependent relationships necessary to create an enriched environment of care in which the resident and workers' needs are addressed[37]. It is therefore suggested as a promising framework for future interventions within the long-term care context.

Also, this study relies in a mixed methodology which can leverage the benefits of both quantitative and qualitative methods, offering a comprehensive analysis and interpretation of the data. Qualitative data was invaluable as it revealed in more detail how DCWs perceive the effects of the intervention while enabling new avenues of research to develop. This includes the need to extend the focus of interventions to top-level managers in order to minimize organizational factors of DCWs' strain and dissatisfaction.

5. References

1. World Health Organization. *Dementia: a public health priority.* Geneva: WHO; 2012.
2. Prince M, Prina M, & Guerchet M. *World Alzheimer Report - Journey of Caring: An analysis of long-term care for dementia*. London: Alzheimer's Disease International; 2013.
3. Stone R. The Long-Term Care Workforce: From Accidental to Valued Profession. In: Wolf D, Folbre N, eds. *Universal Coverage of Long-Term Care in the United States: Can We Get There from Here?* United States: Russell Sage Foundation; 2012.
4. Edberg AK, Bird M, Richards DA, Woods R, Keeley P, & Davis-Quarrell V. Strain in nursing care of people with dementia: Nurses' experience in Australia, Sweden and United Kingdom. *Aging Ment Health*. 2008;12(2): 236-243.
5. Gray-Stanley JA, Muramatsu N. Work stress, burnout, and social and personal resources among direct care workers. *Res Dev Disabil.* 2011;32(3):1065-1074.
6. Brooker D. *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers; 2007.
7. Kitwood T. *Dementia Reconsidered: The Person Comes First.* Buckingham: Open University Press; 1997.
8. Chenoweth L, King MT, Jeon YH, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol.* 2009;8(4):317-325.
9. Fossey J. Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ.* 2006;332(7544):756-761.
10. Sloane PD, Hoeffer B, Mitchell CM, et al. Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *J Am Geriatr Soc.* 2004;52(11):1795-1804.
11. Sidani S, Streiner D, Leclerc C. Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. *Int J Older People Nurs.* 2012;7(1):37-45.
12. McKeown J, Clarke A, Ingleton C, Ryan T, Repper J. The use of life story work with people with dementia to enhance person-centred care. *Int J Older People Nurs.* 2010;5(2):148-158.

13. Barbosa A, Sousa L, Nolan M, Figueiredo D. Effects of Person-Centered Care Approaches to Dementia Care on Staff: A Systematic Review. *Am J Alzheimers Dis Other Demen*. 2014. doi:10.1177/1533317513520213
14. van den Pol-Grevelink A, Jukema JS, Smits CH. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *Int J Geriatr Psychiatry.* 2012;27(3):219-229.
15. Figueiredo D, Barbosa A, Cruz J, Marques A, Sousa L. Empowering Staff in Dementia Long-Term Care: Towards a More Supportive Approach to Interventions. *Educ Gerontol.* 2013;39(6): 413-427.
16. Marques A, Cruz J, Barbosa A, Figueiredo D, Sousa L. Motor and Multisensory Care-Based Approach in Dementia: Long-Term Effects of a Pilot Study. *Am J Alzheimers Dis Other Demen*. 2012; 28(1):24-34.
17. Barbosa **A,** Nolan M, Sousa L, Figueiredo, D. Psycho-educational approaches in long term care homes: exploring direct care workers and managers' perspectives. *Procedia Soc Behav Sci.* 201; 131:406-410.
18. Sidani S, Leclerc C, Streiner D. Implementation of the abilities-focused approach to morning care of people with dementia by nursing staff. *Int J Older People Nur.* 2009; 4(1):48-56.
19. Creswell J, Clark V. *Designing and Conducting Mixed Methods Research* (2nd ed.). United States of America: Sage Publications, Inc; 2011.
20. Pais Ribeiro J, Marques T. A avaliação do stresse: a propósito de um estudo de adaptação da escala de percepção de stresse. *Psicologia, Saúde & Doenças.* 2009;10:237-248.
21. Cohen S, Karmarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav.* 1983;24:385-396.
22. Shapiro SL, Astin JA, Bishop, SR, Cordova M. Mindfulness-based stress reduction for health care professionals: results from a randomized trial. *Int J Stress Manage.* 2005;12(2):164.
23. Melo B, Gomes A, Cruz J. Desenvolvimento e adaptação de um instrumento de avaliação psicológica do "burnout" para os profissionais de Psicologia. In: Associação dos Psicólogos Portugueses, ed. *Avaliação psicologica: formas e contextos.* Braga: Lusografe; 1999:596-603

24. Jeon YH, Luscombe G, Chenoweth L, et al. Staff outcomes from the Caring for Aged Dementia Care REsident Study (CADRES): A cluster randomised trial. *Int J Nurs Stud.* 2012;49(5):508-518.
25. Schrijnemaekers VJJ, van Rossum E, Candel MJJM, et al. Effects of emotion-oriented care on work-related outcomes of professional caregivers in homes for elderly persons. *J Gerontol B-Psychol.* 2003;58(1):S50-S57.
26. van Weert JCM, van Dulmen AM, Spreeuwenberg PMM, Bensing JM, Ribbe MW. The effects of the implementation of snoezelen on the quality of working life in psychogeriatric care. *Int Psychogeriatr.* 2005;17(03):407.
27. Ferreira J, Fernandes R, Haase RF, Santos E. Minnesota Satisfaction Questionnaire - Short Form: estudo de adaptação e validação para a língua portuguesa. *Psychologica.* 2009;51:251-281.
28. Baillon S, Scothern G, Neville PG, Boyle A. Factors that contribute to stress in care staff in residential homes for the elderly. *Int J Geriatr Psychiatry.* 1996;11(3):219-226.
29. Coogle CL, Head CA, Parham IA. The Long-Term Care Workforce Crisis: Dementia-Care Training Influences on Job Satisfaction and Career Commitment. *Educ Gerontol,* 2006;32(8):611-631.
30. Cohen J. *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). New Jersey: Lawrence Erbaum Associates;1988.
31. Houkes I, Janssen PP, Jonge J, Bakker AB. Specific determinants of intrinsic work motivation, emotional exhaustion and turnover intention: A multisample longitudinal study. *J Occup Organ Psychol.* 2003;76(4):427-450.
32. Maslach C, Schaufeli WB, Leiter, MP. Job burnout. *Annu Rev Psychol.* 2001;52:397-422.
33. Aylward S, Stolee P, Keat N, Johncox V. Effectiveness of continuing education in long-term care: a literature review. *Gerontologist.* 2003;43(2):259-271.
34. Davison TE, McCabe MP, Visser S, Hudgson C, Buchanan G, George K. Controlled trial of dementia training with a peer support group for aged care staff. *Int J Geriatr Psychiatry.* 2007;22(9):868-873.
35. Visser SM, McCabe MP, Hudgson C, Buchanan G, Davison TE, George K. Managing behavioural symptoms of dementia: Effectiveness of staff education and peer support. *Aging Ment Health*. 2008;12(1):47-55.

36. McSherry R, Pearce P, Grimwood K, McSherry W. The pivotal role of nurse managers, leaders and educators in enabling excellence in nursing care. *J Nurs Manage,* 2012;20(1):7-19.
37. McCabe MP, Davison TE, George K. Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging Ment Health,* 2007;11(5):505-519.
38. Nolan M, Davies S, Brown J, Keady J, Nolan J. Beyond person-centred care: a new vision for gerontological nursing. *J Clin Nurs*, 2004;13(3a):45-53.

Chapter 3

Effects of a psycho-educational intervention on direct care workers' communicative behaviours with residents with dementia

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Abstract

This study assessed the effects of a person-centred care based psycho-educational intervention on direct care workers' communicative behaviours with people with dementia living in aged-care facilities. An experimental study with a pre-posttest control group design was conducted in four aged-care facilities. Two experimental facilities received an eight-weekly psycho-educational intervention aiming to develop workers' knowledge about dementia, person-centred care competences and tools for stress management. Control facilities received education-only, with no support to deal with stress. A total of 332 morning care sessions, involving fifty-six direct care workers (female, mean age 44.72±9.02), were video-recorded before and two weeks after the intervention. The frequency and duration of a list of verbal and non-verbal communicative behaviours were analysed. Within the experimental group there was a positive change from pre to post-test on the frequency of all workers' communicative behaviours. Significant treatment effects in favour of the experimental group were obtained for the frequency of inform ($p<0.01$, $\eta 2$partial=0.09) and laugh ($p<0.01$, $\eta 2$ partial=0.18). Differences between groups emerged mainly in non-verbal communicative behaviours. The findings suggest that a person-centred care based psycho-educational intervention can positively affect direct care workers' communicative behaviours with residents with dementia. Further research is required to determine the extent of the benefits of this approach.

Keywords: aged-care facilities; communicative behaviour; dementia; direct care workers; person-centred care

1. Introduction

For decades, the care provided for people with dementia in aged-care facilities has been largely dominated by the Bio-medical model. This was based on the biological aspects of the illness, considering brain damage as the only explanation for dementia-related symptoms and behaviours (Sabat, 2008). In the 1990s, the pioneering work of Tom Kitwood called for a broader understanding of dementia and a new culture of dementia care. Kitwood had encouraged a person-centred care (PCC) approach within dementia care, advocating that dementia-related symptoms and behaviours are affected not only by neuropathology, but also by the ways in which the person is treated by others (Kitwood, 1997).

On his ‘dialectical framework’, Kitwood theorises about the interpersonal processes involved in formal caregiving and the impact that workers’ interactions may have on the person with dementia. He defines two groups of interactions that usually occur in the care of people with dementia, categorizing them into Positive Person Work (PPW) and Malignant Social Psychology (MSP) (Kitwood, 1997). The PPW consists of workers’ communicative behaviours that are therapeutic and helpful in maintaining an individual’s personhood, including: recognition, negotiation, collaboration, validation and stimulation. MSP includes communicative behaviours that damage the residents’ self-esteem and personhood, including: invalidation, infantilisation, ignoring and objectification. With this framework, the author emphasises the relational nature of PCC and the need to provide workers with the skills they need to enhance the PPW and reduce the MSP.

A number of PCC-based interventions have been developed to increase the knowledge and communicative behaviours of direct care workers (DCWs), who provide the bulk of care to people with dementia in aged-care facilities (McGilton et al., 2007; Williams, Kemper, & Hummert, 2003). These are generally education-only interventions focusing on specific care tasks, particularly morning care routines (Sidani, Streiner, & Leclerc, 2012). However, findings show that even after the intervention when verbal interaction occurs it is predominantly task-focused, overlooking residents’ social and emotional needs (McGilton et al., 2007; Williams, Kemper, & Hummert, 2003). Also, in-depth analyses of the content of conversations confirm that DCWs’ communication tends to reinforce resident’s dependent behaviours rather than their empowerment (Levy-Storms, 2008; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). This suggests that providing DCWs with information on how they should behave is not enough to lead to communicative behaviours change. While education is a necessary part of behaviour change, previous research has shown that DCWs' emotional wellbeing also affects their ability for interaction (Edvardsson, Winblad, & Sandman, 2008; van Weert, Vandulmen, Spreeuwenberg, Ribbe, & Bensing, 2005). Though, the literature has indicated that heavy workloads, interpersonal conflicts or lack of management support threaten DCWs' emotional wellbeing, being associated with high levels of stress, burnout and dissatisfaction (Edvardsson, Sandman, Nay, & Karlsson, 2009).

Complementing traditional education-only interventions with a supportive component aiming to develop tools for emotional management, can potentially improve person-centred interactions, yet, this has received little attention in the literature (Figueiredo, Barbosa, Cruz, Marques, & Sousa, 2013). Therefore, the current study assessed the effects of a PCC-based psycho-educational (PE) intervention on DCWs' verbal and non-verbal communicative behaviours with residents with dementia during morning care. Specifically, it was hypothesised that this intervention, compared to a PCC-based education-only intervention, would improve DCWs' positive verbal and non-verbal communicative behaviours and reduce DCWs' negative verbal and non-verbal communicative behaviours.

2. Method

2.1. Study design

An experimental study with a pre-posttest control group design was conducted in four aged care residential facilities. Two facilities received a PCC-based PE intervention, whereas two control facilities received an education-only intervention. The decision to establish the education-only intervention as control group was based on the fact that this has become the most widely used approach with DCWs. The study was conducted between November 2011 and March 2013. Ethical approval was obtained from the Health Sciences Research Unit: Nursing (UICISA: E) (Ref. 5-11/2010).

2.2. Settings and participants

The enrolment of the facilities was conducted as follows: (i) facilities were pre-stratified based on staff/resident ratio and residents with dementia/total of residents ratio; (ii) two pairs of facilities were approached for participation; (iii) managers of each facility were informed about the study and asked to participate; no simultaneous participation in similar studies and absence of significant organisational changes during the period of implementation had to be ensured; iv) facilities within each pair were randomly assigned to the experimental or control group using a random number generator. The facility was the unit of randomization to prevent contamination between groups. Study facilities were private, non-profit institutions of collective accommodation with more than 30 licensed beds and with a staff/resident ratio between 1:2 and 1:3.

After randomisation, the service managers of each facility were asked to identify all DCWs that: (i) provided regular personal care to residents with moderate-to-severe dementia, diagnosed by a physician according to DSM-IV; and (ii) worked in the facility for at least 2 months, so adjustments to the residents and facility had been achieved. Temporary workers and trainees were excluded as it was not possible to ensure their participation until the end of the intervention. Once identified, a meeting was arranged and potential DCWs were provided with detailed information about the study and were invited to participate. The voluntary nature of their participation, confidentiality and anonymity were assured and written informed consent was obtained. All 58 DCWs who were eligible agreed to participate and entered the study at baseline – 27 in the experimental group and 31 in the control group. Of these, 56 completed the post-test assessment. Two dropouts occurred in the control group (DCWs were absent from work due to sick leave).

Also, the legal guardians of the identified residents were contacted, informed about the study and asked to sign a written informed consent. From 51 residents with moderate-to-severe dementia, 47 participated (one legal guardian refused participation, one resident refused to be assessed by video and two residents died before data collection).

2.3. Intervention

PCC-based PE intervention

The experimental facilities received a PCC-based PE intervention. This comprised 8 weekly group sessions of approximately 90 minutes, facilitated by a gerontologist and a physiotherapist with training and experience in PCC approaches and psycho-educational groups.

The intervention design was informed by: (i) relevant literature on PE approaches, PCC and dementia; (ii) findings from a pilot study conducted by the authors' research team (Figueiredo et al., 2013; Marques, Cruz, Barbosa, Figueiredo, & Sousa, 2013); and (iii) interviews with DCWs and managers about instrumental and emotional needs (Barbosa, Nolan, Sousa & Figueiredo, 2013).

The intervention included two components: educative and supportive (Table 13).

The educative component aimed to provide DCWs with knowledge and skills concerning person-centred dementia care. The first session provided participants with basic information on dementia, its causes, symptoms and evolution. In sessions 2-8, participants were provided with knowledge and communicative behavioural strategies to interact with residents with dementia. Emphasis was placed on verbal and non-verbal communicative strategies (e.g., speak clearly and slowly, with short, simple sentences, maintain eye contact or smile), motor stimulation strategies (e.g., encourage the person to perform one task or a part of it), and multisensory stimulation strategies (e.g., provide a gentle massage while washing resident's hair). In the following 3 days after each session, the same facilitators assisted DCWs individually during morning care, clarifying doubts and making suggestions to help them implement a more PCC. Morning care (i.e., the period of time between 7:00 and 12:00 a.m. concerning activities relating to bathing, grooming, dressing and toileting) was chosen as this is the period where more interaction between DCWs and residents occurs and challenging behaviours are more frequent (Sidani, Streiner, & Leclerc, 2012).

The supportive component provided DCWs with coping strategies to manage work-related stress and prevent burnout (e.g., time-management and problem-solving). Also, relaxation techniques (e.g., abdominal breathing and guided imagery), stretching and strengthening exercises were practiced. Several active-learning methods were used during sessions, including: group discussions, role-playings or brainstorming.

PCC-based education-only intervention

The control facilities received an education-only intervention with 8 weekly sessions. The coordination, length, order and content of the sessions were the same of the educational component of the PE intervention. It was the absence of the supportive component that distinguished both interventions. Each participant was assisted during morning care by the same professionals, who helped DCWs to deliver a more PCC and clarified doubts that emerged from sessions.

Table 13. Content of the interventions

Session	Component	Experimental Group	Control Group
1	Educative	*Information about PCC and dementia:* Information about the concept and principles of PCC. Basic information on dementia, its causes, symptoms and evolution.	
	Supportive	*Emotional impact of caregiving:* The positive and negative impacts of the caregiving experience on personal and professional life; Abdominal breathing.	-
2	Educative	*Communication in dementia:* Communicative behavioral strategies to interact with residents with dementia. (e.g., give simple choices; use validation; allows time to respond; use individual's name and eye contact).	
	Supportive	*Conflict management:* Improving assertiveness through the DESC technique (Describe; Explain; Specify; Conclude) technique (Bower & Bower, 2004). Stretching and strengthening exercises.	-
3	Educative	*Challenging behaviors:* Information about challenging behaviors and strategies to deal with them.	
	Supportive	*Teamwork:* The importance, benefits and constraints to teamwork; strategies to enhance cooperation between DCWs (e.g., active listen, positive feedback). Cognitive relaxation technique.	-
4	Educative	*The environment and dementia*: Strategies to enhance the physical and social environment for the person with dementia (e.g., decrease background noise; post signs as reminders); information about the risk factors and strategies to prevent falls.	
	Supportive	*Deal with emotions:* Improving emotion-management strategies through the activity "six colors to think" (based on Bono, 1985); Stretching and strengthening exercises.	-
5	Educative	*Motor stimulation:* Information about motor stimulation; strategies to enhance residents' involvement in daily care (e.g., break the small steps of an activity); and techniques for the moving and handling of residents.	
	Supportive	*Time management:* The impact of poor time management on personal and professional life and tools for better time management (e.g., set priorities; use a planning tool). Mental body-scan.	-
6	Educative	*Multisensory stimulation - olfaction:* Information about multisensory stimulation; dementia-related olfactory changes and strategies to stimulate the olfaction during the daily care (e.g., use shower gel of different fragrances; place aroma diffusers in the bedroom)	
	Supportive	*Problem-solving:* Using the problem-solving technique: (a) identify the problem; (b) explain the problem; (c) create solutions; (d) choose one solution; (e) plan the implementation of the solution; (f) evaluate the efficacy. Stretching and strengthening exercises	-
7	Educative	*Multi-sensory stimulation – vision and tactile stimulation:* The importance of vision and touch for people with dementia, dementia-related visual and tactile changes; strategies to stimulate the vision (e.g., reality orientation) and touch (e.g., hand massage during bath)	
	Supportive	*Relaxation*: Yoga	-
8	Educative	*Multi-sensory stimulation – audition and taste:* The importance of audition and taste for people with dementia; dementia-related audition and taste changes; strategies to stimulate the audition (e.g., listen to residents' favorite song) and taste (e.g., brush the person's teeth with toothpastes of different flavors).	
		Celebration and finalization	

2.4. Data Collection

DCWs' background data at baseline was collected through a structured questionnaire including variables such as gender, age, education, marital status and length of time working in the facility.

Video-recordings of morning care routines were used to capture both DCWs' verbal and non-verbal communicative behaviours. Measurements were performed at baseline and two weeks after the intervention. The use of video-recording to assess behavioural observations enables to replay and review data, control observer's fatigue or drift and achieve deeper levels of observation and analysis that are not possible to achieve by means of real-time observations (Haidet, Tate, Divirgilio-Thomas, Kolanowski, & Happ, 2009).

Video-recordings were performed in the resident's bedroom. The camera started at the moment the DCWs entered the room and stopped when they left. Bathing was not recorded. Few strategies were considered to minimise participant's reactivity. Prior to data collection, several video-recordings were performed to familiarise participants with the methodology. ; DCWs were also instructed to stop or remove the video camera if they noticed any resident's negative reaction caused by the device's presence. Once the cameras were placed on a tripod and adequately positioned, the researcher left the room so that a further source of disruption could be avoided.

To ensure that DCWs' communicative behaviour was not due to chance, each participant was video-recorded thrice at baseline and after the intervention. In total, 332 morning care sessions were video-recorded (164 at baseline and 168 at post-intervention). At baseline, 4 participants were only recorded twice as they were absent from work.

2.5. Data analysis

Socio-demographic characteristics of the groups were defined using descriptive statistics and compared with independent t-tests or χ^2 tests as appropriate.

DCWs' communicative behaviour was studied by analysing the frequency and duration of a list of mutually exclusive behaviours (*ethogram*). The categories described in the Kitwood's dialectical framework (Kitwood, 1997), relevant literature on staff's verbal and non-verbal communication (van Weert et al., 2005; Caris-Verhallen, Kerkstra, &

Bensing, 1999) and preliminary observations of the video recordings formed the basis of the *ethogram*. The final list comprised 18 verbal communicative behaviours (Table 14) and 8 non-verbal communicative behaviours (Table 15).

One coder (1st author) rated the DCWs' communicative behaviours according to the *ethogram* using specialised software, Noldus Observer XT (version 11.0) (Noldus International Technology, Wageningen, Netherlands).

Video recordings were edited so they would have the length of the average duration (510 seconds [8 minutes and 30 seconds]) to compare the variables between the different participants and across different moments (pre- and post-intervention). For videos under the average duration (58%), proportional scores were used. Then, for each participant, the average results of the 3 videos collected at each moment were calculated and a repeated-measures ANOVA was run to assess time, group and group*time intervention effects. *Partial eta squared* (η2), which corresponds to the Effect Size, was interpreted as small (≥0.05), medium (0.05-0.25), large (0.25-0.50) and very large (≥0.50) (Cohen, 1988). The statistical power of the test was obtained. According to this, the greater the power the less likely the chances of making a Type II error, i.e., failing to detect an effect that is present (1 - ß). The established level of significance was $p < 0.05$. Statistical analyses were performed using SPSS v20.0 (IBM Corp., Armonk, NY).

Inter-observer reliability

Inter-observer reliability with two independent coders was performed for 30% of the videos. This value is similar to those of previous studies (Bourgeois, Dijkstra, Burgio, & Allen, 2004). The frequency and duration of each category in each moment were considered, using the intra-class correlation coefficient (ICC) equation (2,1) and the Bland and Altman method. The ICC(2,1) values were interpreted as follows: >0.75 was excellent, 0.40–0.75 was moderate and <0.40 was poor (Fleiss, 1986). The results ranged between 0.45 and 1.0, indicating a moderate to excellent reliability. Given the absence of values below 0.40, all rates were accepted.

Bland and Altman 95% limits of agreement were measured and the scatter plots were analysed for all categories. A good agreement between the coders was found and no evidence of systematic bias was observed.

Table 14. Verbal communicative behaviours

Categories	Description
Positive verbal communicative behaviours	
Consult	Consulting the person with dementia about his or her preferences, desires and needs. Includes questions that invite resident's judgment. Examples include: • Would you like your shoes on or off? • Do you want to wear a skirt or pants?
Inform	Guiding the resident in terms of what to expect and providing information about what is going to happen during the task. Examples include: • Now I'm going to comb your hair. • Today you will take a bath.
Involve	Giving the resident the opportunity to take care for him/herself as much as possible and just 'completing' the care task when necessary. Examples include: • Could you help me with this? • Hold the toothbrush with your hand.
Reward	Rewarding the person and his/her behaviour, giving compliments and using expressions of encouragement. Examples include: • Well done, Sr. John. • You can do it, Sr. John.
Validate	Acknowledging the subjective reality of a person's emotions and feelings, and giving a response on the feeling level, without correcting the residents' reality or frame of reference, even if it is chaotic. Using statements to interpret or recognise the emotional state of the resident during the interaction. Examples include: • This is distressing for you, I understand. • How do you feel about it?
Assess comfort	Conveying interest and concern for the welfare and comfort of the person with dementia. Examples include: • How are you feeling today? • Does your leg hurt?
Distract	Amusing the person through humorous commentaries or distracting him/her in a positive way by guiding the conversation away from something unpleasant.
Sensory stimulation	Providing sensory information, without the intervention of concepts and intellectual understanding; for example through music, touch or aromas. Examples include: • Feel how nice and soft this towel is. • This cream smells good!
Conversation about the person	Showing interest in the resident's life or background. Examples include: • You were a teacher, weren't you? • You used to like gardening, didn't you?
Social conversation	Friendly conversation that conveys an interest in the resident and is not related to instrumental care. Includes statements that acknowledge that the resident said something. Examples include: • You have a very nice dress. Where did you get it? • Thank you!
Negative verbal communicative behaviours	
Task-oriented conversation	Communication that is related to task accomplishment or focused on nursing or therapeutic topics. Examples include: • Where are your glasses? • The doctor said not to eat bread.
Conversation with a third person	Communication to a third person. Examples include: • Can you please give me a towel? (to another DCW)

Categories	Description
Ignore	Ignoring residents' statements by responding with an unrelated statement or question, interrupting or changing the topic of conversation. Carrying on a conversation in the presence of a person as if he/she is not present. Examples include: • Today she [*the resident*] is very friendly.
Infantilize	Patronising or treating and talking to the person with dementia as if he/she was a child. Examples include: • Good girl, you behaved so well.
Invalidate	Failing to acknowledge the subjective reality of a person's experience and especially what he or she is feeling. Correcting the resident on cognitive facts. Examples include: • Your husband is dead. • It's Wednesday today, not Monday.
Mockery	Disdain, pointing out or making fun of residents' behaviour or actions. Placing the person towards his/her difficulties. Examples include: • What's my name? Have you forgotten?
Criticise	Showing disapproval or criticise residents' performance or behaviour. Examples include: • That's wrong. You are hopeless.
Impose	Forcing a person to do something, overriding desire or denying the possibility of choice on his or her part. Statements can be considered dominating or controlling. Examples include: • You will dress this sweater because it is the freshest you have. • Be quiet.

Table 15. Non-verbal communicative behaviours

Categories	Description
Affirmative Nodding	Nodding head as a sign of approval, encouragement, or interest in the resident.
Resident-Directed Eye Gaze	Looking at the face of the resident.
Smile	Expression in which the corners of the mouth are directed upwards, denoting affability towards the resident.
Laugh	Opening the mouth (totally or partially), making a sound commonly associated with the act of laughing.
Withholding	Refusing a residents' request or question. Includes statements from the resident that the DCW does not acknowledge (e.g., resident asks if she can return to her room and the DCW does not respond).
Affective touch	Spontaneous and affective touch that is not necessary for the completion of a task (e.g., a pat on the back, a hug).
Guiding touch	Using touch to draw the person's attention or guide him/her for a task.
Instrumental touch	Deliberate physical contact, which is necessary for the completion of a task.

3. Results

3.1. Participants

Participants were all female with a mean age of 44.72±9.02 years old. The majority were married (67.2%), 46.4% had the primary and middle school and 41.4% the high school. The average length of service was 9.61±3.72 years. No significant differences were found between the groups in terms of socio-demographic data (Table 16).

Table 16. Baseline characteristics of DCWs (n=58)

Outcome	Total (n=58) N (%)	Experimental group (n=27) N (%)	Control Group (n=31) N (%)	χ^2	*df*	p-value
Gender						
Female	58 (100.0)	27 (100.0)	31 (100.0)	No statistical analysis possible		
Age in years						
M (SD)	44.72 (9.02)	43.37 (10.00)	45.90 (8.04)	1.069 [a]	56	0.290
Marital Status						
Married	39 (67.2)	17 (63.0)	22 (71.0)			
Widowed	3 (5.2)	1 (3.7)	2 (6.5)			
Single	4 (6.9)	2 (7.4)	2 (6.5)	1.148	4	0.887
Divorced/separated	9 (15.5)	5 (15.5)	4 (12.9)			
Other	3 (5.2)	2 (7.4)	1 (3.2)			
Education						
Primary school[b]	15 (25.9)	4 (14.8)	11 (35.5)			
Middle school[c]	12 (20.7)	6 (22.2)	6 (19.4)			
High school[d]	24 (41.4)	11 (40.7)	13 (41.9)	6.857	4	0.144
College degree	1 (1.7)	1 (3.7)	0 (0.0)			
Other	6 (10.3)	5 (18.5)	1 (3.2)			
Length of service (years)						
M (SD)	9.61 (3.72)	9.84 (4.86)	9.42 (2.51)	-0.418 [a]	56	0.678

Abbreviations: M= mean; SD= standard deviation; *df*= degrees of freedom

[a] t-test student

[b]1–4 years of education;[c]5–9 years of education; [d]10–12 years of education.

3.2. DCWs' communicative behaviour

No significant differences between groups were found at baseline for any communicative behaviour.

Within the experimental group there was a positive change from pre to post-test on the frequency of all DCWs' communicative behaviours.

Regarding participants' verbal communicative behaviours, the frequency of the category "inform" increased significantly among DCWs of the experimental group and decreased among the control group (p<0.01; η2partial=0.09; power=0.593). Also, positive, but non-significant effects, were obtained in the experimental group for the frequency of 'consult', 'distract', 'invalidate', 'criticise', 'impose' and for the frequency and duration of 'conversation about the person'. Both groups reported significant differences from pre to post-test in the frequency of 'reward' (p<0.01; η2partial=0.14; power=0.814), duration of ‘social conversation’ ($p<0.05$; $\eta2$partial=0.08; power=0.586), frequency and duration of ‘involve’ ($p<0.01$; $\eta2$partial (frequency)=0.17; power (frequency)=0.898; $\eta2$partial (duration)=0.12; power (duration)=0.506), and ‘sensory stimulation’ ($p<0.05$; $\eta2$partial (frequency)=0.09; power (frequency)=0.632; $\eta2$partial (duration)=0.07; power (duration)=0.506).

In the non-verbal communicative behaviours, the frequency of ‘laugh’ changed significantly. The amount of laughs increased in DCWs of the experimental group and decreased in DCWs of the control group ($p<0.01$, $\eta2$ partial=0.18; power=0.922). Only the experimental group showed positive (but not significant) effects on the frequency and duration of ‘smile’, ‘resident-direct eye gaze’ and ‘affective touch’. Both groups reported a significant decrease in the frequency of ‘withholding’ ($p<0.01$; $\eta2$partial=0.13; power= 0.810) (Table 17).

Table 17. Changes in DCWs' verbal and non-verbal communicative behaviour

Variables		Experimental group (n=31)		Control group (n=31)		p-value[a]	η2 partial[a]	Power[a]	p-value[b]	η2 partial[b]	Power[b]
		Pre	Pos	Pre	Pos						
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)						
Verbal communicative behaviour											
Consult	Freq	1.00 (1.00)	1.04 (1.11)	1.60 (1.83)	1.24 (1.28)	0.395	0.01	0.349	0.294	0.02	0.063
Inform	Freq	7.89 (4.54)	8.95 (5.34)	8.23 (4.41)	6.99 (3.91)	0.861	0.00	0.053	0.030*	0.09	0.593
Involve	Freq	3.46 (3.15)	4.04 (3.13)	3.50 (3.28)	6.13 (2.72)	0.006**	0.17	0.898	0.073	0.06	0.634
	Dur	12.38 (14.08)	19.51 (20.02)	19.14 (21.89)	28.68 (18.94)	0.008**	0.12	0.768	0.694	0.00	0.068
Reward	Freq	1.33 (1.44)	1.90 (1.73)	0.75 (0.70)	1.34 (1.17)	0.000**	0.14	0.814	0.953	0.00	0.050
Validate	Freq	0.26 (0.64)	0.28 (0.75)	0.13 (0.34)	0.17 (0.34)	0.559	0.00	0.066	0.846	0.00	0.145
Assess comfort	Freq	0.34 (0.47)	0.35 (0.39)	0.38 (0.58)	0.43 (0.79)	0.792	0.00	0.192	0.857	0.00	0.326
Distract	Freq	0.37 (0.79)	0.64 (1.24)	0.24 (0.60)	0.15 (0.34)	0.486	0.00	0.106	0.130	0.04	0.327
Sensory stimulation	Freq	0.10 (0.21)	0.33 (0.45)	0.11 (0.33)	0.32 (0.82)	0.023*	0.09	0.632	0.904	0.00	0.052
	Dur	0.51 (1.62)	1.62 (2.64)	0.34 (0.98)	3.08 (9.59)	0.049*	0.07	0.506	0.399	0.01	0.133
Social conversation	Freq	4.56 (2.46)	5.11 (2.70)	6.44 (451)	6.95 (4.18)	0.306	0.02	0.174	0.993	0.00	0.050
	Dur	32.59 (28.80)	41.69 (22.63)	37.30 (25.44)	49.74 (33.38)	0.031*	0.08	0.586	0.732	0.00	0.063
Conversation about the person	Freq	0.02 (0.10)	0.04 (0.14)	0.12 (0.25)	0.06 (0.16)	0.509	0.00	0.100	0.210	0.03	0.238
	Dur	0.07 (0.32)	0.41 (1.93)	1.17 (2.76)	0.80 (2.08)	0.971	0.00	0.050	0.328	0.02	0.163
Instrumental conversation	Freq	2.55 (2.04)	2.41 (2.24)	2.10 (1.66)	1.94 (1.15)	0.608	0.00	0.080	0.972	0.00	0.050
	Dur	12.22 (10.88)	10.17 (9.26)	10.73 (9.85)	10.73 (9.96)	0.475	0.00	0.109	0.489	0.00	0.109
Conversation with others	Freq	5.18 (3.94)	5.01 (2.93)	5.55 (4.06)	4.02 (2.89)	0.103	0.05	0.371	0.191	0.03	0.256
	Dur	28.83 (29.83)	33.05 (20.59)	14.68 (17.90)	20.77 (12.02)	0.129	0.04	0.807	0.827	0.00	0.099
Ignore	Freq	1.81 (1.44)	1.78 (1.73)	2.12 (2.10)	1.63 (1.56)	0.385	0.01	0.138	0.448	0.01	0.117
Infantilize	Freq	0.02 (0.09)	0.01 (0.65)	0.28 (0.51)	0.11 (0.28)	0.101	0.05	0.374	0.128	0.04	0.330

Variables		Experimental group (n=31)		Control group (n=31)		p-value[a]	η2 partial[a]	Power[a]	p-value[b]	η2 partial[b]	Power[b]
		Pre	Pos	Pre	Pos						
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)						
Invalidate	Freq	0.07 (0.27)	0.00	0.13 (0.25)	0.17 (0.39)	0.730	0.00	0.063	0.242	0.03	0.213
Mockery	Freq	0.11 (0.22)	0.09 (0.22)	0.54 (0.69)	0.25 (0.44)	0.073	0.06	0.435	0.120	0.04	0.342
Criticise	Freq	0.32 (0.47)	0.06 (0.23)	0.46 (0.72)	0.57 (0.75)	0.508	0.00	0.100	0.090	0.05	0.377
Impose	Freq	0.44 (0.83)	0.21 (0.39)	0.56 (0.58)	0.83 (1.57)	0.920	0.00	0.051	0.149	0.04	0.301
Non-verbal communicative behaviour											
Affirmative Nodding	Freq	0.41 (0.79)	0.65 (1.09)	0.55 (0.84)	0.51 (0.99)	0.416	0.01	0.127	0.238	0.03	0.217
Resident-directed eye gaze	Freq	1.71 (1.85)	2.09 (1.94)	1.91 (2.36)	2.03 (2.26)	0.364	0.02	0.147	0.657	0.00	0.072
	Dur	16.72 (30.29)	23.48 (37.66)	25.43 (56.24)	19.68 (33.73)	0.94	0.00	0.051	0.361	0.02	0.148
Smile	Freq	0.28 (0.57)	0.37 (0.67)	0.31 (0.86)	0.23 (0.54)	0.980	0.00	0.050	0.477	0.00	0.108
	Dur	0.55 (1.17)	0.71 (1.68)	2.65 (11.90)	0.89 (2.11)	0.380	0.01	0.141	0.490	0.00	0.106
Laugh	Freq	1.04 (1.10)	1.77 (1.64)	1.01 (1.01)	0.62 (0.82)	0.304	0.02	0.175	0.001**	0.18	0.922
	Dur	11.11 (19.29)	7.04 (11.00)	10.28 (29.11)	2.10 (3.03)	0.060	0.06	0.476	0.520	0.00	0.098
Withholding	Freq	0.38 (0.72)	0.06 (0.16)	0.08 (0.23)	0.01 (0.06)	0.000**	0.13	0.810	0.070	0.06	0.450
Affective touch	Freq	0.67 (0.53)	0.9 (0.78)	1.18 (1.33)	0.75 (1.00)	0.271	0.02	0.194	0.058	0.07	0.478
	Dur	2.29 (3.11)	2.84 (570)	3.53 (4.42)	4.05 (9.03)	0.590	0.00	0.083	0.988	0.00	0.050
Instrumental touch	Freq	10.28 (2.92)	10.05 (2.83)	9.82 (2.79)	8.99 (2.34)	0.192	0.03	0.101	0.447	0.01	0.254
	Dur	290.49 (176.1)	307.66 (49.39)	326.37 (251.40)	268.9 (69.58)	0.530	0.00	0.096	0.242	0.03	0.213
Awareness touch	Freq	0.15 (0.45)	0.51 (1.29)	0.44 (0.71)	0.44 (0.61)	0.247	0.03	0.210	0.23	0.03	0.221

Abbreviations: Freq, frequency (i.e., number of occurrences); Dur, duration (i.e.,length of the behaviour in seconds); SD, Standard deviation.
*p<0.05; **p<0.001

4. Discussion

The overall findings support the initial hypothesis that adding a supportive component to traditional education-only interventions improves DCWs' communicative behaviours.

Both groups showed positive significant improvements on various behaviours, including higher frequency and duration of involvement and sensory stimulation, more reward, longer social conversation and a reduced duration of withholding. These findings suggest that education can provide DCWs with useful positive verbal skills relevant for the quality of dementia care. Moreover, they also offer further support for the applicability of multisensory stimulation (MSS) during residents' care provision (Figueiredo et al., 2013; Marques, et al., 2013). This can be an undemanding PCC-based approach that may improve DCWs/resident interaction while allowing working completion (van Weert et al., 2005).

However, the results suggest that the PE intervention had a broader impact, with the frequency of all behavioural categories being positively affected at posttest. Additionally, group differences emerged in a number of verbal communicative behaviours. The experimental group experienced a significant improvement in inform and a trend towards improvement in the frequency of consult, distract, conversation about the person, invalidation, criticism and imposition. Concerning non-verbal communicative behaviours, group differences were even more pronounced. The experimental group presented significantly more laughs, and positive but no significant improvements in the frequency and duration of smile, resident-directed eye gaze and affective touch than the control group. These results are encouraging as it is becoming increasingly acknowledged that good dementia care is a synonymous of good interpersonal relationships between people with dementia and DCWs that rely more on emotional, sensitive, and empathetic interactions rather than on verbal expressiveness (Brooker, 2007).

Overall, findings suggest that the provision of emotional support might improve respectful conversation and emotional availability to communicate and enable the expression of interest, warmth and friendliness for the resident with dementia. This support can facilitate DCWs' regulation and awareness of their own and residents' emotions, thus favourably affecting their ability to communicate. Therefore, adding to an education-only intervention a supportive component that meets workers' emotional needs can be more effective for DCWs' performance and contribute to improve PPW and reduce MSP. A PE intervention may therefore offer DCWs a way to enhance the provision of

PCC, by minimising careless and thoughtless interactions and improving the personhood of individuals with dementia they worked with.

A number of limitations need however to be acknowledged. Data obtained from the video-recordings could have been influenced by mechanical limitations, including the presence of external noises or the position of the camera that could have occasionally hindered the observation of the communicative behaviours. Besides, participants' performance during observation may have been vulnerable to the "Hawthorne Effect", i.e., DCWs being aware of video-recording possibly behaved differently (Haidet et al., 2009). This effect was probably minimised as participants were recorded on several occasions, which allow them to become gradually used to the camera. It is likely that non-verbal communication is more complex than described, with some behaviours having different interpretations, e.g., smiling can convey friendless but also cynicism or arrogance (Caris-Verhallen, Kerkstra, & Bensing, 1999). Although a good inter-observer reliability was identified for all behavioural categories, the intricacy of non-verbal communication demands additional research. Also, it was not possible to blind the researchers to the intervention or assessments. Studies with a double-blinded design should be conducted to clarify findings. Finally, follow-up assessments to determine any changes over time and cost-effectiveness analysis to assess the feasibility of this intervention are recommended.

Nonetheless, the results are promising and highlight the need to address not only DCWs' technical expertise, but also their emotional and relational skills. This fits into the principles of the *relationship-centred care* (RCC), focused on the important dimensions of interdependent relationships necessary to create an enriched environment of care (Nolan, Davies, Brown, Keady, & Nolan, 2004). The *ethogram* showed moderate to excellent observer reliability, which is suggestive of its applicability. The authors encourage other researchers to conduct future evaluations of the tool in diverse care settings in order to further develop its acceptability, utility and validity.

5. Conclusion

To the best of our knowledge this is the first study designed to evaluate the effects of a PCC-based psycho-educational intervention on DCWs' communicative behaviours with residents with dementia. The results are encouraging and support the initial hypothesis that adding to an educational intervention a supportive component, aiming to provide DCWs with tools for stress and emotional management can improve person-centred interactions. Future research is warranted to investigate the long-term sustainability, cost-effectiveness and extent of the benefits of this intervention on both DCWs and residents with dementia.

6. References

Barbosa, A., Nolan, M., Sousa, L., & Figueiredo, D. (2014). Psycho-educational approaches in long-term care homes: Direct care workers and managers' perspectives. *Procedia - Social and Behavioral Sciences, 131*, 406-410. doi: http://dx.doi.org/10.1016/j.sbspro.2014.04.138

Bourgeois, M. S., Dijkstra, K., Burgio, L. D., & Allen, R. S. (2004). Communication skills training for nursing aides of residents with dementia. *Clinical Gerontologist, 27*(1-2), 119-138. doi: 10.1300/J018v27n01_10

Brooker, D. (2007). *Person-centred dementia care: Making services better.* London, England: Jessica Kingsley Publishers.

Caris-Verhallen, W., Kerkstra, A., & Bensing, J. (1999). Non-verbal behaviour in nurse-elderly patient communication. *Journal of Advanced Nursing, 29*, 808-818. doi: 10.1046/j.1365-2648.1999.00965.x

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Lawrence Erbaum Associates.

Edvardsson, D., Sandman, P. O., Nay, R., & Karlsson, S. (2009). Predictors of job strain in residential dementia care nursing staff. *Journal of Nursing Management, 17*, 59-65. doi: 10.1111/j.1365-2834.2008.00891.x

Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: Current status and ways forward. *The Lancet Neurology, 7*, 362-367. doi: 10.1016/s1474-4422(08)70063-2

Figueiredo, D., Barbosa, A., Cruz, J., Marques, A., & Sousa, L. (2013). Empowering staff in dementia long-term care: Towards a more supportive approach to interventions. *Educational Gerontology, 39*, 413-427. doi: 10.1080/03601277.2012.701105

Fleiss, J. (1986). *The design and analysis of clinical experiment.* New York, NY: John Wiley & Sons, Inc.

Haidet, K. K., Tate, J., Divirgilio-Thomas, D., Kolanowski, A., & Happ, M. B. (2009). Methods to improve reliability of video-recorded behavioral data. *Research in Nursing and Health, 32*, 465-474. doi: 10.1002/nur.20334

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham, England: Open University Press.

Levy-Storms, L. (2008). Therapeutic communication training in long-term care institutions: Recommendations for future research. *Patient Education and Counseling, 73*, 8-21. doi: 10.1016/j.pec.2008.05.026

Marques, A., Cruz, J., Barbosa, A., Figueiredo, D., & Sousa, L. (2012). Motor and multisensory care-based approach in dementia: Long-term effects of a pilot study. *American Journal of Alzheimer's Disease & Other Dementias, 28*, 24-34. doi: 10.1177/1533317512466691

McGilton, K., Boscart, V., Fox, M., Sidani, S., Rochon, E., & Sorin-Peters, R. (2007). A systematic review of the effectiveness of communication interventions for health care providers caring for patients in residential care settings. *Worldviews on Evidence-Based Nursing, 6*, 149-159. doi: 10.1111/j.1741-6787.2009.00155.x.

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing, 13*, 45-53. doi: 10.1111/j.1365-2702.2004.00926.xJCN926

Sabat, S.R. (2008). A bio-psycho-social approach to dementia. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 70-84). Maidenhead, England: McGraw Hill Education.

Sidani, S., Streiner, D., & Leclerc, C. (2012). Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. *International Journal of Older People Nursing, 7*, 37-45. doi: 10.1111/j.1748-3743.2011.00273.x

van Weert, J., Vandulmen, A., Spreeuwenberg, P., Ribbe, M., & Bensing, J. (2005). Effects of snoezelen, integrated in 24h dementia care, on nurse–patient communication during morning care. *Patient Education and Counseling, 58*, 312-326. doi: 10.1016/j.pec.2004.07.013

Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2008). A different story: Exploring patterns of communication in residential dementia care. *Ageing & Society, 28*, 629-651. doi: 10.1017/S0144.686x07006927

Williams, K., Kemper, S., & Hummert, M. L. (2003). Improving nursing home communication: An intervention to reduce elderspeak. *Gerontologist, 43*, 242-247. doi: 10.1093/geront/43.2.242

Chapter 4

Person-centeredness in direct care workers caring for residents with dementia: Effects of a psycho-educational intervention

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Abstract

Objectives: This study assessed the effects of a psycho-educational intervention on direct care workers' person-centeredness during morning care to residents with dementia. **Design:** An experimental study with a controlled pretest-posttest design was conducted in four aged-care facilities with fifty-six direct care workers (all female, mean age 44.72±9.02). Two experimental facilities received a psycho-educational intervention aiming to promote workers' person-centred care competences and stress management; control facilities received an education-only intervention, with no support to manage stress. Participants were video-recorded during morning care provision, before and two weeks after the intervention. A total of 112 video-recordings were coded for person-centred care using the Global Behaviour Scale (GBS). **Results:** Participants from both groups reported significantly higher scores on eight of eleven items of the GBS. Also, positive significant differences were obtained in both groups for the GBS total score at post-test (F=10.596; p=0.02); improvements were higher for the experimental group, with values nearly reaching the level of significance (F=3.906; p=0.054). **Conclusion:** The overall findings suggest that a psycho-educational intervention is a feasible means to increase direct care workers' person-centeredness. However, these are preliminary results and further research is needed to explore the long-term sustainability and extent of the benefits of this intervention on both workers and residents with dementia.

Keywords: aged-care facilities; behaviour; dementia; direct care workers; person-centred care

1. Introduction

In the past decade, there has been a surge of interest in person-centred care (PCC) as a means of improving the care provided to people with dementia in aged-care facilities (Kitwood, 1997).

Person-centeredness has its roots in the humanistic psychology (Rogers, 1961), and was later contextualized into dementia care by Kitwood (1997) as a response to “malignant social psychology”, i.e., caregiving relationships which devalue, dehumanize and depersonalize the person with dementia. Ideas about PCC have been discussed by several authors, with the term being commonly used to describe an approach to practice that strives to maintain personhood in spite of declining cognitive ability and that recognizes that an individual’s life experience, unique personality and network of relationships should be valued and taken into account (Brooker, 2007; Kitwood, 1997; McCormack, 2004).

According to previous studies (Grosch, Medvene, & Wolcott, 2008; White, Newton-Curtis, & Lyons, 2008) the implementation of PCC in aged-care facilities can be operationalised at two main organizational levels: (i) institutional, through for example, flexible policies that allow residents to participate fully in their environment, respect the residents’ right to privacy and dignity or value and foster individual interests; (ii) interpersonal, through workers’ relationship behaviours and skills more focused on the person rather than the task (e.g., showing interest, orientating the resident to task, offering choices or providing positive feedback).

A small but growing literature has focused on the latter level, as evidenced by the development of significant theoretical frameworks, such as the ‘relationship-centred care’ (Nolan, Davies, Brown, Keady, & Nolan, 2004), and the design and implementation of PCC-based education programs to increase the relational behaviours of the direct care workers (DCWs) (i.e., workers that are most closely involved in providing care to residents) during specific care tasks (McGilton et al., 2007; Williams, Kemper, & Hummert, 2003). Despite the important contribution of these studies, they present two major limitations. First, the recognition that educational interventions have limited efficacy for improving DCWs’ behaviour (Nolan et al., 2008). Hence, previous research having shown that DCWs’ emotional wellbeing also affects their interactions (Drebing, McCarty, & Lombardo, 2002; Edvardsson, Winblad, & Sandman, 2008). Moreover, heavy workloads, interpersonal conflicts or lack of management support threaten DCWs’ emotional wellbeing, and are associated with high levels of stress, burnout and dissatisfaction and reduced quality of care (Edvardsson, Sandman, Nay, & Karlsson, 2009; Gray-Stanley & Muramatsu, 2011).

Second, few studies have included direct assessments whether or not the intervention actually increased the DCWs' person-centeredness. Most intervention studies have relied on proxy and self-report outcome measures or newly developed tools lacking widespread use and validation (Edvardsson & Innes, 2010). Besides, when direct measures have been used (Van Weert, Vandulmen, Spreeuwenberg, Ribbe, & Bensing, 2005), the purpose was to code or count specific behaviours, which might omit information about its quality or functions.

The purpose of this study was therefore to assess the effects of a psycho-educational (PE) programme on the quality of DCWs' interactions with residents with dementia. It is hypothesized that compared to education-only, an intervention offering both educational and support for stress and emotional management contributes to more person-centeredness during morning care.

2. Methods

2.1. Design

This experimental study used a controlled pretest-postest design. The study was conducted in four aged-care facilities. Recruitment was as follows: (1) facilities were matched for staff/resident ratio and proportion of residents with dementia; (2) two pairs of facilities were approached for participation; (3) managers of each selected facility were contacted to introduce the study and asked about their willingness to participate; no simultaneous participation in similar studies and no significant organisational changes during the intervention implementation had to be ensured; iv) facilities within each pair were randomly assigned to the experimental group – PCC-based PE intervention - or control group – PCC-based education-only intervention - using a random number generator. Study facilities were private, non-profit institutions of mixed accommodation with a staff/resident ratio between 1:2 and 1:3 and a residents with dementia/total of residents' ratio between 1:3 and 1:5.

2.2. Participants

DCWs were included if they: (1) provided morning personal care (i.e., period of time between 07am and 12am when DCWs are involved in activities related to bathing, grooming, dressing and toileting) to people with dementia on a regular basis; and (2) were employed for at least 2 months, so that adaptation to residents had already occurred. Temporary DCWs and trainees were excluded as it was not possible to ensure their participation until the end of the study.

Following an initial screening by the service managers of each facility, a meeting with potentially eligible DCWs was scheduled to inform them about the purpose of the study and what their participation entailed. All 58 eligible DCWs agreed to participate and entered the study at baseline – 27 in the experimental group and 31 in the control group. Of these, 56 had completed the post-test assessment. Dropouts (n=2) occurred in the control group (DCWs were absent from work).

2.3. Intervention

PCC-based PE intervention

The experimental facilities received a PCC-based PE intervention informed by: (1) relevant literature on PE approaches, PCC and dementia (Barbosa et al., 2013; Chenoweth et al., 2009; Van Weert et al., 2005); (2) findings from a previous pilot study conducted by the authors' research team [names deleted to maintain the integrity of the review process]; and (3) interviews with DCWs and managers about instrumental and emotional needs [names deleted to maintain the integrity of the review process].

The intervention included 8 weekly group sessions of approximately 90 minutes led by a gerontologist and a physical therapist, both trained in PCC approaches and psycho-educational groups. Each session followed a similar format, organised into two components: education and support (Table 18).

The educative component was intended to enhance DCWs' knowledge and skills concerning person-centred dementia care. Content was mainly focused on strategies to interact with residents with dementia, particularly verbal and non-verbal communicative strategies, motor and multisensory stimulation strategies (Table 19). In order to clarify doubts and make suggestions to help DCWs implement a more PCC, in the 3 days after each session the gerontologist and the physical therapist assisted each DCW individually during morning care.

The supportive component aimed to improve DCWs' ability to cope with job-related stress and burnout, and included two parts: strategies to manage work-related stress and prevent burnout (e.g., time-management, problem-solving and teamwork) and a final moment of relaxation or physical exercise. Participants were encouraged to apply these coping strategies during working hours or in their home and to discuss these efforts during the meetings.

A variety of active learning methods were used across sessions, such as brainstorming, role-plays, case studies or task assignments.

Table 18. Content of the psycho-educational intervention

Session	Themes
1	Information about PCC and dementia Emotional impact of caregiving
2	Communication in dementia Conflict management
3	Challenging behaviours Teamwork
4	The environment and dementia Deal with emotions
5	Motor stimulation. Time management
6	Multisensory stimulation - olfaction Problem-solving
7	Multi-sensory stimulation – vision and tactile stimulation Relaxation
8	Multi-sensory stimulation – audition and taste Finalisation and celebration

PCC-based education-only intervention

Control facilities received an education-only intervention. The frequency, coordination, length, order and content of the sessions were the same of the educational component of the PE intervention. It was the absence of the supportive component that distinguished both interventions. Each participant was assisted during morning care by the same professionals, who helped DCWs to deliver a more PCC and clarified doubts that emerged from sessions.

Table 19. Strategies to interact with the person

Verbal and non-verbal communication strategies
Maintain eye contact
Face the resident directly
Address the resident by name
Give short, simple and direct instructions
Give positive feedback when resident follows direction
Talk about resident’s life history
Multisensory stimulation
Use a shower gel or a body lotion with a pleasant fragrance
Place aroma diffusers in the bedroom
Let the person feel the texture of the sponge bath or the warm towels
Provide a gentle massage while washing his/her hair
Put a relaxing music in the bedroom while dressing and grooming
Reduce the noise created by machinery, voices, slamming doors, loud music or other existing sounds
Motor stimulation
Encourage the person to perform one task, or a part of it (e.g., wash the arms, help remove the foam from the body), by giving him/her small and simple instructions, step by step
Demonstrate how to make the task
Give physical guidance or use gestures during the completion of the task
Avoid rushing the person during the task
Encourage the person and praise him/her after the completion of the task
Ask the person to participate in simple tasks, introducing progressively more complex tasks

2.4. Data Collection

DCWs’ socio-demographic data (gender, age, education, marital status and length of time working in the facility) were first collected through a structured questionnaire.

In order to assess DCWs’ person-centeredness, morning care interactions were video-recorded at baseline and two weeks after the intervention. Video-recordings occurred in the resident’s bedroom and covered mouth care, toileting, washing face, and brushing hair. To preserve residents’ privacy, bathing was not recorded. Recordings started at the moment the DCWs entered the room and stopped when they left. To minimise participants’ reactivity, several strategies were considered: (1) a number of recordings were performed prior to data collection to familiarise participants with the methodology; (2) DCWs were instructed to stop or remove the camera if they noticed any resident’s behaviour change caused by the device presence; (3) once the cameras were adequately positioned (i.e., from the best viewpoint while not interfering with care), the researcher asked DCWs to provide care in the manner they normally would and left the room to avoid a further source of disruption; and (4) each DCW was intended to be video-recorded thrice in the baseline and thrice after the intervention.

From a total of 332 videos (164 at baseline and 168 at post-intervention; average duration=510 seconds) 112 videos (two videos by DCW, one for each time point) were randomly selected to be coded by the 1st author using the Global Behaviour Scale (GBS) (Grosch et al., 2008). GBS is used to make global judgements about the quality of interactions. It consists of 11 items organised in a 7-point semantic differential format (e.g., “Put task before person” (1) versus “Put person before task” (7)). Scores for each of the 11 items are added and divided by the total number of the GBS (total=77) to determine the DCWs average score. Higher scores indicate more PCC behaviours. GBS has demonstrated high internal consistency, with a Cronbach’s alpha coefficient (α) of 0.91 for the original version.

Inter-observer reliability

The assessment of inter-observer reliability of the GBS was performed by two independent coders using 30% of the videos (n=34 videos). This value is similar to those of previous studies (Bourgeois, Dijkstra, Burgio, & Allen, 2004). The intra-class correlation coefficient (ICC) equation (2.1) and the Bland and Altman method were calculated for each moment (pretest and posttest).

The ICC (2.1) values were interpreted as follows: >0.75 was excellent, 0.40–0.75 was moderate and <0.40 was poor (Fleiss, 1986). The values obtained for the ICC were 0.73 (0.36-0.92) at baseline and 0.91 (0.66 -0.97) after the intervention, indicating a moderate to excellent reliability. Bland and Altman 95% limits of agreement were measured and the scatter plots were analysed. A good agreement between the coders was found and no evidence of proportional bias was observed.

2.5. Data analysis

Socio-demographic characteristics of the groups at baseline were characterised using descriptive statistics and compared with independent t-tests for continuous data or χ^2 tests for categorical data. The independent t-test was also used to compare baseline GBS total scores.

In order to determine whether there were any differences on the GBS scores from pre to post-test between and within the groups, a repeated measures ANOVA was conducted with the group (experimental, control) defined as a between-subjects factor and time point (baseline, post-test) as a within-subjects factor. Partial eta squared (η^2) is reported as an index of effect size and interpreted as small (≥0.05), medium (0.05-0.25), large (0.25-0.50) and very large (≥0.50) (Cohen, 1988).

The alpha level for statistical significance was set at 0.05 throughout. All analyses were conducted using the SPSS v20.0 (IBM Corp., Armonk, NY).

2.6. Ethical issues

The study received full approval from the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra, Portugal (Ref. 5-11/2010).

All DCWs were informed about the voluntary nature of their participation and their anonymity and confidentiality were assured. Written informed consent was obtained. To ensure protection for individuals with cognitive impairment, both assent (from the individual with cognitive impairment) and consent (from their legal guardian) were obtained.

3. Results

Participants were all female with a mean age of 44.72±9.02 years. The majority were married (67.2%), 46.4% had primary and middle school education and 41.4% high school. The average length of service was 9.61±3.72 years. No significant differences were found between the groups in terms of socio-demographic data (Table 20).

Table 20. Baseline characteristics of DCWs (n=58)

Outcome	Total (n=58) N (%)	Experimental group (n=27) N (%)	Control Group (n=31) N (%)	χ^2	*df*	p-value
Gender						
Female	58 (100.0)	27 (100.0)	31 (100.0)	No statistical analysis possible		
Age in years						
M (SD)	44.72 (9.02)	43.37 (10.00)	45.90 (8.04)	1.069[a]	56	0.290
Marital Status						
Married	39 (67.2)	17 (63.0)	22 (71.0)	1.148	4	0.887
Widowed	3 (5.2)	1 (3.7)	2 (6.5)			
Single	4 (6.9)	2 (7.4)	2 (6.5)			
Divorced/separated	9 (15.5)	5 (15.5)	4 (12.9)			
Other	3 (5.2)	2 (7.4)	1 (3.2)			
Education						
Primary school[b]	15 (25.9)	4 (14.8)	11 (35.5)	6.857	4	0.144
Middle school[c]	12 (20.7)	6 (22.2)	6 (19.4)			
High school[d]	24 (41.4)	11 (40.7)	13 (41.9)			
College degree	1 (1.7)	1 (3.7)	0 (0.0)			
Other	6 (10.3)	5 (18.5)	1 (3.2)			
Length of service (years)						
M (SD)	9.61 (3.72)	9.84 (4.86)	9.42 (2.51)	-0.418[a]	56	0.678

Abbreviations: M= mean; SD= standard deviation; *df*= degrees of freedom

[a] t-test student

[b] 1–4 years of education; [c] 5–9 years of education; [d] 10–12 years of education

Baseline total GBS scores did not differ significantly between groups. Mean scores of 46.60 (±16.30) and 49.39 (±13.10) were obtained for the experimental and control groups respectively. Table 21 shows the results of the repeated measures ANOVA. Participants from both experimental (mean pre-test=46.60±16.30; mean post-test=56.71±17.56) and control groups (mean pre-test=49.64±13.32; mean post-test=52.79±15.33) reported significantly higher scores on GBS total score at post-test as compared to those at baseline (F=10.596; p=0.000; η^2= 0.175). Improvements were higher for the experimental group, with values very close to significance (F=3.906; p=0.054; η^2= 0.071).

Table 21. Results of the repeated measures ANOVA

	Experimental group ±n=27		**Control group ±n=31**				
GBS items	**Pre-test**	**Post-test**	**Pre-test**	**Post-test**	**p-value[a]**	**p-value[b]**	**η^2**
1. Treating like a person vs. Treating in stereotyped way	4.03±1.22	4.56±1.31	3.79±1.23	4.20±1.23	0.001	0.148	0.067
2. Treating as worthy of a relationship vs. Indifferent to bond	2.92±1.59	4.22±2.02	3.45±1.86	4.10±1.37	0.000	0.164	0.035
3. Respecting dignity vs. Not respecting dignity	0.55±1.62	0.89±2.10	0.28±1.07	0.00±0.00	0.903	0.199	0.030
4. Put person before the task vs. Put task before the person	3.88±1.60	4.11±1.55	3.93±1.30	4.96±1.45	0.001	0.021	0.096
5. Providing positive social environment vs. Not providing positive social environment	3.07±1.96	4.04±1.72	3.31±1.71	3.72±1.49	0.008	0.273	0.022
6. Working cooperatively vs. Working in a directive manner	3.11±1.71	3.96±1.84	3.86±1.64	5.10±1.65	0.000	0.387	0.014
7. Affirming vs. Over nurturing	4.56±1.05	5.11±1.42	4.57±1.06	5.14±1.23	0.003	0.965	0.000
8. Tolerates frustration vs. Intolerant	4.29±1.10	4.85±1.48	4.71±1.21	4.89±1.47	0.040	0.285	0.022
9. Takes likes/dislikes into account vs. Ignores likes/dislikes	2.22±1.45	2.88±1.82	2.21±2.02	2.53±2.04	0.081	0.536	0.007
10. Responsive to spontaneous needs vs. Unresponsive to needs	3.37±1.27	3.70±2.01	3.21±1.89	3.75±1.75	0.087	0.686	0.003
11. Positive affect vs. Negative affect	3.85±1.56	4.85±1.51	3.93±1.76	4.21±1.54	0.006	0.116	0.046
Total GBS	46.60±16.30	56.71±17.56	49.64±13.32	52.79±15.33	0.000	0.054	0.071

Data are presented as mean±standard deviation. [a]Time; [b] interaction time*group. η^2=Partial eta squared

The majority of the GBS items has significantly improved in both groups: ‘treating like a person vs. treating in stereotyped way’ (p =0.001); ‘treating as worthy of a relationship vs. indifferent to bond or connection’ (p=0.000); ‘put person before the task vs. put task before the person’ (p=0.001); ‘providing positive social environment vs. not providing positive social environment’ (p=0.008); ‘working cooperatively vs. working in a directive manner’ (p=0.000); ‘affirming vs. over nurturing’ (p=0.003); ‘tolerates frustration vs. intolerant’ (p=0.04) and ‘positive affect vs. negative affect’ (p=0.006). A significant interaction effect was found on only one item – ‘put person before the task vs. put task before the person’ (p=0.021) - with both groups showing improvement.

4. Discussion

This experimental study sought to assess the effects of a PCC based psycho-educational intervention on DCW’s person-centeredness during morning care to residents with dementia. The overall results evidenced that both groups showed positive significant differences from pre to post-test on eight of eleven items of the GBS. As well, positive significant differences were obtained in both groups for the GBS total score. These findings emphasize that PCC based education-only interventions can be effective in changing DCWs’ behaviours. However, the PE intervention had a broader impact, with findings at the limits of significance (p=0.054). Although non-significant between groups, findings are relevant and suggest that adding a supportive component to education-only interventions might better prepare them to espouse PCC. It is possible that addressing DCWs’ emotional needs might improve workers’ awareness and evaluation of their own and residents’ emotions and potentially improve the quality of the care provision. Being better equipped to recognize and manage emotions may allow workers to experience fewer incidents of job related stress, burnout and dissatisfaction, which are recognised to negatively impact DCW-resident relationship (Edvardsson, Sandman, Nay, & Karlsson, 2009; Gray-Stanley & Muramatsu, 2011). This is further supported by the results published in an earlier study that had suggested that a PE intervention can reduce DCWs’ emotional exhaustion (Barbosa, Nolan, Sousa, & Figueiredo, 2014). The importance of DCWs’ emotional support to develop interactions is still understudied in the field of gerontology. However, the relevance of this has been recently acknowledged within the ‘relationship-centred care’ (RCC) (Nolan et al., 2004). RCC takes the concept of PCC one step further by capturing the important dimensions of interdependent relationships necessary to create an enriched environment of care in which the residents and workers' needs are addressed (Nolan et al., 2004). This represents a promising framework for future interventions within the long-term care context.

The finding that both groups recorded values close to zero in item 3 ('respecting dignity vs. not respecting dignity') is worth of consideration. In order to assign a rating to this item the caregiver needed to be engaged in behaviours as covering up the resident during a task or keeping doors or curtains closed. While these behaviours make evident person-centeredness, they were not always observed during morning care provision. This occurred because several recorded tasks did not require that the person was covered or the camera position inhibited to capture if the doors or curtains were closed. As behaviours were not observed the item was assigned with zero.

A few limitations have to be considered. First, the findings are limited by the fact that the relatively small sample size could have reduced the statistical power to detect significant changes between groups. The individual assistance during morning care in both groups can also offer an explanation for the lack of significant differences. The extent to which individual assistance may help to endorse practice change is worthy of further consideration.

Second, it was not possible to blind the researchers to the experimental or control groups or assessments. Future studies with a double-blinded design should be conducted to clarify findings. Moreover, it could be useful to assess the long-term effects of this intervention, as it may take time to DCWs practice and stabilize their performance. Finally, although efforts were made to overcome participants' reactivity, it is possible that video-recording may have led DCWs to modify their behaviour.

Nonetheless, the current study contributes to the literature by providing relevant and unique knowledge about the effects of a pioneering intervention on DCWs' person-centeredness. With the increasing demand for person-centred care, it is essential to address DCWs' strain, by promoting effective teamwork, time management, problem-solving or peer relationships, as this can also improve the quality of care provided. The use of GBS to assess person-centeredness is also worthy of consideration. Commonly, behavioural measures have been used for recording specific behaviours; however, a global measure like GBS can be more responsive in measuring the manner in which behaviours are enacted. Indeed, DCWs can give residents a choice, but can do so in ways that communicate genuine interest or in ways that are mechanical and rote (Lann-Wolcott, Medvene & Williams, 2011). Through GBS it is possible to assess the quality of

DCWs' behaviours. The high inter-observer reliability obtained for the scale further supports its reliability and validity to measure PCC.

5. Conclusion

This study provides preliminary evidence supporting the value of interventions to go beyond DCWs' knowledge and instrumental skills to also address emotional and relational skills, as this holds promise as a means of improving person-centeredness. This approach represents an alternative to better prepare DCWs to interact with residents with dementia, but so far this has received little attention in the literature. Thus, further research is needed to explore the long-term sustainability and extent of the benefits of this intervention on both DCWs and residents with dementia.

6. References

Barbosa, A., Nolan, M., Sousa, L., & Figueiredo, D. (2014). Supporting direct care workers in dementia care: Effects of a psychoeducational intervention. *American Journal of Alzheimer's Disease & Other Dementias*. doi: 10.1177/1533317514550331

Bourgeois, M. S., Dijkstra, K., Burgio, L. D., & Allen, R. S. (2004). Communication skills training for nursing aides of residents with dementia: The impact of measuring performance. *Clinical Gerontologist*, *27*(1-2), 119-138. doi: 10.1300/J018v27n01_10

Brooker, D. (2007). *Person-centred dementia care: Making services better.* London, England: Jessica Kingsley Publishers.

Chenoweth, L., King, M. T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *Lancet Neurology, 8*(4), 317-325. doi: 10.1016/S1474-4422(09)70045-6

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Lawrence Erbaum Associates.

Drebing, C., McCarty, E. F., & Lombardo, N. B. E. (2002). Professional caregivers for patients with dementia: Predictors of job and career commitment. *American Journal of Alzheimer's Disease and Other Dementias, 17*(6), 357-366. doi: 10.1177/153331750201700604

Edvardsson, D., & Innes, A. (2010). Measuring Person-centered care: A critical comparative review of published tools. *Gerontologist, 50*(6), 834-846. doi: 10.1093/geront/gnq047

Edvardsson, D., Sandman, P., Nay, R., & Karlsson, S. (2009). Predictors of job strain in residential dementia care nursing staff. *Journal of Nursing Management, 17*(1), 59-65. doi: 10.1111/j.1365-2834.2008.00891.x

Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: Current status and ways forward. *The Lancet Neurology, 7*(4), 362-367. doi: 10.1016/s1474-4422(08)70063-2

Fleiss, J. (1986). *The design and analysis of clinical experiment.* New York, NY: John y & Sons, Inc.

Gray-Stanley, J. A., & Muramatsu, N. (2011). Work stress, burnout, and social and personal resources among direct care workers. *Research in Developmental Disabilities, 32*(3), 1065-1074. doi: 10.1016/j.ridd.2011.01.025

Grosch, K., Medvene, L. J., & Wolcott, H. (2008). Person-centered caregiving instruction for geriatric nursing assistant students: Development and evaluation. *Journal of Gerontological Nursing, 34*, 23-31.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham, England: Open University Press.

McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal of Clinical Nursing, 13*(3a), 31-38. doi: 10.1111/j.1365-2702.2004.00924.x

McGilton, K., Boscart, V., Fox, M., Sidani, S., Rochon, E., & Sorin-Peters, R. (2007). A systematic review of the effectiveness of communication interventions for health care providers caring for patients in residential care settings. *Worldviews on Evidence-Based Nursing, 6*, 149-159. doi: 10.1111/j.1741-6787.2009.00155.x.

Nolan, M., Davies, S., Brown, J., Wilkinson, A., Warnes, T., McKee, K., . . . Stasi, K. (2008). The role of education and training in achieving change in care homes: a literature review. *Journal of Research in Nursing, 13*(5), 411-433. doi: 10.1177/1744987108095162

Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing, 13*(3a), 45-53. doi: 10.1111/j.1365-2702.2004.00926.xJCN926

Lann-Wolcott, H., Medvene, L. J., & Williams, K. (2011). Measuring the person-centeredness of caregivers working with nursing home residents with dementia. *Behavior therapy*, *42*(1), 89-99. doi: 10.1016/j.beth.2010.02.005.

Van Weert, J., Vandulmen, A., Spreeuwenberg, P., Ribbe, M., & Bensing, J. (2005). Effects of snoezelen, integrated in 24h dementia care, on nurse–patient communication during morning care. *Patient Education and Counseling, 58*(3), 312-326. doi: 10.1016/j.pec.2004.07.013

White, D. L., Newton-Curtis, L., & Lyons, K. S. (2008). Development and initial testing of a measure of person-directed care. *Gerontologist, 48* (suppl 1), 114-123.doi:10.1093/geront/48.Supplement_1.114

Williams, K., Kemper, S., & Hummert, M. L. (2003). Improving nursing home communication: An intervention to reduce elderspeak. *Gerontologist, 43*, 242-247. doi: 10.1093/geront/43.2.242

Chapter 5

Effects of a psycho-educational intervention for direct care workers caring for people with dementia: Results from a 6-month follow-up study

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Abstract

This study aimed to assess the effects of a psycho-educational intervention, designed to improve direct care workers' stress, burnout and job satisfaction and person-centered communicative behavior with people with dementia. A pretest-posttest control group design was conducted in four aged-care facilities. Two experimental facilities received a psycho-educational intervention; two control facilities received an education-only. Data were gathered from fifty three care workers at baseline, immediately and six months after the intervention, through self-administrated instruments and video-recorded morning care sessions.

The experimental group showed a significant decrease in care workers' burnout and a significant improvement in several communicative behaviors (e.g., involvement). Stress levels deteriorated at six months and no intervention effects were found for job satisfaction. The findings highlight the importance of providing care workers with both technical competences and tools for stress management as this might be associated with a reduction of their levels of exhaustion and improved communicative behaviors.

Keywords: aged-care facilities, dementia, person-centered care, direct care workers, psycho-educational intervention

1. Introduction

People with dementia are one of the fastest growing groups of people living with long-term conditions. The number of people living with dementia worldwide in 2013 was estimated at 44.35 million, reaching 75.62 million in 2030 and 135.46 million in 2050 [1]. Along with these projections, there will be an associated increase in demand for long-term care mainly provided by aged-care facilities[1].

In an aged-care facility, the bulk of care that residents receive is provided by direct care workers (DCWs)[2]. These workers are responsible for helping frail and disabled older adults carry out the most basic activities of daily life, such as bathing, dressing, toileting, and eating, during which they also provide the personal interaction that is essential to residents' quality of life and care [2]. However, stressors resulting from inadequate education and training in dementia care, high workload, interpersonal conflicts or lack of management support have been shown to be prevalent in DCWs' work [3,4]. Such stressors place DCWs at high risk of experiencing stress, burnout and job dissatisfaction which are known to create a disruption in the worker-resident relationship and hinder the delivery of quality care[3,5].

The provision of education to DCWs has been long regarded as an essential component for improving the quality of dementia care[6,7]. This is often designed to improve DCWs' skills based on person-centered care (PCC) approaches, which have become synonymous with "best practice"[8,9].

Person-centered dementia care has its roots in the work of Tom Kitwood[10], who was inspired by Carl Rogers and his client-centered counseling. Kitwood (1997), soon followed by Nolan et al. (2004) and their *relationship-centered care*, stressed the influence of interpersonal relationships as an essential aspect for understanding the dementia experience, theorizing that some of the deterioration seen in people with dementia was caused not only by the disease process itself, but also by how the person is treated. These authors emphasized the relational nature of PCC and the need to provide workers with the skills they need to enhance positive interactions (e.g., consult or validate) (labeled *positive person work* - PPW) and reduce negative communicative behaviors (e.g., ignore or infantilization) that depersonalize experiences of the person with dementia (labeled *malignant social psychology* - MSP)[10], thus creating an enriched environment of care[8].

In notable randomized controlled studies, DCWs were provided with PCC based education-only interventions designed to reduce the residents' levels of agitation and aggression [11-13] and to enhance residents' engagement in daily activities[14]. Researchers have demonstrated the potential for these interventions to improve DCWs' knowledge and enhance their willingness to encourage residents' autonomy, independence and communication [15]; however their effects on stress, burnout or job satisfaction are modest, and often neither long-lasting or significant[16,17]. This suggests that interventions are mainly focused on improving DCWs' knowledge and instrumental skills and are less concerned with their emotional and relational skills, which, despite the rhetoric of PCC are still undervalued. Providing DCWs with both technical competences and tools for stress and emotional management holds promise as a means of driving forward benefits for DCWs and care provision. This approach may better prepare DCWs to deal with their multifaceted and emotionally demanding job, potentially improving person-centered interactions, job satisfaction and wellbeing. However, to the authors' knowledge, no studies assessing the efficacy of psycho-educational interventions in the context of formal care have been conducted.

This study aimed to examine the immediate and the 6-month effects of a Person Centered Care based psycho-educational intervention (PCC-based PE intervention) targeted at DCWs caring for people with dementia in aged-care facilities. It was hypothesized that, compared with an education-only intervention (control group), an intervention offering both educational and emotional support would reduce DCWs' perceived stress, burnout and job dissatisfaction. It was also expected that, compared to the control group, the PCC-based PE intervention would decrease the frequency and duration of DCWs' MSP behaviors and enhance the frequency and duration of PPW behaviors.

2. Methods

2.1. Design

This experimental study used a pre-posttest control group design and was conducted in four aged-care residential facilities. The study was approved by an ethics committee [names deleted to maintain the integrity of the review process].

Data were collected at: (i) baseline assessment (T1), in all facilities 3 weeks prior to the intervention; (ii) posttest (T2), 2 weeks after the end of the intervention and; (iii) follow-up (T3), 6 months after the intervention.

2.2. Procedure

The facilities of the local area were the study was conducted were stratified into groups by the staff/resident ratio and residents with dementia/total of residents' ratio. Then, two pairs of facilities of the same created group were approached by the research team and were given the opportunity to participate in the study. All four facilities agreed to participate and were randomly allocated to the experimental group - PE intervention - or control group - education-only intervention – using a random number generator. Randomization could not occur at the individual level due to possible treatment effects if the same facility functioned as both experimental and control sites. Study facilities were private, non-profit institutions of collective accommodation with more than 30 licensed beds and with a staff/resident ratio between 1:2 or 1:3.

2.3. Sample

The study sample includes DCWs (may be called under different names in different countries, for example, nursing aides or care assistants), who represent the largest component of the long-term care workforce and are responsible for helping frail and disabled older adults carry out the most intimate and basic activities of daily living. To be included in the study, DCWs had to be employed for at least two months (so adjustments to the residents and facility had been achieved) and provide morning personal care (i.e., period of time between 07am and 12am that involved activities related to bathing, grooming, dressing and toileting) to people with a diagnosis of moderate to severe dementia. Temporary DCWs and trainees were excluded as it was not possible to ensure their participation until the end of the study. The identification of the eligible DCWs was supported by facility managers. Three DCWs were excluded from the study due to being temporary.

A meeting with the fifty-eight identified DCWs was scheduled to provide detailed information about the study and invite them to participate. They were informed about the voluntary nature of their participation and their anonymity and confidentiality were assured. All DCWs agreed to participate and their informed signed consent was obtained at the end of the meeting.

Twenty-seven DCWs received a psycho-educational intervention and 31 DCWs participated in the control group.

Of these, 53 DCWs completed all three rounds of data collection. Two dropouts occurred in the control group and 3 in the experimental group. The dropouts were due to DCWs' absence from work during the assessment periods, as a result of sick leave (n=2), vacation (n=2) or dismissal (n=1) (Figure 5).

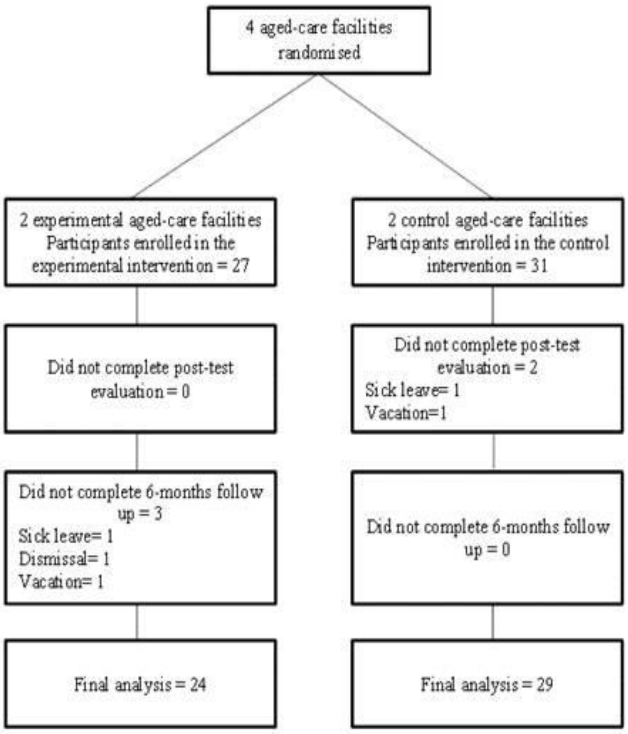

Figure 5. DCWs' attrition flow chart

The legal guardians of the identified residents were also contacted, informed about the study and asked to sign a written informed consent. From 51 residents with moderate-to-severe dementia, 47 participated (one legal guardian refused participation, one resident refused permanently to be assessed by video and two residents died before collecting any data).

2.4. Intervention

PCC-based PE intervention

The experimental facilities received a PCC-based PE intervention informed by: (i) relevant literature on PE approaches, PCC and dementia[11,18]; (ii) findings from a previous pilot study conducted by the authors' research team[19,20]; and (iii) interviews with DCWs and managers about instrumental and emotional needs[21]. The intervention included 8 weekly 90 minute sessions, coordinated by a gerontologist and a physical therapist with training and experience in PCC approaches and psycho-educational groups. Each session followed a similar format, organized into two components: education and support.

The education component aimed to provide DCWs with: (i) principles to integrate PCC within the care routines (e.g., incorporate biographical knowledge in personal care); (ii) basic knowledge about dementia; and (iii) PCC-based interaction strategies, including motor stimulation (e.g., encourage the person to perform one task or a part of it) and multisensory stimulation (e.g., provide a gentle massage while washing resident's hair). In the 3 days following each PE session, the gerontologist and the physical therapist assisted DCWs individually during morning care, clarifying doubts and making suggestions to help them implement a more PCC approach.

The supportive component aimed to provide DCWs with coping strategies to manage work-related stress and prevent burnout (e.g., time-management, assertiveness and problem-solving). At the end of each supportive component, relaxation techniques, stretching and strengthening exercises were practiced. Detailed information about the intervention can be found elsewhere (chapters 2 and 3) and is summarized in Table 22.

PCC-based education-only intervention

The control facilities received an education-only intervention. The coordination, length, order and content of the sessions were the same as the educational component of the PE intervention. It was the absence of the supportive component that distinguished both interventions. Each participant was assisted during morning care by the same professionals, who helped DCWs to deliver a more PCC and clarified doubts that emerged from sessions.

2.5. Measures

DCWs' perceived stress

DCWs' perceived stress was measured using the Portuguese version of the Perceived Stress Scale (PSS)[22]. The PSS is a 14-item self-report questionnaire rated on a 5-point Likert-type scale ranging from "never" (0) to "very often" (4). The items evaluate the degree to which individuals believe their life has been unpredictable, uncontrollable, and overloaded during the previous month. Higher scores correspond to higher degrees of perceived stress.

Table 22. Content of the interventions

Session	Component	Experimental Group	Control Group
1	Educative	*Information about PCC and dementia:* Information about the concept and principles of PCC. Basic information on dementia, its causes, symptoms and evolution.	
	Supportive	*Emotional impact of caregiving:* The positive and negative impacts of the caregiving experience on personal and professional life; Abdominal breathing.	-
2	Educative	*Communication in dementia:* Communicative behavioral strategies to interact with residents with dementia. (e.g., give simple choices; use validation; allows time to respond; use individual's name and eye contact).	
	Supportive	*Conflict management:* Improving assertiveness through the DESC technique (Describe; Explain; Specify; Conclude) technique (Bower & Bower, 2004). Stretching and strengthening exercises.	-
3	Educative	*Challenging behaviors:* Information about challenging behaviors and strategies to deal with them.	
	Supportive	*Teamwork:* The importance, benefits and constraints to teamwork; strategies to enhance cooperation between DCWs (e.g., active listen, positive feedback). Cognitive relaxation technique.	-
4	Educative	*The environment and dementia*: Strategies to enhance the physical and social environment for the person with dementia (e.g., decrease background noise; post signs as reminders); information about the risk factors and strategies to prevent falls.	
	Supportive	*Deal with emotions:* Improving emotion-management strategies through the activity "six colors to think" (based on Bono, 1985); Stretching and strengthening exercises.	-
5	Educative	*Motor stimulation:* Information about motor stimulation; strategies to enhance residents' involvement in daily care (e.g., break the small steps of an activity); and techniques for the moving and handling of residents.	
	Supportive	*Time management:* The impact of poor time management on personal and professional life and tools for better time management (e.g., set priorities; use a planning tool). Mental body-scan.	-
6	Educative	*Multisensory stimulation - olfaction:* Information about multisensory stimulation; dementia-related olfactory changes and strategies to stimulate the olfaction during the daily care (e.g., use shower gel of different fragrances; place aroma diffusers in the bedroom)	
	Supportive	*Problem-solving:* Using the problem-solving technique: (a) identify the problem; (b) explain the problem; (c) create solutions; (d) choose one solution; (e) plan the implementation of the solution; (f) evaluate the efficacy. Stretching and strengthening exercises	-
7	Educative	*Multi-sensory stimulation – vision and tactile stimulation:* The importance of vision and touch for people with dementia, dementia-related visual and tactile changes; strategies to stimulate the vision (e.g., reality orientation) and touch (e.g., hand massage during bath)	
	Supportive	*Relaxation*: Yoga	-
8	Educative	*Multi-sensory stimulation – audition and taste:* The importance of audition and taste for people with dementia; dementia-related audition and taste changes; strategies to stimulate the audition (e.g., listen to residents' favorite song) and taste (e.g., brush the person's teeth with toothpastes of different flavors).	
		Celebration and finalization	

The Cronbach's alpha coefficient of the scale showed a score of α=0,88. Scores for the criterion validity ranged between 0,4 and 0,8 and the examination of the factorial validity with the one-factor structure accounted for 43.96% of variance. Overall, the acceptable psychometric properties of the Portuguese version of the PSS are similar to those obtained in other versions[23].

DCWs' burnout

The 22-item Maslach Burnout Inventory (MBI) - Human Services Survey was used to assess the DCWs' experience of burnout[24]. The MBI is the most widely used instrument to assess burnout and is divided into three subscales: 8 items assess emotional exhaustion (EE), i.e., feelings of being emotionally exhausted by one's work; 5 items measure depersonalization (DP), i.e., the negative attitudes toward recipients' care or treatment; and 8 items assess personal accomplishment (PA), i.e., feelings of competence and successful achievement in work. The respondents are asked to report the frequency with which such feelings are experienced on a 7-point Likert-type scale, ranging from "never" (0) to "every day" (6). A combination of high scores on EE and DP, and a low score on PA, correspond to a high level of burnout. The Cronbach's alpha coefficient for the Portuguese version showed a score of $\alpha=0.75$ and reliability coefficients of 0.80 for EE, 0.71 for DP and 0.70 for PA. The validity of the three-factor structure of the MBI was found to provide a reasonable fit to the data, explaining 43.4% of the total variance. The psychometric properties of the used version are consistent with the ones of previous studies[25].

DCWs' job satisfaction

The short-form Minnesota Satisfaction Questionnaire (MSQ)[26] was used to assess DCWs' job satisfaction. It includes 20 items rated on a 5-point Likert scale ranging from "extremely dissatisfied" (1) to "extremely satisfied" (5). Item responses are summed or averaged to create a total score – the lower the score, the lower the level of job satisfaction. Besides a total score, the MSQ can also be scored for intrinsic and extrinsic satisfaction. The intrinsic subscale includes 6 items with scores ranging between 1 and 30 and refers to how people feel about the nature of the job tasks themselves. The extrinsic satisfaction subscale contains 8 items ranging from 8 to 40 and refers to how people feel about aspects of the work situation that are external to the job tasks. The psychometric properties of the used version of the MSQ are acceptable. High internal consistency was found for the global scale ($\alpha=0.93$), and for the intrinsic ($\alpha=0.88$) and extrinsic subscales (α=0.82). These values are higher than the ones found for the original scale[27]. Strong test-retest correlations were found (>0.80), which denotes adequate stability coefficients and corroborates the findings obtained in previous studies[27]. The factorial analysis confirmed the adequacy of the two-factor structure of the MSQ, which explained 62.69% of the total variance.

DCWs' person-centered communication

In order to capture both DCWs' verbal and non-verbal communicative behaviors, video-recordings of morning care routines were used. Video-recordings were performed in the resident's bedroom; the moment DCWs entered the room was defined as the starting point and when they left the room as the ending point. Bathing was not recorded to assure privacy to the person with dementia. Some procedures were followed to minimize participants' or residents' reactivity (i.e., response during data collection that affects the natural course of behavior as a result of being observed): (i) prior to data collection, several video-recordings were performed in order to familiarize participants with the methodology; (ii) DCWs were instructed to stop or remove the video camera if they noticed any resident's negative reaction caused by the device presence; and (iii) once the cameras were placed on a tripod and adequately positioned, the researcher left the room so that a further source of disruption could be avoided.

To prevent random DCWs' communicative behaviors, DCWs were video-recorded thrice at each assessment point. In total, 474 morning care sessions were video-recorded. At baseline, 3 participants were only recorded twice as they were absent from work.

DCWs' communicative behavior was studied by analyzing the frequency and duration of a list of mutually exclusive behaviors (*ethogram*). The categories described in the Kitwood's dialectical framework[10], relevant literature on staff's verbal and non-verbal communication[28,29] and preliminary observations of the video recordings informed the construction of the *ethogram*. The final list comprised 18 verbal communicative behaviors (Table 23) and 8 non-verbal communicative behaviors (Table 24). One coder (1st author) rated the DCWs' communicative behaviors according to the *ethogram* using specialized software, Noldus Observer XT (version 11.0) (Noldus International Technology, Wageningen, Netherlands). The coder was previously trained to use the software.

Table 23. Verbal communicative behaviors

Categories	Description
Positive verbal communicative behaviours	
Consult	Consulting the person with dementia about his or her preferences, desires and needs. Includes questions that invite resident's judgment. Examples include: • Would you like your shoes on or off? • Do you want to wear a skirt or pants?
Inform	Guiding the resident in terms of what to expect and providing information about what is going to happen during the task. Examples include: • Now I'm going to comb your hair. • Today you will take a bath.
Involve	Giving the resident the opportunity to take care for him/herself as much as possible and just 'completing' the care task when necessary. Examples include: • Could you help me with this? • Hold the toothbrush with your hand.
Reward	Rewarding the person and his/her behaviour, giving compliments and using expressions of encouragement. Examples include: • Well done, Sr. John. • You can do it, Sr. John.
Validate	Acknowledging the subjective reality of a person's emotions and feelings, and giving a response on the feeling level, without correcting the residents' reality or frame of reference, even if it is chaotic. Using statements to interpret or recognise the emotional state of the resident during the interaction. Examples include: • This is distressing for you, I understand. • How do you feel about it?
Assess comfort	Conveying interest and concern for the welfare and comfort of the person with dementia. Examples include: • How are you feeling today? • Does your leg hurt?
Distract	Amusing the person through humorous commentaries or distracting him/her in a positive way by guiding the conversation away from something unpleasant.
Sensory stimulation	Providing sensory information, without the intervention of concepts and intellectual understanding; for example through music, touch or aromas. Examples include: • Feel how nice and soft this towel is. • This cream smells good!
Conversation about the person	Showing interest in the resident's life or background. Examples include: • You were a teacher, weren't you? • You used to like gardening, didn't you?
Social conversation	Friendly conversation that conveys an interest in the resident and is not related to instrumental care. Includes statements that acknowledge that the resident said something. Examples include: • You have a very nice dress. Where did you get it? • Thank you!
Negative verbal communicative behaviours	
Task-oriented conversation	Communication that is related to task accomplishment or focused on nursing or therapeutic topics. Examples include: • Where are your glasses? • The doctor said not to eat bread.
Conversation with a third person	Communication to a third person. Examples include: • Can you please give me a towel? (to another DCW)

Table 24. Non-verbal communicative behavior

Categories	Description
Affirmative Nodding	Nodding head as a sign of approval, encouragement, or interest in the resident.
Resident-Directed Eye Gaze	Looking at the face of the resident.
Smile	Expression in which the corners of the mouth are directed upwards, denoting affability towards the resident.
Laugh	Opening the mouth (totally or partially), making a sound commonly associated with the act of laughing.
Withholding	Refusing a residents' request or question. Includes statements from the resident that the DCW does not acknowledge (e.g., resident asks if she can return to her room and the DCW does not respond).
Affective touch	Spontaneous and affective touch that is not necessary for the completion of a task (e.g., a pat on the back, a hug).
Guiding touch	Using touch to draw the person's attention or guide him/her for a task.
Instrumental touch	Deliberate physical contact, which is necessary for the completion of a task.

2.6. Data Analysis

Repeated measures analysis of variance (ANOVA) were used to determine the existence of significant differences on DCWs' perceived stress, burnout, job satisfaction and person-centered interactions at three points in time. Specifically, a series of one between-subjects variable (experimental vs. control) and one within-subjects variable (pretest, posttest, follow-up) repeated measures ANOVA was performed. This statistical technique was used to test intervention, time, and intervention by time interaction effects. *Partial eta squared* (η^2), which corresponds to the Effect Size, was interpreted as small (≥ 0.05), medium (0.05-0.25), large (0.25-0.50) and very large (≥ 0.50)[30].

All variables were previously tested for normality. The level of significance was set at 0.05. All analyses were conducted using the SPSS v20.0 (IBM Corp., Armonk, NY).

Inter-observer reliability

Inter-observer reliability with two independent coders was performed for 30% of the videos. This value is similar to those of previous studies[31]. The frequency and duration of each category in each moment were considered, using the intra-class correlation coefficient (ICC) equation (2.1) and the Bland and Altman method. The ICC(2,1) values were interpreted as follows: >0.75 was excellent, 0.40–0.75 was moderate and <0.40 was poor[32]. The results ranged between 0.45 and 1.0, indicating a moderate to excellent reliability.

Bland and Altman 95% limits of agreement were measured and the scatter plots were analyzed for all categories. A good agreement between the coders was found and no evidence of systematic bias was observed.

Comparison of Sample at Baseline

The experimental and control groups were compared on the basis of demographic variables and measured outcomes. Significance was set at the 0.05 level. The t-test for independent samples was used to compare the two groups on the basis of age and length of service and DCWs' outcomes; χ^2 tests were used to compare the two groups on the basis of dichotomous variables, including gender, education and marital status. Participants were all female with a mean age of 44.72±9.02 years. The majority were married (67.2%), 46.4% had primary and middle school education and 41.4% high school. The average length of service was 9.61±3.72 years. None of the differences were statistically significant at baseline (Table 25).

Table 25.Baseline characteristics of DCWs (n=58)

Outcome	Total (n=58) N (%)	Experimental group (n=27) N (%)	Control Group (n=31) N (%)	χ^2	*df*	p-value
Gender						
Female	58 (100.0)	27 (100.0)	31 (100.0)	No statistical analysis possible		
Age in years						
M (SD)	44.72 (9.02)	43.37 (10.00)	45.90 (8.04)	1.069 [a]	56	0.290
Marital Status						
Married	39 (67.2)	17 (63.0)	22 (71.0)			
Widowed	3 (5.2)	1 (3.7)	2 (6.5)			
Single	4 (6.9)	2 (7.4)	2 (6.5)	1.148	4	0.887
Divorced/separated	9 (15.5)	5 (15.5)	4 (12.9)			
Other	3 (5.2)	2 (7.4)	1 (3.2)			
Education						
Primary school[b]	15 (25.9)	4 (14.8)	11 (35.5)			
Middle school[c]	12 (20.7)	6 (22.2)	6 (19.4)			
High school[d]	24 (41.4)	11 (40.7)	13 (41.9)	6.857	4	0.144
College degree	1 (1.7)	1 (3.7)	0 (0.0)			
Other	6 (10.3)	5 (18.5)	1 (3.2)			
Length of service (years)						
M (SD)	9.61 (3.72)	9.84 (4.86)	9.42 (2.51)	-0.418 [a]	56	0.678

Abbreviations: M= mean; SD= standard deviation; *df*= degrees of freedom

[a] t-test student

[b] 1–4 years of education; [c] 5–9 years of education; [d] 10–12 years of education

3. Results

3.1. DCWs' perceived stress, burnout and job satisfaction

Data concerning DCWs' outcomes is displayed in Table 26.

A negative significant time interaction effect was obtained on perceived stress, with both groups reporting higher scores at 6 month follow-up than at baseline and immediately after the intervention ($p>0.001$). Effect sizes were large ($\eta^2=0.36$).

Analyses showed a significant time interaction effect on the MBI subscale 'personal accomplishment'. After a decrease in personal accomplishment scores immediately after the PE intervention, at 6 months, scores had improved in the experimental group and the control group showed a decline over time in this variable ($p>0.05$). Effect sizes were moderate ($\eta^2=0.08$). Although no significant differences were found for the remaining MBI subscales, DCWs from the PE intervention showed improved levels of emotional exhaustion and depersonalization at 6 months follow-up. In the control group the values of all the MBI subscales deteriorated at 6 months follow-up.

No significant differences were obtained for total, intrinsic or extrinsic job satisfaction. A modest but positive change on total job satisfaction from pre to post-test, followed by a deterioration at 6 months follow-up, was found for both groups.

Table 26. Changes in DCWs' stress, burnout and job satisfaction

Outcome	Experimental group (n=24)			Control group (n=29)						
	T1	T2	T3	T1	T2	T3	Time effect	ES	Group x Time effect	ES
		Mean (SD)			Mean (SD)					
PSS	19.42 (5.90)	18.79 (6.48)	27.25 (4.59)	20.55 (6.31)	20.10 (4.79)	25.55 (6.99)	F=28.255, *df*(2) p=0.000	0.36	F=1.346, *df*(2) p=0.265	0.03
MBI										
EE	17.0 (11.41)	15.8 (8.60)	13.82 (9.76)	12.67 (10.59)	15.42 (9.72)	16.25 (10.70)	F=0.132, *df*(2) p=0.876	0.00	F=2.145, *df*(2) p=0.123	0.05
DP	5.25 (5.05)	6.88 (6.40)	3.20 (3.85)	6.07 (5.71)	5.52 (4.01)	6.54 (5.89)	F=0.848; *df*(2) p=0.431	0.02	F=3.048, *df*(2) p=0.052	0.06
PA	40.42 (4.94)	38.54 (8.42)	39.50 (5.80)	40.69 (6.20)	37.31 (8.02)	34.17 (8.48)	F=4.604, *df*(2) p=0.012	0.08	F=2.649, *df*(2) p=0.076	0.05
MSQ										
MSQ intrinsic	24.29 (2.31)	24.00 (2.16)	24.33 (2.16)	22.55(4.19)	21.55(3.53)	20.62 (5.19)	F=1.619, *df*(2) p= 0.203	0.03	F=1.733; *df*(2) p=0.182	0.01
MSQ extrinsic	26.58 (4.67)	26.37 (3.56)	26.04 (4.42)	24.62(4.84)	25.59(4.15)	26.55 (6.41)	F=0.635, *df*(2); p=0.532	0.04	F=2.007; *df*(2); p=0.140	0.04
Total	72.96 (5.99)	73.83 (8.48)	72.29 (7.92)	68.14 (9.05)	68.55 (10.13)	68.48 (15.38)	F=0.209, *df*(2) p=0.811	0.00	F=0.163, *df*(2) p=0.849	0.00

Abbreviations: PSS= Perceived Stress Scale; MBI= Maslach Burnout Inventory; EE=Emotional Exhaustion; DP= Depersonalization; PA= Personal Accomplishment; MSQ= Minnesota Satisfaction Questionnaire; ES= Effect Size

3.2. DCWs' person-centered communication

Data concerning DCWs' person-centered communication can be found in Table 27.

Within the PE group, the frequency of the majority (24 out 26 behaviors) of person-centered behaviors improved immediately after the intervention (T2). However, 22 out 26 behaviors dropped at 6 months follow-up. For 10 of these behaviors, the frequencies were lower than those found at baseline. Among these, significant time and group interaction effects were found for the frequency of 'inform' ($p>0.01$, η^2partial=0.18) and 'laugh' ($p>0.01$, η^2partial=0.10). In the PE group, their frequency improved from T1 to T2 and dropped at follow-up. In the control group, the frequency of 'inform' reduced at T2 and values were sustained at follow-up, whereas 'laugh' improved at follow-up. Also, significant time effects were obtained for the frequency of 'validation' ($p>0.01$, η^2partial=0.10) and 'play' ($p>0.05$, η^2partial=0.07), with both groups experiencing a decline over time in these variables. Improvements were noticed in the frequency of 'involvement', 'withholding' and 'orientation'. Positive significant time effects were found for the frequency of the first two behaviors. The frequency of 'involvement' ($p>0.05$, η^2partial=0.07) and 'withholding' ($p>0.05$, η^2partial=0.11) improved over time in the experimental group and reduced at 6 months follow-up in the control group.

Concerning the duration of person-centered interactions, an improvement in 8 out 11 variables was noticed. Among these, a significant time effect was found for the duration of 'social conversation' ($p>0.01$, η^2partial=0.09), with both groups reporting an improvement over time in this variable. Declines over time were found for 'conversation about the person', 'instrumental conversation' and 'resident-directed eye gaze'. Significant time effects were obtained for the duration of 'instrumental conversation' ($p>0.05$, η^2partial=0.08) and 'resident-directed eye gaze' ($p>0.05$, η^2partial=0.07), with the experimental and control groups deteriorating over time.

4. Discussion

This study sought to examine the effects of a PCC-based PE intervention on DCWs' stress, burnout, job satisfaction and person-centered communication.

Findings suggest that a PE intervention can positively impact DCWs' burnout. Compared to DCWs in the control group, those who received the PE intervention reported a decrease in their levels of burnout (with significant findings found for the MBI subscale ‘personal accomplishment’) at both post-intervention and 6 months follow-up. This promising result suggests that, over time, adding a supportive component to PCC-training might enable DCWs to feel pleased about themselves and satisfied with their accomplishments on the job.

The findings did not support the hypothesis that, compared to education-only intervention, a PE intervention would improve DCWs’ job satisfaction. A modest but positive change on total job satisfaction from pre to post-test, followed by a deterioration at 6 months follow-up, was found for both groups. One explanation for these results might be related to the measure used to assess job satisfaction. The MSQ is based on the conceptualization of job satisfaction as a multidimensional construct, considering several aspects that were not covered by the intervention (e.g., managers’ support and organization conditions). Also, despite the guarantee of confidentiality, participants might have been reluctant to answer questions related to leadership’s role or policies of the organization. The individual assistance during morning care in both groups can also offer some light about the lack of significant differences between groups. By allowing workers to have immediate guidance and support to handle challenging situations, it can have an independent effect on DCWs’ job satisfaction. The extent to which individual assistance may impact DCWs’ outcomes requires further consideration.

Strongest effects were found immediately after the intervention, with diminishing strength at the 6 month follow-up, on perceived stress and on most DCWs’ person-centered communicative behaviors. Several reasons may explain these findings. First, the intervention ran for a short period of time (8 weeks). As it is important to keep DCWs under intervention long enough so they can experience lasting positive changes, maintenance strategies, such as ‘booster sessions’ (i.e., brief, periodic contacts intended to remind participants of intervention goals or encourage them to continue using the learned skills) are clearly needed. Moreover, it is possible that the results have been influenced by uncontrolled factors, such as the facility organizational culture. Contextual factors, in particular a supportive leadership and a reward culture of openness and accuracy, have been repeatedly cited in the literature as critically important to the success of interventions in terms of outcomes for DCWs[33]. According to the literature, DCWs are often not acknowledged by their managers and feel that their work is unappreciated, which negatively affects their state of wellbeing and care provision[34]. Therefore, efforts in improving leadership and management skills can be determinant to engender more positive impacts on DCWs. This might involve, for example, training to prepare for the challenges of leading change and support to provide adequate staff supervision and positive feedback systems[33]. However, more research is needed to determine what leadership skills can indeed be helpful. Another factor may be related to the progressive nature of dementia, which means that the symptoms gradually worsen over time increasing DCWs' stress and reducing job satisfaction. Also, the increased perceived stress at 6 month follow-up can be the result of an enhanced DCWs' awareness of stress on the job; the repeatedly completion of a measure on perceived stress may contribute to increase DCWs' understanding and consciousness of stress over time. At last, the possible pressure to provide better care after the interventions could have triggered higher stress levels. Nevertheless, some person-centered behaviors were positively affected by the PE intervention and should be highlighted. DCWs from the experimental group experienced a significant improvement in the frequency of involvement and withholding and in the duration of social conversation. Also, positive but no significant improvements were found in the duration of multisensory stimulation and several non-verbal communicative behaviors, including smile, laugh and affective touch. These are promising results as it is becoming increasingly acknowledged that good dementia care is underpinned by interpersonal relationships between people with dementia and DCWs that rely more on emotional, sensitive, and empathetic interactions rather than on verbal expressiveness [9]. The fact that at 6 months follow-up results were more positive for the duration of behaviors suggest that DCWs spend more time communicating with fewer interruptions. Besides, these findings indicate that DCWs might have selected over time those communicative behaviors that showed to be more effective, making more use of them.

Results must be, however, interpreted with caution as DCWs were not always recorded with the same resident and this may have influenced the results. Future studies should try to create and follow the same dyads. Besides, DCWs' performance, particularly immediately after the intervention, may have been influenced by the "Hawthorne effect", which means that DCWs being aware of video-recording possibly behaved differently. Though, DCWs' familiarization with the methodology may have minimized this effect at 6 months follow-up[35].

Other methodological limitations have also to be considered. The sample size was relatively small and might have reduced the statistical power to detect more significant changes. Hence when cluster designs are used, there are two sources of variance in the observations: the variability of patients within a cluster; and the variability between clusters. These two sources combine to produce an increase in the variance, and both must be considered in the analysis. The effect of the increased variance due to a cluster design is to increase the size of the standard errors and thus to widen confidence intervals and increase p-values, compared with a study of the same size using individual randomization[36]. In effect, the sample size is reduced and power is lost, and thus, sample sizes have to be inflated. Moreover, it was not possible to blind researchers to the experimental or control groups or assessments. Future studies with a double-blinded design should be conducted to clarify the findings.

Nevertheless, our findings are of interest as they provide evidence that a PE intervention may be an effective approach to reduce DCWs' burnout levels and improve person-centered behaviors. Further research is warranted to determine the extent of the benefits of this approach on residents with dementia and on other DCWs' outcomes such as depression, anxiety and perceived mastery. One of the strengths of the study is the consideration of a 6 months follow-up evaluation. This is important as most studies tend to rely only on pre and immediately posttest assessments[17]. Also, the use of video-recording provided a suitable method to assess interactions. Video-recording enables replaying and reviewing the data, to control the observer's fatigue and to achieve deeper levels of observation and analysis that are not possible to achieve by means of real-time observations[35]. The high inter-observer reliability obtained for the *ethogram* further supports its reliability and validity to measure PCC interactions. Yet, conducting future evaluations of the *ethogram* in order to further develop its acceptability, utility and validity is strongly recommended.

Overall, the results suggested that providing DCWs with training and emotional support is more effective in reducing burnout and improve adequate communicative behaviors than an education-only intervention. These findings highlight the importance of interventions in dementia care settings to go beyond DCWs' knowledge and instrumental skills to also address emotional skills. The addition of booster follow-up sessions to help maintain and extend the positive long-term effects of the intervention is highly encouraged. Also, DCWs' outcomes are largely associated to factors within the organization, thus culture-change initiatives (e.g., breaking down hierarchies, leadership commitment and DCWs empowerment) are further encouraged, as this is determinant to achieve and sustain practice changes.

Table 27. Changes in DCWs' verbal and non-verbal communicative behavior

Categories		Experimental group (n=24)			Control group (n=29)			time p-value	Partial eta squared	group× time p-value	Partial eta squared
		T1	T2	T3	T1	T2	T3				
		Mean (SD)			Mean (SD)						
Verbal communicative behavior											
Consult	Freq	1.02 (1.02)	1.05 (1.13)	0.82 (1.05)	1.60 (1.83)	1.24 (1.28)	0.80 (1.18)	0.097	0.05	0.412	0.02
Inform	Freq	8.69 (4.40)	9.45 (5.60)	4.70 (3.68)	8.23 (4.41)	6.99 (3.91)	6.98 (5.20)	0.013*	0.16	0.008*	0.18
Involve	Freq	3.46 (3.15)	3.55 (3.20)	4.85 (3.03)	3.50 (3.28)	6.13 (2.72)	5.00 (2.64)	0.027*	0.07	0.100	0.05
	Dur	13.06 (14.92)	17.58 (18.04)	24.00 (14.88)	19.14 (21.89)	28.68 (18.94)	21.36 (12.61)	0.053	0.06	0.099	0.05
Reward	Freq	1.37 (1.49)	1.81 (1.72)	1.49 (1.70)	0.75 (0.70)	1.34 (1.17)	1.38 (1.25)	0.048*	0.06	0.454	0.02
Validate	Freq	0.32 (0.70)	0.35 (0.83)	0.02 (0.10)	0.13 (0.34)	0.17 (0.34)	0.03 (0.10)	0.006*	0.37	0.101	0.02
Assess comfort	Freq	0.35 (0.48)	0.35 (0.48)	0.19 (0.32)	0.38 (0.58)	0.43 (0.79)	0.49 (0.74)	0.964	0.00	0.531	0.01
Distract	Freq	0.41 (0.84)	0.55(1.13)	0.09 (0.21)	0.25 (0.60)	0.15 (0.34)	0.08 (0.17)	0.486	0.00	0.130	0.04
Sensory stimulation	Freq	0.12 (0.23)	0.33 (0.46)	0.32 (0.42)	0.11 (0.33)	0.32 (0.82)	0.44 (1.45)	0.023*	0.09	0.904	0.00
	Dur	0.60 (1.74)	1.71 (2.78)	2.06 (3.11)	0.34 (0.98)	3.08 (9.59)	1.06 (3.55)	0.129	0.44	0.399	0.01
Social conversation	Freq	4.69 (2.64)	5.28 (2.84)	5.19 (3.00)	6.44 (451)	6.95 (4.18)	6.13 (3.09)	0.306	0.02	0.993	0.00
	Dur	33.39 (30.55)	43.79 (23.04)	46.75 (40.92)	37.30 (25.44)	49.74 (33.38)	63.40 (45.99)	0.009**	0.55	0.732	0.00
Conversation about the person	Freq	0.02 (0.11)	0.03 (0.14)	0.02 (0.08)	0.12 (0.25)	0.06 (0.16)	0.07 (0.17)	0.509	0.00	0.210	0.03
	Dur	0.09 (0.35)	0.43 (2,09)	0.05 (0.23)	1.17 (2.76)	0.80 (2.08)	1.99 (8.08)	0.907	0.55	0.09	0.01
Instrumental conversation	Freq	2.79 (2.10)	2.50 (2.37)	3.18 (2.62)	2.10 (1.66)	1.94 (1.15)	2.81 (2.34)	0.608	0.00	0.972	0.00
	Dur	13.41 (11.25)	10.68 (9.81)	19.43 (19.03)	10.73 (9.85)	10.73 (9.96)	15.01 (13.96)	0.040*	0.62	0.082	0.01
Conversation with others	Freq	5.14 (4.02)	4.86 (2.93)	3.89 (2.84)	5.55 (4.06)	4.02 (2.89)	3.89 (2.84)	0.006*	0.09	0.462	0.01
	Dur	21.33 (17.63)	25.32 (14.81)	20.52 (13.83)	14.68 (17.90)	20.77 (12.02)	19.14 (12.52)	0.182	0.04	0.628	0.01

Categories		Experimental group (n=24)			Control group (n=29)			time p-value	Partial eta squared	group× time p-value	Partial eta squared
		T1	T2	T3	T1	T2	T3				
		Mean (SD)			Mean (SD)						
Ignore	Freq	1.82 (1.47)	1.70 (1.73)	2.14 (2.07)	2.12 (2.10)	1.63 (1.56)	1.65 (1.75)	0.613	0.00	0.457	0.02
Infantilize	Freq	0.02 (0.09)	0.00	0.00	0.28 (0.51)	0.12 (0.28)	0.21 (0.42)	0.334	0.02	0.409	0.02
Invalidate	Freq	0.07 (0.27)	0.00	0.02 (0.07)	0.13 (0.25)	0.17 (0.39)	0.20 (0.10)	0.909	0.00	0.418	0.02
Mockery	Freq	0.11 (0.22)	0.09 (0.22)	0.34 (0.70)	0.54 (0.69)	0.25 (0.44)	0.57 (1.12)	0.074	0.05	0.543	0.01
Criticise	Freq	0.47 (0.73)	0.07 (0.25)	0.28 (0.49)	0.46 (0.72)	0.57 (0.75)	0.24 (0.53)	0.386	0.02	0.051	0.06
Impose	Freq	0.49 (0.89)	0.16 (0.37)	0.37 (0.60)	0.56 (0.58)	0.83 (1.57)	0.22 (0.47)	0.228	0.059	0.104	0.09
Non-verbal communicative behavior											
Affirmative Nodding	Freq	0.45 (0.85)	0.74 (1.16)	0.22 (0.65)	0.55 (0.84)	0.51 (0.99)	0.72 (1.19)	0.630	0.02	0.170	0.07
Resident-directed eye gaze	Freq	1.90 (1.99)	2.08 (1.93)	0.85 (0.98)	1.91 (2.36)	2.03 (2.26)	1.91 (2.34)	0.106	0.05	0.169	0.04
	Dur	19.18 (32.24)	26.56 (40.08)	4.17 (6.03)	25.43 (56.24)	19.68 (33.73)	11.69 (17.92)	0.032*	0.07	0.461	0.02
Smile	Freq	0.32 (0.62)	0.35 (0.62)	0.33 (0.43)	0.31 (0.86)	0.23 (0.54)	0.85 (1.21)	0.120	0.08	0.109	0.09
	Dur	0.61 (1.25)	0.71 (1.76)	1.29 (3.12)	2.65 (11.90)	0.89 (2.11)	5.99 (13.81)	0.199	0.03	0.373	0.02
Laugh	Freq	1.15 (1.05)	1.78 (1.71)	0.94 (1.12)	1.01 (1.01)	0.62 (0.82)	1.03 (1.14)	0.526	0.01	0.004*	0.106
	Dur	9.24 (17.38)	7.39 (12.30)	8.61 (19.40)	10.28 (29.11)	2.10 (3.03)	3.75 (5.09)	0.550	0.01	0.934	0.001
Withholding	Freq	0.41 (0.76)	0.06 (0.16)	0.00	0.08 (0.23)	0.01 (0.06)	0.07 (0.29)	0.024*	0.114	0.06	0.11
Affective touch	Freq	0.69 (0.57)	0.68 (0.62)	0.48 (0.56)	1.18 (1.33)	0.75 (1.00)	0.94 (1.28)	0.324	0.02	0.393	0.02
	Dur	2.22 (3.28)	1.69 (1.96)	1.86 (3.61)	3.53 (4.42)	4.05 (9.03)	3.68 (7.08)	0.992	0.00	0.854	0.00
Instrumental touch	Freq	10.33 (2.61)	10.21 (2.90)	10.82 (2.25)	9.82 (2.79)	8.99 (2.34)	10.44 (2.92)	0.085	0.05	0.616	0.01
	Dur	281.06 (169.8)	311.31 (52.67)	296.29 (43.72)	326.37 (251.40)	268.9 (69.58)	284.08 (51.45)	0.849	0.00	0.27	0.03
Awareness touch	Freq	0.16 (0.49)	0.56 (1.39)	0.23 (0.38)	0.44 (0.71)	0.44 (0.61)	0.43 (0.63)	0.343	0.02	0.34	0.02

Abbreviations: Freq, frequency (i.e., number of occurrences); Dur, duration (i.e.,length of the behaviour in seconds); SD, Standard deviation.
*p<0.05; **p<0.001

6. References

1. Alzheimer's Disease International. *World Alzheimer Report 2013: An analysis of long-term care for dementia.* London: Alzheimer's Disease International;2013.
2. Stone R. The long-term care workforce: From accidental to valued profession. In: Wolf D, Folbre N, eds. *Universal coverage of long-term care in the United States: Can we get there from here?* United States: Russell Sage Foundation; 2012.
3. Gray-Stanley JA, Muramatsu N. Work stress, burnout, and social and personal resources among direct care workers. *Research in Developmental Disabilities.* 2011;32(3):1065-1074.
4. Edberg A-K, Bird M, Richards DA, Woods R, Keeley P, Davis-Quarrell V. Strain in nursing care of people with dementia: Nurses' experience in Australia, Sweden and United Kingdom. *Aging & Mental Health.* 2008;12(2):236-243.
5. Edvardsson D, Sandman P, Nay R, Karlsson S. Predictors of job strain in residential dementia care nursing staff. *J Nurs Manag.* 2009;17(1):59-65.
6. Menne HL, Ejaz FK, Noelker LS, Jones JA. Direct Care Workers' Recommendations for Training and Continuing Education. *Gerontology & Geriatrics Education.* 2007;28(2):91-108.
7. Nolan M, Davies S, Brown J, et al. The role of education and training in achieving change in care homes: a literature review. *Journal of Research in Nursing.* 2008;13(5):411-433.
8. Nolan M, Davies S, Brown J, Keady J, Nolan J. Beyond person-centred care: a new vision for gerontological nursing. *Journal of Clinical Nursing.* Mar 2004;13(3a):45-53.
9. Brooker D. *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers; 2007.
10. Kitwood T. *Dementia Reconsidered: The person comes first* Buckingham, UK: Open University Press; 1997.
11. Chenoweth L, King MT, Jeon YH, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol.* Apr 2009;8(4):317-325.
12. Fossey J. Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ.* 2006;332(7544):756-761.

13. Sloane PD, Hoeffer B, Mitchell CM, et al. Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *Journal of the American Geriatrics Society.* Nov 2004;52(11):1795-1804.
14. Sidani S, Streiner D, Leclerc C. Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. *International journal of older people nursing.* Mar 2012;7(1):37-45.
15. Edvardsson D, Winblad B, Sandman P. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology.* 2008;7(4):362-367.
16. van den Pol-Grevelink A, Jukema JS, Smits CH. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry.* 2012;27(3):219-229.
17. Barbosa A, Sousa L, Nolan M, Figueiredo D. Effects of person-centered care approaches to dementia care on staff: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias.* 2014.
18. van Weert J, Vandulmen A, Spreeuwenberg P, Ribbe M, Bensing J. Effects of snoezelen, integrated in 24h dementia care, on nurse–patient communication during morning care. *Patient Education and Counseling.* 2005;58(3):312-326.
19. Figueiredo D, Barbosa A, Cruz J, Marques A, Sousa L. Empowering staff in dementia long-term care: Towards a more supportive approach to interventions. *Educ Gerontol.* 2013;39(6):413-427.
20. Marques A, Cruz J, Barbosa A, Figueiredo D, Sousa LX. Motor and Multisensory Care-Based Approach in Dementia: Long-Term Effects of a Pilot Study. *Am J Alzheimers Dis Other Demen.* Dec 7 2012.
21. Barbosa A, Nolan M, Sousa L, Figueiredo D. Psycho-educational Approaches in Long-term Care Homes: Direct Care Workers and Managers' Perspectives. *Procedia - Social and Behavioral Sciences.* 2014;131(0):406-410.
22. Pais Ribeiro J, Marques T. A avaliação do stresse: a propósito de um estudo de adaptação da escala de percepção de stresse. *Psicologia, Saúde & Doenças.* 2009;10(2):237-248.
23. Lee E-H. Review of the psychometric evidence of the perceived stress scale. *Asian Nursing Research.* 2012;6(4):121-127.

24. Melo B, Gomes A, Cruz J. Desenvolvimento e adaptação de um instrumento de avaliação psicológica do “burnout” para os profissionais de Psicologia. In: Associação dos Psicólogos Portugueses, ed. *Avaliação psicologica: formas e contextos*. Braga: Lusografe; 1999:596-603.
25. Poghosyan L, Aiken LH, Sloane DM. Factor structure of the Maslach Burnout Inventory: An analysis of data from large scale cross-sectional surveys of nurses from eight countries. *International Journal of Nursing Studies.* 2009;46(7):894-902.
26. Ferreira J, Fernandes R, Haase RF, Santos E. Minnesota Satisfaction Questionnaire - Short Form: estudo de adaptação e validação para a língua portuguesa. *Psychologica.* 2009;51:251-281.
27. Weiss DJ, Dawis RV, England GW. *Manual for the Minnesota Satisfaction Questionnaire.* Minneapolis: University of Minneapolis;1967.
28. Caris-Verhallen W, Kerkstra A, Bensing J. Non-verbal behaviour in nurse-elderly patient communication. *Journal of Advanced Nursing.* 1999;29(4):808-818.
29. Williams K, Harris B, Lueger A, Ward K, Wassmer R, Weber A. Visual cues for person-centered communication. *Clinical Nursing Research.* 2011;20(4):448-461.
30. Cohen J. *Statistical Power Analysis for the Behavioral Sciences* 2nd ed. New Jersey: Lawrence Erbaum Associates; 1988.
31. Bourgeois MS, Dijkstra K, Burgio LD, Allen RS. Communication skills training for nursing aides of residents with dementia: The impact of measuring performance. *Clin Gerontologist.* 2004;27(1-2):119-138.
32. Fleiss J. The Design and Analysis of Clinical Experiments: Taylor & Francis; 1986.
33. Jeon YH, Merlyn T, Chenoweth L. Leadership and management in the aged care sector: a narrative synthesis. *Australasian Journal on Ageing.* 2010;29(2):54-60.
34. Barbosa A, Nolan M, Sousa L, Figueiredo D. Supporting direct care workers in dementia care: effects of a psychoeducational intervention. *Am J Alzheimers Dis Other Demen.* 2015;30(2):130-138.
35. Haidet KK, Tate J, Divirgilio-Thomas D, Kolanowski A, Happ MB. Methods to improve reliability of video-recorded behavioral data. *Res Nurs Health.* Aug 2009;32(4):465-474.
36. Campbell MK, Elbourne DR, Altman DG. CONSORT statement: extension to cluster randomised trials. *BMJ.* 2004;328(7441):702-708.

Chapter 6

Implementing a psycho-educational intervention for care assistants working with people with dementia in aged-care facilities: A qualitative study of facilitators and barriers

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Abstract

Psycho-educational interventions hold promise as a means of driving forward benefits for care assistants and care provision as they incorporate both illness-specific education and support for stress-reduction. This qualitative study examines the facilitators and barriers to the implementation of such an intervention for care assistants working with people with dementia in aged-care facilities.

Seven focus-group interviews involving 21 care assistants (female; mean age 43.37±10.0) and individual semi-structured interviews with two managers (female; mean age 45.5 ± 10.26) were conducted two weeks and six months after the intervention, in two aged-care facilities. Interviews were recorded, transcribed and submitted to content analysis by two independent researchers.

Factors facilitating implementation included: intervention format and delivery; provision of emotional support; provision of individual assistance; coordinators' relationship skills; and positive care assistants' attitudes. Barriers included: short-duration of the intervention; resource constraints; limited management support; negative care assistants' attitudes; and residents' level of disability.

Findings enable the interpretation of the experimental results and underscore the importance of collecting the perception of different grades of staff to obtain information relevant to plan effective interventions.

Keywords: dementia; focus-groups; person-centred care; workforce issues

1. Introduction

Care assistants occupy a pivotal role in the care of persons with dementia. They are responsible for the majority of daily care to people with dementia in aged-care facilities, being most likely to influence residents' quality of life (1). Yet, despite the demanding nature of their role, they receive little training, are often underappreciated, lack support and experience heavy workloads (1). These conditions are significant sources of care assistants' stress, burnout and job dissatisfaction, which are known to create a disruption in the worker-resident relationship and hinder the delivery of quality care (2, 3). The association between care assistants' wellbeing and provision of person or relationship-centred care has been recognised, with several authors emphasising that if workers are to deliver such a care they need to have their own needs acknowledged and addressed (4, 5). Hence, both person-centred and relationship-centred care place greater emphasis on emotional support, which allows connection, involvement and the promotion of worker wellbeing (4).

Psycho-educational (PE) interventions hold promise as a means of driving forward benefits for care assistants and care provision as they incorporate both illness-specific education and support to foster coping with concrete strategies for problem-solving and stress-reduction. These approaches have been primarily focused on family carers of people with dementia, where they have been associated with positive and consistent effects on several outcome indicators (e.g., burden, depression, anxiety) (6, 7). The commonalities and intersections of formal and informal care (e.g., both can be equally stressful or overwhelming), suggest that adapting the PE intervention for care assistants can better prepare them to deal with their multifaceted role. Yet, PE interventions in the context of formal care have received little attention in the literature. Rather, the majority of research has focused skills training or knowledge based interventions aimed at enhancing care assistants' technical competences (8, 9).

The authors of the current manuscript conducted a controlled pre-posttest study in four aged-care facilities to assess the impact of a PE intervention on care assistants. Understanding whether and why an intervention fails or succeeds depends, not only on the measurement of outcomes, but also on identifying those factors that act as either facilitators or barriers to its successful implementation.

The purpose of the present study was to describe care assistants and managers' perceptions about the factors that were relevant to the success or failure of the PE intervention. This is the first study, to the best of our knowledge, to explicitly explore the facilitators and barriers to PE interventions targeted at care assistants in aged-care facilities from two perspectives. This aim is to provide new insights into the factors that would support the potential more widespread application of such approaches in this important setting.

Psycho-educational intervention content and results

The psycho-educational intervention sought to provide care assistants with information concerning person-centred dementia care and strategies to cope with several work-related stresses. A literature review about interventions for care assistants, findings from a pilot-study (10, 11) and pre-test interviews with different grades of staff informed the design of the intervention (12).

The intervention consisted of eight ninety minute weekly sessions containing two key components: educative and supportive. Each session followed the same sequence and structure: (i) discussion of the prior session's 'homework' assignment; (ii) overview of the content of the current session; (iii) educative component; (iv) supportive component; and (v) homework assignment to be completed prior to the next session. The sessions were facilitated by a gerontologist and a physical therapist experienced in leading groups. In the three days following each session, the same professionals assisted each care assistant individually during morning care to reinforce the key learning points. A more detailed description of the intervention can be found in Table 28.

Published data show that, compared to the education-only group, the PE intervention was not more effective in reducing care assistants' stress or job dissatisfaction, but findings demonstrated a significant reduction in their levels of burnout. Participants reported that the intervention contributed to improved knowledge about dementia and enhanced their feelings of being worthwhile, as well improving group cohesion, emotional management and self-awareness (13). Also, findings revealed positive short-term effects on care assistants' communicative behaviours with residents with dementia (14, 15).

Table 28. Content of the psycho-educational intervention

Session	Component	Content of the psycho-educational intervention
1	Educative	*Information about PCC and dementia:* Information about the concept and principles of PCC. Basic information on dementia, its causes, symptoms and evolution.
	Supportive	*Emotional impact of care:* The positive and negative impacts of the care experience on personal and professional life; Abdominal breathing.
2	Educative	*Communication in dementia:* Verbal and non-verbal communicative strategies to interact with residents with dementia (e.g., give simple choices; use validation; allows time to respond; use individual's name and eye contact).
	Supportive	*Conflict management:* Improving assertiveness through the DESC technique (Describe; Explain; Specify; Conclude) technique (Bower & Bower, 2004). Stretching and strengthening exercises.
3	Educative	*Challenging behaviours:* Information about challenging behaviours and strategies to deal with them.
	Supportive	*Teamwork:* The importance, benefits and constraints to teamwork; strategies to enhance cooperation between DCWs (e.g., active listen, positive feedback). Cognitive relaxation technique.
4	Educative	*The environment and dementia*: Strategies to enhance the physical and social environment for the person with dementia (e.g., decrease background noise; post signs as reminders); information about the risk factors and strategies to prevent falls.
	Supportive	*Deal with emotions:* Improving emotion-management strategies through the activity "six colours to think" (based on Bono, 1985); Stretching and strengthening exercises.
5	Educative	*Motor stimulation:* Information about motor stimulation; strategies to enhance residents' involvement in daily care (e.g., break the small steps of an activity); and techniques for the moving and handling of residents.
	Supportive	*Time management:* The impact of poor time management on personal and professional life and tools for better time management (e.g., set priorities; use a planning tool). Mental body-scan.
6	Educative	*Multisensory stimulation - olfaction:* Information about multisensory stimulation; dementia-related olfactory changes and strategies to stimulate the olfaction during the daily care (e.g., use shower gel of different fragrances; place aroma diffusers in the bedroom)
	Supportive	*Problem-solving:* Using the problem-solving technique: (a) identify the problem; (b) explain the problem; (c) create solutions; (d) choose one solution; (e) plan the implementation of the solution; (f) evaluate the efficacy. Stretching and strengthening exercises
7	Educative	*Multi-sensory stimulation – vision and tactile stimulation:* The importance of vision and touch for people with dementia, dementia-related visual and tactile changes; strategies to stimulate the vision (e.g., reality orientation) and touch (e.g., hand massage during bath)
	Supportive	*Relaxation*: Yoga
8	Educative	*Multi-sensory stimulation – audition and taste:* The importance of audition and taste for people with dementia; dementia-related audition and taste changes; strategies to stimulate the audition (e.g., listen to residents' favourite song) and taste (e.g., brush the person's teeth with toothpastes of different flavours).
		Celebration and finalization - Participants reflected on the balance of their participation in the group. Photographs of the whole group were taken and a snack was prepared.

2. Methods

2.1. Design

The post-intervention qualitative evaluation was an important part of the overall experimental pretest-posttest design that was conducted in four aged-care facilities. After being matched for staff/resident ratio and proportion of residents with dementia, facilities were randomly assigned to the psycho-educational intervention (experimental) or education-only intervention (control). Detailed information about the design of the original study can be found elsewhere (Chapters 2, 3 and 4). For the purpose of this study, only data from the experimental group were examined. The main study was approved by an ethics committee.

2.2. Setting

The two aged-care facilities (non-profit-making facilities of collective accommodation) had a staff/resident ratio between 1:2 and 1:3 and a residents with dementia/total of residents' ratio between 1:3 and 1:5. Organisationally, at the head of each facility was the administrator (the person or company responsible for management and administrative operations). Below was the care-home or middle manager (a qualified professional in social work who supervises the care assistants, oversees residents' care and performs administrative functions). The frontline workers, the vast majority of which are care assistants, are supported by a small number of part-time nurses, doctors, physical or occupational therapists.

2.3. Participants

The managers of each facility were informed about the study and asked to identify all care assistants that met the following inclusion criteria: i) provide regular personal care to people with dementia (e.g., bathing, and toileting); and (ii) had been employed for at least 2 months. Temporary workers, trainees, care assistants working only on the night shift and other health and social care practitioners (physicians, nurses and social workers) were excluded as the latter in particular have little interaction with the residents. A meeting with eligible care assistants and managers was scheduled to provide detailed information about the study and invite them to participate. Potential participants were informed about the purpose of the study and the voluntary nature of their participation. Anonymity and confidentiality were guaranteed and written informed consent was obtained prior to any data collection.

All eligible care assistants (n=27) in the two experimental facilities were offered the PE intervention. Of these, 25 completed the posttest focus-group interviews and 21 the six-month follow-up interviews. Absence from work was the main reason for dropouts. Also, the two managers were individually interviewed immediately and six months after the intervention.

Care assistants were all female, mostly married (63.0%) and with a mean age of 43.37 years (±10.0). The average length of employment as care assistants was 9.84 years (±4.86). Both managers were female and had a college degree in social work. Their mean age was 45.5 years (± 10.26) and the average length of employment was 11.5 years (±6.36) (Table 29).

Table 29. Participants' sociodemographic characteristics

Outcome	N (%)
Direct care workers (n=27)	
Gender	
Female	27 (100.0)
Age in years	
M (SD)	43.37 (10.00)
Marital Status	
Married	17 (63.0)
Widowed	1 (3.7)
Single	2 (7.4)
Divorced/separated	5 (15.5)
Other	2 (7.4)
Education	
Primary school	4 (14.8)
Middle school	6 (22.2)
High school	11 (40.7)
College degree	1 (3.7)
Other	5 (18.5)
Average length of employment	
M (SD)	9.84 (4.86)
Managers (n=2)	
Gender	
Female	2 (100.0)
Age in years	
M (SD)	45.50 (10.26)
Marital Status	
Married	2 (100.0)
Education	
College degree	2 (100.0)
Average length of employment	
M (SD)	11.5 (6.36)

Abbreviations: M, mean; SD, standard deviation

2.4. Data collection

Focus-group interviews

A total of seven focus-group interviews were conducted two weeks and six months after the end of the intervention. Each focus-group involved four to eight care assistants and met once for no more than 90 minutes in a quiet room at the facility.

An experienced researcher moderated the groups, which were audio-recorded with the permission of the participants. Questions were formulated using a semi-structured interview guide that was revised by all the authors. Interviews began with an identical introduction, informing participants that they would be asked their opinions about the intervention and reassuring confidentiality. It was emphasised that there were no right or wrong answers. First, participants were invited to freely describe their opinions about the intervention. Subsequent questions were focused on aspects that may have positive or negative influenced the effectiveness of the intervention (Table 30). Each interview was transcribed *verbatim*.

Table 30. Interview guide

What general considerations do you want to make about the intervention?
What did you like most and least about the intervention?
What factors hindered the implementation of the intervention?
What kind of readjustments in its contents and structure do you suggest?

Individual semi-structured interviews

Semi-structured, 30-45 minute individual interviews were held with the manager of each facility two weeks and six months after the intervention. The interview guide was similar to that used for the focus-group with care assistants, and explored the managers' opinions about the intervention and main factors that may have an influence (positive or negative) on the effectiveness of the intervention (Table 30). The meetings began with the interviewer reviewing the topics to be discussed and assuring the anonymity and confidentiality of data. Questions were then generated and followed by probes and paraphrasing of content to elicit more detail. Each interview was audio-recorded and transcribed.

2.5. Data analysis

Both the individual and the focus-group interviews were subjected to thematic analysis. The process of creating and developing the codes and themes was gradually refined by two independent judges (AB and DF) as follows (16): (i) data were transcribed and repeatedly read so that the judges became familiar with it; (ii) a list of preliminary codes was created; (iii) the codes were sorted into subthemes and then organised into the key-themes; (iv) the themes were reviewed and refined to form a coherent pattern; (v) clear definitions and names for each (sub) theme were generated; (vi) critical feedback was provided by all the other authors. Data were managed using qualitative data analysis software - webQDA (University of Aveiro, Portugal).

3. Results

Data analysis showed that factors relating to the intervention, the workers, the organisation and residents were perceived as critical to successful implementation. A summary of the facilitators and barriers is provided in Table 31. Facilitators included: (i) the intervention format and delivery (duration of the sessions and their timing); (ii) provision of emotional support; (iii) provision of individual assistance; (iv) coordinators' characteristics*;* and (v) care assistants' positive attitudes. Barriers included: (i) intervention format and delivery (short-duration); (ii) time and human constraints; (iii) limited management support; iv) care assistants' negative attitudes; and (v) residents' level of disability.

While facilitators and barriers are presented separately, they were in reality inter-linked and were not mutually exclusive. Similarities and differences emerged between care assistants' and managers views. The themes described below are supported using illustrative extracts from the data. All names have been changed to protect participants' anonymity.

3.1. Facilitators

Intervention format and delivery

Both care assistants and managers considered that the intervention was useful, interesting and relevant to the care assistants' day to day work, with the content of the sessions being much appreciated. The number and length of the sessions were seen as appropriate as they did not cause the care assistants to suffer *'from fatigue'*. Both interviewees stated that the delivery of the intervention fitted into the routine of the home and that shift change-over was the most appropriate time to deliver the intervention as it '*allowed the participation of a large number of care assistants'*.

Provision of emotional support

Both managers and care assistants valued the supportive component. For managers, the emotional support was the most important part of the intervention. They saw the addition of a supportive component as being essential to improving the care assistants' motivation and feelings of being supported. It allowed and encouraged them to talk about their anxieties and emotional problems and fostered positive relationships between co-workers. The manager below described how this had positively impacted on their attitudes towards work:

> *"The fact that they were in a group where they could think, share, vent and talk about themselves and about their problems helped them considerably (…). I think they are more aware of how to manage their own stress. Although tired, they are calmer in relation to work and know how to control their emotions."* [Rita, manager]

Additionally, the supportive component raised the managers' awareness of the need to provide a physical space specifically for care assistants where these could meet and talk freely about themselves and their feelings about their work:

> *"I think that a small and cosy space for DCWs where they could have dialogue, share and clarify what each other is missing. I believe this is something that could be useful to them and to practice."* [Maria, manager]

The care assistants themselves were particularly enthusiastic about the relaxation exercises that were practiced at the end of the supportive component. They reported that all too often the emphasis of any education is placed on the technical aspects of care and the residents' well-being while overlooking their own. The relaxation sessions were seen to counter this, they were rewarding.

> *"I appreciated all the supportive sessions. As this was an intervention about dementia I thought it would be only focused on residents (…) but we could (also) relax, which is something that we had never had (before)".* [Anna, care assistant]

The realisation of the benefits of relaxation, led the administration of one of the facilities to consider the development of a specific space where workers could relax.

> *"They [care assistants] all found the relaxation very rewarding and during those minutes they could relieve and relax. The administration has demonstrated openness and flexibility to create relaxation activities with workers."* [Maria, manager]

Provision of individual assistance

The individual assistance given to the care assistants during morning care was highly appreciated by both care assistants and managers and was considered crucial to establishing changes in practice. It offered time for reflection and feedback and an opportunity to practice and reinforce skills:

> *"Our last training was very informative. Having sessions and then several days of practical assistance was essential. Care assistants don't (just) need more knowledge, they need to practice, they need to implement what they learnt".* [Maria, manager]
> *"It was very important to have the theory coupled with the practice. During individual assistance we were relaxed, we didn't rush things. We tried to work as we have been taught and this has become routine".* [Andrea, care assistant]

Coordinators' relationship skills

The coordinators were described as being kind and supportive by participants and this was seen as key to the success of the programme. Care assistants felt that the coordinators were approachable and made themselves available to discuss problems. Hence, the care assistants felt that their feelings were really listened to, rather than being ignored. The *'openness, empathy and understanding'* demonstrated by the coordinators provided an opportunity for sharing, not only with the coordinators but between themselves. Care assistants therefore felt at ease and forged closer connections with their co-workers through *'discussion of their personal experiences'*. Furthermore having 'experts' involved sharing their knowledge and experience was appreciated by the care assistants, who reported that this made them feel more confident.

> *"The coordinators' work was very important. They valued us, which is something that we need. Despite being experts we never felt distantness, they knew how to interact with us."* [Andrea, care assistant]

Care assistants' positive attitudes

Based on their observations both care assistants and managers noted that the care assistants were highly satisfied with and motivated by the PE intervention. One manager noted that the intervention led care assistants to work with enthusiasm.

> *"I never have seen them [care assistants] so motivated with an initiative. They were devoted to improve."* [Maria, manager]

3.2. Barriers

Intervention format and delivery

As already noted some aspects of the format and delivery of the intervention were viewed positively, whereas others were not. Although the duration of the sessions and their timing during the day were viewed positively, both managers and some care assistants reported that the short-duration of the intervention as a whole was a limitation and that additional sessions and more formal follow-up would have been beneficial to help establish any changes in practice. Care assistants in particular stressed the need for more emotional support to improve both their own wellbeing and care practices.

> *"The supportive component, especially the relaxation, could be longer. Over time we become exhausted and can no longer deal with the residents' mood changes. That would help us."* [Catherine, care assistant]

This suggests that despite the initial enthusiasm for such sessions, and the intention to provide both time and space for them to continue, they lapsed after the formal intervention had concluded. As suggested below, this may have been due to pressures on limited resources, with other activities having to take a priority.

Lack of time and human resources.

Two weeks and six months after the implementation of the intervention, heavy workload, resulting in ‘time constraints’, ‘understaffing’ and ‘multi-responsibilities’, were reported by care assistants as the major factor hindering changes to practice being sustained. Participants found it difficult to follow many of the intervention recommendations, for example, taking time to communicate with residents, due to time constraints and the busyness of their shifts:

> *“Our problem is lack of time. That’s our problem. We should have cleaning staff and care staff (…) so we would be less busy and stressed and we would have more time to interact with the residents”.* [Anna, care assistant]

At 6 months follow-up, managers also highlighted the problems posed by the lack of time and human resources. As one manager noted care assistants often felt ‘*frustrated given the impossibility to put everything into practice’.* The demotivating effects of being aware of the potentially beneficial changes to practice that are possible but subsequently not being able to put them into practice is a something that has been well described in the literature, and will be considered further in the discussion. In addition to constraints imposed by lack of resources, care assistants also felt that their managers were not as supportive as they might have been.

Lack of management support and encouragement

Care assistants recognised that their managers were an essential source of ongoing advice and guidance, but considered them to be too far removed from the reality of life and problems *‘on the floor’*. Care assistants felt that their skills and commitment were rarely acknowledged and that their work was went largely unappreciated. This was seen to impact negatively on their job performance and morale. This may explain why some of the early benefits of the intervention were not sustained over time.

Some care assistants suggested that the integration of training for managers into the intervention would be a way of creating a more supportive environment that would both recognise their contribution and support them to transfer the skills and knowledge they had into practice. Particular emphasis was placed on the need for interpersonal skills training for managers.

> *"We need a manager that could supervise and be an effective leader (…) our efforts need to be recognised (…) when we feel confident we provide better care than when we have our confidence damaged".* [Claire, care assistant]
> *"It would be important if they [managers] knew how to communicate with us…they are…. destructive. Instead of saying 'that's wrong!' they could rather say 'you can do better the next time!'".* [Rose, care assistant]

Interestingly, at six months follow-up the managers perceived themselves as pivotal to achieving and sustaining practice change, but, as with the care assistants, they found themselves too *'busy attending to the daily demands of keeping the organization going'* and having *'no time'* to support care assistants. This suggests a 'firefighting' approach in which what limited time there is, is devoted to the essential tasks necessary to keep basic organisational functions operating.

Therefore, although the managers were aware of the purpose of the intervention and recognised the need to be more involved so that they could better support care assistants, this proved impossible in practice:

> *"It is important that we could be more involved or that meetings could be scheduled so we might understand how they are working and how to support them."* [Rita, manager]

Care assistants' negative attitudes

Paradoxically, while the care assistants described a lack of managerial support as a barrier to achieving lasting change, care assistants' own resistance to change was the only barrier reported by managers immediately after the intervention. One manager argued that as many care assistants had been in their role for considerable periods of time they had become rigid and developed a closed-mind, which made them highly resistant to change and less willingly and able to adjust to new situations. Managers also stressed that a number of the care workers were (or had become) 'indifferent' to their work and that those who did wanted to improve their practice were often discouraged by their more resistant colleagues. The inclusion of periodic follow-ups to the intervention was mentioned as a way to provide ongoing support for care assistants, to keep them motivated to change:

> *"I feel that, for a while, they did things well, but they eventually returned to their previous behaviours... that's where I think there must be more effort…maybe through regular workshops to revive their knowledge."* [Maria, manager]

For one manager, training care assistants' about dementia-related occupational activities would be a facilitator to change. This would allow care assistants to escape from the routine and to feel empowered:

> *"My suggestion is the inclusion of an additional component ... it would be interesting that care assistants could develop some occupational activities with people with dementia during their free-time".* [Rita, manager]

Residents' level of disability

Given the high levels of physical and cognitive disability amongst the residents with dementia, managers thought that it was difficult to see how the intervention had directly benefited them, something that, combined with the limitations of time and resources, they believed could demotivate the care assistants:

> *"We know they [residents with dementia] need more of our time, but they are all so dependent that interaction becomes impossible …having one worker per resident was the ideal."* [Rose, care assistant]

4. Discussion

The present study sought to obtain the perspectives of both care assistants and managers about the facilitators and barriers to the success of a PE intervention for care assistants working with people with dementia in aged-care facilities.

Findings suggested that several factors inhibit or facilitate the impact and sustainability of the intervention, including the: nature of the intervention itself; the organisational context; care assistants' and managers' attitudes and behaviours; and residents' level of disability. Moreover, findings pointed to both important similarities and differences between managers and care assistants' perceptions.

The majority of the interviewees appreciated the content and duration of the intervention. However, some participants felt that ongoing training and regular updates would have been beneficial in promoting lasting change. This is consistent with previous research which, using a pharmacological metaphor, has suggested that the effects of an intervention are contingent upon the dose received: the larger and more sustained the dose delivered the larger the effects (17). However, it is not only the intervention itself that is important but the opportunities for participants to be encouraged and enabled to apply what they have learned in their day-to-day work with on-going support and reinforcement (18).

Both managers and care assistants stressed the pivotal role of the supportive component in improving motivation and feelings of being supported. This is a key finding that highlights the importance of care assistants being provided not only with technical competences, but also with emotional support that both recognise and provide them with the means to address their own needs.

A long trajectory (an average length of employment of almost ten years) in a highly physical and emotional demanding job, with heavy workloads and poor working conditions, might predict care assistants' burnout and explain why the supportive component has been largely appreciated. As already noted, the role of care assistants is essential in providing care for people with dementia, although the well-being of these workers remains poorly understood and addressed (19). Supporting care assistants to recognise and address stressful situations may well be critical to sustaining practice change and performance improvement (13). Valuing people with dementia but also those who care for them is a key-element of relationship-centred care (20). Relationship-centred care, as captured by the Senses Framework, highlights the importance of the interdependent relationships necessary to create and sustain an enriched environment of care in which the needs of both residents and workers are acknowledged and addressed (20). This approach has been widely adopted in the UK in initiatives such as '*My* Home Life' (21) which seek to ensure that care homes are positive places to live, work and to visit. This could provide a potentially useful model to frame future interventions within a care home context so that they recognise and seek to address the needs of multiple groups.

Another key element of the current intervention was providing individualised assistance to participants during morning care. This is consistent with previous studies that have pointed out that opportunities to practice and reinforce skills are essential to sustaining practice change, as this helps to integrate the new knowledge into existing routines and allows participants to explore how to change the way they work most effectively (18, 22).

Immediately after the intervention, care assistants identified the importance of the organisational context to achieving change. This was characterised by a lack of time and human resources and a limited management support, which served as major factors inhibiting change. Conversely, managers focused on the care assistants' resistance to change as the main barrier to success. Only at 6 month follow-up, managers had recognised the importance of organisational context to achieving change. Overall, these findings highlight the importance of collecting the perception of different grades of staff and conducting follow-up assessments in order to obtain depth information that might be fundamental to plan effective interventions. Additionally, the findings underscore the importance of good channels of communication between managers and care assistants and leadership from the former group, as care assistants perceived that management was distanced from the realities of practice and neither understood nor appreciated their everyday efforts. Rather, given the staffing constraints, management clearly expected care assistants to work "beyond contract".

There has been a great deal written about the importance of leadership in achieving and maintaining change in care settings (See Patterson *et al.* 2011 for a review). All too often, managers focus on the administrative components of their role as opposed to developing their leadership skills. As a result they often lack a full understanding of how to implement and support successful change, fail to motivate others to change and do not reward or recognize individuals who make an effort to change the way things are done (23-25). This suggests the need for the sort of culture change promoted by initiatives such as '*My* Home Life' (21) in the United Kingdom or in the United States of America via 'PioneerNetwork' (26). Both encourage person or relationship-centred care through reorientation of the facility's culture - its values, attitudes, and norms - along with its supporting infrastructure, such as breaking down hierarchies, building organisational commitment and giving care assistants more control over work environment (27).

However, improving the care of people with dementia and valuing those who provide this care also requires culture change at professional and societal levels. It is entirely unreasonable to expect care homes, and the people who work in them, to change their culture if the importance of work in such environments is not fully recognised, supported and rewarded. Interventions such as PE will not be optimally effective until such far reaching changes occur.

We would argue that the present study has provided important insights into the potential value of PE interventions designed to support care assistants working with people with dementia, and how these might be developed in the future. However, it is important not to make sweeping claims and to recognise the limitations of the present study. Given that the first author was involved in all aspects of both delivering the intervention and data collection the influence of a *halo effect* (i.e., the impact of the researcher's personal biases and idiosyncrasies) must be considered. Moreover, although efforts were made to ensure that all the participants were fully involved in the focus-groups interview, it is possible that group-conformity i.e., a tendency for participants to conform with the opinions of the most outspoken elements, existed. Finally, the insights produced cannot be generalized to other people or settings. Nevertheless, they are consistent with several other studies that have explored the impact of training or educational initiatives in care homes (17, 28). The findings further reinforce the importance of seeing these initiatives as an important stimulus for change, but one that must be embedded within a more comprehensive, multifaceted and ongoing effort that focuses on the needs of all groups who live, work and visit such settings.

Table 31. Facilitators and barriers to the implementation of the intervention

	Post-test		6 month follow-up	
	Care assistants	Managers	Care assistants	Managers
(1) Related to the intervention				
Intervention format and delivery	+/-	+/-	-	-
Provision of emotional support	+	+		
Provision of individual assistance	+	+		
Coordinators' characteristics	+			
(2) Related to the organisation				
Time and human resources	-		-	-
Management support	-		-	-
(3) Care assistants' attitudes	-/+	-/+	-	-
(4) Residents' level of disability				-

Notes:+ Facilitators, -Barriers

5. References

1. Stone R. The long-term care workforce: From accidental to valued profession. In: Wolf D, Folbre N, editors. Universal coverage of long-term care in the United States: Can we get there from here? United States: Russell Sage Foundation; 2012.
2. Edvardsson D, Sandman P, Nay R, Karlsson S. Predictors of job strain in residential dementia care nursing staff. J Nurs Manag. 2009;17(1):59-65. Epub 2009/01/27.
3. Gray-Stanley JA, Muramatsu N. Work stress, burnout, and social and personal resources among direct care workers. Research in Developmental Disabilities. 2011;32(3):1065-74.
4. Brooker D. Person-centred dementia care: making services better. London: Jessica Kingsley Publishers; 2007.
5. Kitwood T. Dementia Reconsidered: The person comes first Buckingham, UK: Open University Press; 1997.
6. Gallagher-Thompson D, Coon DW. Evidence-based psychological treatments for distress in family caregivers of older adults. Psychol Aging. 2007;22(1):37-51.
7. Guerra SR, Mendes ÁF, Figueiredo DM, Sousa LX. ProFamilies-dementia: A programme for elderly people with dementia and their families. Dementia. 2012;11(5):589-96.
8. Sidani S, Streiner D, Leclerc C. Evaluating the effectiveness of the abilities-focused approach to morning care of people with dementia. International journal of older people nursing. 2012;7(1):37-45. Epub 2011/06/03.
9. Chenoweth L, King MT, Jeon YH, Brodaty H, Stein-Parbury J, Norman R, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. Lancet Neurol. 2009;8(4):317-25. Epub 2009/03/14.
10. Figueiredo D, Barbosa A, Cruz J, Marques A, Sousa L. Empowering staff in dementia long-term care: Towards a more supportive approach to interventions. Educ Gerontol. 2013;39(6):413-27.
11. Marques A, Cruz J, Barbosa A, Figueiredo D, Sousa LX. Motor and Multisensory Care-Based Approach in Dementia: Long-Term Effects of a Pilot Study. Am J Alzheimers Dis Other Demen. 2012. Epub 2012/12/12.
12. Barbosa A, Nolan M, Sousa L, Figueiredo D. Psycho-educational Approaches in Long-term Care Homes: Direct Care Workers and Managers' Perspectives. Procedia - Social and Behavioral Sciences. 2014;131(0):406-10.

13. Barbosa A, Nolan M, Sousa L, Figueiredo D. Supporting direct care workers in dementia care: effects of a psychoeducational intervention. Am J Alzheimers Dis Other Demen. 2015;30(2):130-8.

14. Barbosa A, Marques A, Sousa L, Nolan M, Figueiredo D. Effects of a psycho-educational intervention on direct care workers' communicative behaviours with residents with dementia. Health Communication.

15. Barbosa A, Nolan M, Sousa L, Figueiredo D. Person-centredness in direct care workers caring for residents with dementia: Effects of a psycho-educational intervention. Dementia. 2015.

16. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.

17. Kuske B, Hanns S, Luck T, Angermeyer MC, Behrens J, Riedel-Heller SG. Nursing home staff training in dementia care: a systematic review of evaluated programs. International Psychogeriatrics. 2006;19(05):818.

18. Nolan M, Davies S, Brown J, Wilkinson A, Warnes T, McKee K, et al. The role of education and training in achieving change in care homes: a literature review. Journal of Research in Nursing. 2008;13(5):411-33.

19. Zimmerman S, Williams CS, Reed PS, Boustani M, Preisser JS, Heck E, et al. Attitudes, stress, and satisfaction of staff who care for residents with dementia. Gerontologist. 2005;45 Spec No 1(1):96-105. Epub 2005/10/19.

20. Nolan M, Davies S, Brown J, Keady J, Nolan J. Beyond person-centred care: a new vision for gerontological nursing. Journal of Clinical Nursing. 2004;13(3a):45-53. Epub 2004/03/19.

21. Owen T, Meyer J. My home life: Promoting quality of life in care homes. 2012.

22. Moyle W, Hsu MC, Lieff S, Vernooij-Dassen M. Recommendations for staff education and training for older people with mental illness in long-term aged care. International Psychogeriatrics. 2010;22(07):1097-106.

23. Jeon YH, Merlyn T, Chenoweth L. Leadership and management in the aged care sector: a narrative synthesis. Australasian Journal on Ageing. 2010;29(2):54-60.

24. Lopez S. Culture change management in long-term care: A shop-floor view. Polit Soc. 2006;34(1):55-80.

25. Patterson M, Nolan M, Rick J, Brown J, Adams R, Musson G. From metrics to meaning: culture change and quality of acute hospital care for older people. NIHR SDO programme project. 2011;3(1501):93.

26. Fagan RM. Pioneer network: Changing the culture of aging in America. Journal of Social Work in Long-Term Care. 2003;2(1-2):125-40.

27. Koren MJ. Person-centered care for nursing home residents: the culture-change movement. Health affairs (Project Hope). 2010;29(2):312-7.

28. Kramer N, Smith M. Training nursing assistants to care for nursing home residents with dementia. In: Molinari V, editor. Professional psychology in long term care. New York: Hatherleigh Press; 2000. p. 227-56.

General conclusion

Introduction

The main purpose of the present research project was to develop, implement, and evaluate the effects of a PCC-based PE intervention on DCWs caring for people with dementia in aged-care facilities.

The thesis started with a systematic literature review on the effects of PCC approaches on DCWs' stress, burnout and job satisfaction. The results of this literature review informed the development of the experimental study with a pre-posttest control group design, conducted in four aged-care facilities. Specifically, this study aimed to assess the effects of the PCC-based PE intervention on DCWs': (i) perceived stress, burnout, and job satisfaction; (ii) verbal and non-verbal communicative behaviours; (iii) and quality of interactions with residents with dementia. In addition, the medium-term efficacy of the intervention on DCWs' outcomes was assessed, and a qualitative analysis of both DCWs and managers' perceptions about the factors that were relevant to the success or failure of the PE intervention was performed.

The following section reflects on the results and implications of the studies that have been reported on in this thesis. Theoretical and methodological reflections are made and recommendations for future research and practice are given.

1. Summary of main findings

From the systematic review conducted to assess the effectiveness of providing DCWs with training to deliver PCC approaches on their stress, burnout and job satisfaction, it was found that only seven references turned out to satisfy all the inclusion criteria (Chapter 1). Notwithstanding the limitations concerning the search strategy (e.g., only studies published in scholarly peer-reviewed journals and in English language were included), this small number of studies confirms the lack of attention that has been placed on the DCWs' job-related wellbeing and emphasizes the future development of this research area.

Studies consisted of education-only interventions whose ultimate goal was to improve the wellbeing of the people with dementia; no interventions providing emotional support to DCWs were found. Five studies have shown a tendency towards the effectiveness of PCC approaches (e.g., multisensory stimulation) on DCWs' stress, burnout and job satisfaction. While this suggests that PCC may play a role in relation to

DCWs' job-related wellbeing, differences in the type of design, outcomes, number of participants and duration of intervention hindered more robust conclusions.

Despite the inability to address all the methodological limitations identified by the systematic review, an effort was made in the experimental study to overcome limitations that were within the author's reach (e.g., inclusion of a control group and follow-up assessments).

Chapters 2, 3 and 4 report the short-term effectiveness of a PE intervention on DCWs' outcomes. Data gathered from a pre-posttest control study with 56 DCWs suggested that participants who received a PCC-based PE intervention reported significantly less *emotional exhaustion* (subscale of the MBI) than the control group. The perceived enhanced group cohesion, emotional management and self-care awareness reported by the participants during the focus-group interviews, could have accounted for this promising result. No statistically significant effects in favour of the experimental group were found for DCWs' stress and job satisfaction (Chapter 2).

Data obtained from video-recorded morning care episodes suggested that, compared to the control group, the PCC-based PE intervention had a broader impact on DCWs' communicative behaviours. Within the experimental group there was a positive change from pre to post-test on the frequency of all DCWs' verbal and nonverbal communicative behaviours, with improvements being significant for *inform* and *laugh*. Differences between the PE intervention and the educational-only interventions were more evident for nonverbal communicative behaviours, with the former showing enhanced results (Chapter 3). Positive significant differences were obtained in both groups for the quality of DCWs' interactions with residents with dementia. However, findings at the limits of significance are suggestive of a broader impact in favour of the experimental group (Chapter 4).

At six months follow-up the experimental group continued to be more effective than the control group in reducing DCWs' levels of burnout (with significant findings found for the subscale *personal accomplishment*). Over time, however, job satisfaction, perceived stress and most of DCWs' person-centred communicative behaviours have deteriorated in both groups. Positive, but non-significant, results in favour of the PCC-based PE intervention were found for the duration of a number of nonverbal communicative behaviours, including *smile*, *laugh* and *affective touch* (Chapter 5).

Alongside the effectiveness of the study, DCWs and managers of the experimental group were interviewed to gain an in-depth insight into the barriers and facilitators to the implementation of the PCC-based PE intervention. Both groups were overall satisfied with the intervention format and delivery and stressed the pivotal role of the supportive component in improving motivation and feelings of being supported. The facilitators' openness, empathy and understanding were seen as being of great importance. Also, the individual assistance given to DCWs during morning care was highly appreciated and considered crucial to establishing changes in practice. Barriers to implementation were related to the lack of time and human resources, limited management support and encouragement, DCWs' own resistance to change and residents' high level of disability. Such factors were considered to negatively impact on DCWs' job performance, motivation and morale (Chapter 6). A number of important lessons were drawn from this qualitative study to help to refine the intervention for the purpose of optimising its implementation and effectiveness.

Based upon the results one might conclude that the study provided limited although promising support for the impact of a PCC-based PE intervention on DCWs. There was evidence that the intervention could assist in reducing these workers' burnout and modest positive findings were found for DCWs' interaction. However, the study did not confirm the presumed beneficial effects of the intervention on DCWs' perceived stress and job satisfaction, with a decline in six month follow-up being noticed for both variables.

2. Theoretical and methodological considerations

The above-mentioned findings raise the question of which mechanisms are underlying the success and failure of the intervention. Specific strengths and limitations of the individual studies have already been presented in the previous chapters, thus, this section will address the main theoretical and methodological issues that can provide valuable information for the interpretation of the study results.

2.1. Theoretical considerations

Given the *explorative* nature of this study and the above-cited limitations, it is worthwhile to theoretically interpret the inconsistent effects found for the assessed variables.

The fact that the PCC-based PE intervention did play a role in relation to DCWs' burnout is an indication of the participants growing ability to adequately manage their emotions when interacting with people with dementia. DCWs' reports confirm such finding (Chapter 2). However, it was not possible to rule out the potential effects of other factors. It may be that the awareness of perceived enhanced care provision is related to less burnout. Also, it might be possible that the intervention first resulted in improved residents' wellbeing and that the awareness of this improvement directly decreased DCWs' burnout. Indeed, according to previous research, care workers' perceived competence to care and residents' wellbeing were related to lower burnout scores (Hasson, 2006; van Weert et al., 2004; Zimmerman et al., 2005).

On the other hand, the study showed modest effects on DCWs' communicative behaviours and no continued effects on perceived stress and job satisfaction. This lack of sustained findings may be due to the failure of the intervention to attend to the factors known to facilitate, reinforce and sustain competences. Such factors are related to the intervention (e.g., duration and strategies for continuous development) and to the organisation and management support.

Findings from the focus-group interviews showed that the short-duration of the intervention was a limitation and that strategies for continuous development, including individualised assistance and follow-up sessions, would have been beneficial to support change (Chapter 6). Present results have much in common with previous studies in which the need of *reinforcing* factors - factors that provide an individual with cues or reminders to implement new skills or that reinforce the use of new skills - have been highlighted (Craft, Haviland, Woodside, & Konrad, 2007; Stein-Parbury et al., 2012; Stolee et al., 2009). Such factors are relevant to behaviour change and are more effective in affecting change than information alone (Craft et al., 2007; Stein-Parbury et al., 2012; Stolee et al., 2009).

Beyond factors associated with the intervention itself, focus-group participants argued that the support and commitment from managers was a key-element to change. Participants have particularly emphasized the inclusion of the management in the intervention to ensure that the entire facility was working toward common goals, and the importance of a supportive environment for applying what they have learned.

This result confirms that the adoption and success of an intervention depends on the broader organisational context, particularly on top-management support (Kuske et al., 2006; Moyle, Hsu, Lieff, & Vernooij-Dassen, 2010; Nolan et al., 2008; Stolee et al., 2009).

Although the managers from the studied aged-care facilities verbalised their support and allowed DCWs to participate, they were unable to move beyond the challenges of time and staffing constraints - challenges that are pervasive in the sector. However, organisational support goes beyond simply supporting an individual's participation in the intervention. At the very least, managers need a sound understanding of dementia and the key principles of PCC, need skills in coaching and should be able to promote reflective practice (Loveday, 2011). Regarding this, Broad (1997) provides a useful inventory that encompasses these and other key-managerial factors to enhance the effectiveness of any intervention: clear performance specifications (expected outputs, standards); necessary support (resources, priorities, responsibility, authority, time); and clear consequences (reinforcement, incentives, rewards). The recognition of the importance of management support to promote change has been stressed in international dementia plans (Department of Health, 2009), with call for the development of explicit leadership for dementia care within care homes.

Also, a number of other factors might have impacted on the outcomes of the intervention. These included staffing ratios, the physical environment and organisations' policies (Chapter 6). Such factors reflect the resource limitations that are structurally embedded in aged-care facilities and that represent part of the challenge to improving care and DCWs' wellbeing (Lopez, 2006; Stone & Wiener, 2001). Indeed, an intervention may add additional pressure on an already burdened sector, and its relevance may be lost in the daily struggle to provide quality of care (Luff, Ferreira, & Meyer, 2011). Although the researcher tried to fit in with the rhythm and norms of each facility, these had rigid routines with established activities timetables. These certainly affected DCWs' job-related wellbeing and reduced PCC practice as residents' choice was compromised and the flexibility to address constantly changing needs was inhibited. DCWs saw their role as primarily to provide physical care and there were fewer opportunities to fulfil resident's social and psychological needs. Given the increased number of people with dementia entering care, improving staffing levels could be decisive to change. However, current funding models do not ease optimal staff-resident ratios. To meet the current and future long-term care demands of an ageing society, explicit policies must be developed to expand the supply of personnel entering the field (Stone, 2012). These might include the creation of financial incentives, such as grant programmes, scholarships or traineeships to foster greater interest among people considering the aged-care field, or the adoption of more cost-effective solutions, such as proactively encouraging the family members' participation or recruiting volunteers to provide assistance.

In essence, this means that DCWs' role must be valued at the societal level. Contemporary social values are downgrading the importance accorded to caring, and as a consequence, the DCWs' skills and expertise are rarely fully recognised or rewarded (Ryan, Nolan, Enderby, & Reid, 2004). According to Stone (2001), it is indeed at the societal level that there is the need for the most urgent debate: “The relational aspects of care must be rewarded, both materially and socially so that workers continue to be motivated to engage in the most important non-instrumental tasks of care” (Stone, 2001, p.173).

Overall, the findings encourage us to reframe, rethink and reconsider how care facilities are structured and how the care is provided. The type of environment that this research suggests as needed reflects many of the characteristics of Kitwood’s “type B settings” (Kitwood, 1997). “Type B settings” are based on respect and trust, interpersonal relationships are highly valued and communication channels are well developed. The managers’ role is more one of enabling and facilitating than of controlling, and there is a strong commitment to minimise any differential of power (Kitwood, 1997).

The importance of such an environment has been claimed by several international initiatives and movements, including: *My Home Life* (Owen & Meyer, 2012), a UK-wide initiative that promotes quality of life and delivers positive change in care facilities for older people; the *Pionneer Network* (Fagan, 2003), an American organization dedicated to making fundamental changes in values and practices to create a culture of aging that is life-affirming, satisfying, humane and meaningful; the *Wellspring model* (Stone et al., 2002), which focuses on interdisciplinary resource teams for quality improvement through consultation and education; the *Green House Project* (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006), which advocates for small-scale homes, thereby moving away from care in large institutions; or the *Dementia Care Mapping* which is a specific assessment tool and philosophy that attempts to measure both quality of care and quality of life to improve PCC (Brooker, 2005a). Fundamentally, these initiatives encourage person or relationship-centred care through reorientation of the facility’s culture - its values, attitudes, and norms - along with its supporting infrastructure, such as breaking down hierarchies, building organisational commitment and empowering DCWs.

Although is clear that the PCC-based PE intervention can play a leading role in reducing DCWs’ burnout and establishing positive interactions, an intervention can only be effective as part of a wider strategy. One that enables a shift in the way that people with dementia and those who care for them are understood and valued.

2.2. Methodological considerations

A number of methodological options had an impact on the results. These relate to the study design, the outcome measures and characteristics of both education-only and PE interventions.

Study design

The randomised controlled trial (RCT) is viewed as the gold standard for evaluating interventions, as they estimate the impact of an intervention through direct comparison with a randomly allocated control group (Moher et al., 2010). However, in the area of practice-based research, completely randomization designs are often unsuitable (Sanson-Fisher, Bonevski, Green, & D'Este, 2007).

Pre-posttest control study designs share similarities with RCTs but the criterion for assignment is selected by the researcher, while in the former the assignment occurs 'naturally,' i.e., without the researcher's intervention (Sanson-Fisher et al., 2007). In the present study, the unit of allocation was at the facility-level to avoid contamination that would occur if individuals in the same facility were randomised to different intervention arms. Aged-care facilities with protocol with the University of Aveiro were matched on the basis of staff/resident ratio and proportion of residents with dementia. Such matching aimed to increase the power of the study to detect intervention effects as well as increasing its face validity. Then, two pairs matched facilities were included, with one facility in each matched pair randomly assigned to the PE intervention and the other facility to the educational-only intervention. Random allocation may have helped to promote comparable study groups at baseline, but large numbers of facilities would have been needed to benefit from randomization.

The rationale for adopting such a design rested on practical considerations and, predictably, it presents a few drawbacks. First, it introduced a selection bias. Although it was observed that potential workers' confounding variables, as demographic characteristics (e.g., age, length of service or education), were equally distributed between the groups at baseline, these might differ on aspects which were not assessed, but are relevant when interpreting effects on DCWs' outcome measures, such as personality characteristics. Second, cluster designs need larger samples as two sources concur to increase variance: the variability of participants within a cluster; and the variability between clusters (Hahn, Puffer, Torgerson, & Watson, 2005; Sanson-Fisher et al., 2007). The effect of the increased variance due to a cluster design is that the sample size is reduced and power is lost (Hahn et al., 2005; Sanson-Fisher et al., 2007). No power calculation was performed for the study. The sample size was small, which might have reduced the statistical power to detect more significant changes. Lastly, a three-arm cluster design, i.e., the addition of a further control group that does not receive any intervention, would be important to better understand the impact of each educative and supportive component.

The present study has, however, scientific assets that other studies in this field lack and that were identified as a need for future research. The inclusion of a six months follow-up evaluation is one of these strengths. Studying and reporting medium-term results contributed much to the knowledge of the overall efficacy of the intervention.

Outcome measures

A mixed methods approach (i.e., quantitative and qualitative data collection) was used and considered successful to provide more informative and comprehensive research results. This meets recent calls for more mixed methods in the field of practice research, as these can produce findings that answer a broader scope of questions, often with greater depth (Johnson, Onwuegbuzie, & Turner, 2007; Powell, Proctor, & Glass, 2014).

Quantitative data was assessed through video-recording and self-administered questionnaires, while qualitative data consisted of open-ended information gathered through focus-groups and individual interviews.

The use of video-recordings is a rather innovative and useful instrument in studying dementia care (van Weert, Vandulmen, Spreeuwenberg, Ribbe, & Bensing, 2005). Hence, they have been mostly used to explore the variables that might influence nurses' communication with older people (Caris-Verhallen, Gruijter, Kerkstra, & Bensing, 1999; Caris-Verhallen, Kerkstra, van der Heijden, & Bensing, 1998). The advantage of using video-recordings is that they can be played back repeatedly, allowing verbal and non-verbal interactions to be observed and analysed in detail, promoting a reliable assessment (Elder, 1999; Latvala, Vuokila-Oikkonen, & Janhonen, 2000). The dangers of the *Hawthorne effect*, by which participants may change their behaviours because they are aware they are being observed (Latvala et al., 2000), were recognised in the study, and considerable time was spent integrating the methodology into the research setting. There was no doubt that at the beginning, DCWs were very aware that they were being observed, and so the researcher invested time within each facility to create trust, to learn about the culture, and to clarify misinformation about the methodology. The importance of allocating adequate time for preparation and support has been acknowledged before (Luff et al., 2011). As well, it was decided to record each DCW thrice at each assessment point; this reduced the probability that DCWs' behaviours were due to chance. Along with this, data from previous studies suggests that over a period of time participants become used to the camera (Latvala et al., 2000), and so it is supposed that the *Hawthorne effect* was minimised. While the collection and analysis of observational data was time consuming, this measurement approach was considered to be of greater validity.

Structured tools were used to support observations. The high inter-observer reliability obtained for both the Global Behaviour Scale (used to measure DCWs' person-centeredness) and the *ethogram* (used to measure DCWs' communicative behaviours that support PCC) supports their reliability and validity. Although several observational protocols exist to assess DCWs' communicative behaviours, these tools are time-intensive to administer (Brooker, 2005b; Edvardsson & Innes, 2010; Gaugler, Hobday, & Savik, 2013). Hence, an effective and easy-to-administer instrument in dementia remains a gap in the methodological armoury. The *ethogram* developed for this study may be a valid and reliable tool to easily determine the presence of PCC elements in DCWs-person with dementia interactions. Thus, future evaluations of this tool in order to further develop its acceptability, utility and validity are needed.

The self-administered questionnaires were the most sensitive, reliable and valid instruments available in their Portuguese version to assess the established outcomes. The MBI (Annex 1) has been largely used, being considered the standard tool for measuring burnout. The preference for the PSS (Annex 2) and the MSQ (Annex 3) was based on their acceptable psychometric properties and widespread use. Despite this, measures may have been subject to influences of social desirability (i.e., the tendency of respondents to answer questions in a manner that will be viewed favourably by others). Although confidentiality was assured, DCWs may have been reluctant to complete the measures honestly. Moreover, given the DCWs' varying levels of education, questionnaires could have been too long and complex for some participants.

The use of qualitative data provided a better understanding of the processes and more detailed information about the context, thus adding insights into the *how* of implementation (Powell et al., 2012). Overall, and given that the first author was involved in all aspects of both delivering the intervention and data collection the influence of a *halo effect* (i.e., the impact of the researcher's personal biases and idiosyncrasies) must be considered, particularly in relation to qualitative data. Non-blinded outcome measurements may have introduced information bias, which might have led to an overestimation of effects. Also, the timing of the measurements, after two weeks and six months seems adequate given the content and duration of the intervention. However, one could argue that change takes longer to become visible and measurable.

Interventions

The PCC-based PE intervention was compared to an educational-only intervention. Such a decision was supported by the fact that educational-only interventions have become the most widely used approach to introduce DCWs with the PCC philosophy. The purpose was therefore to compare a PE intervention with the *usual* intervention.

The use of a standardized or validated educational intervention was not considered. From the systematic review (Chapter 1) it was noticed that interventions were specific and culturally adapted and, as a consequence, very dissimilar. Also, previous studies have proposed that interventions have best results when the real needs of participants are investigated prior to designing the intervention (Kuske et al., 2006; Nolan et al., 2008). This is considered fundamental to plan sustainable interventions and tailor them to the culture and particularities of the facilities in which they are to be implemented. Indeed, as previously stated:

"(...) A programme must always be geared to where the staff is in its intellectual and emotional readiness, otherwise training will either signify words alone, or resistance will be raised to such a level that no approach will be effective" (Meyer, 1966 cited in Nolan et al., 2008, p. 421).

Thus, prior to intervention, interviews with DCWs and managers were conducted to get a deeper insight about their needs and expectations (Barbosa, Nolan, Sousa, & Figueiredo, 2014a; Barbosa, Nolan, Sousa, & Figueiredo, 2014b) (Appendix 1 and 2). The results revealed areas in need of improvement regarding staff competence, psychosocial work environment, and quality of care. Also, the intervention was tested in a pilot-study conducted in one aged-care facility with six DCWs (Figueiredo, Barbosa, Cruz, Marques, & Sousa, 2013).

The lack of understanding regarding the *active ingredients* of the intervention is worth of consideration. Participants in the control group received some *active ingredients* of the PE intervention approach (e.g., individualised assistance) which might have created an insufficient contrast between the groups. This needs to be considered in future research.

3. Relevance of the research

As changes continue to occur in the long-term care field, it is important that DCWs are supplied with knowledge and the skills they need to meet the needs of an increasing number of people with dementia living in aged-care facilities.

This thesis builds on and contributes to work in the field of PCC and represents a significant advancement in the design of educational interventions within aged-care facilities. This is to the best of our knowledge the first study to assess the effects of a PE intervention in the context of formal care.

A PE intervention challenges the more traditional model of educational interventions; the addition of a supportive component provides an opportunity to respond to a myriad of determinants that are often neglected but are essential to DCWs and care provision. Indeed, emphasis has been typically placed on care workers' instrumental needs rather than emotional and relational issues, which despite the rhetoric of PCC, are still undervalued. Research participants stressed the pivotal role of the supportive component in improving motivation and feelings of being supported. This is a key-finding that highlights the importance of DCWs being provided with emotional support that both recognise and provide them with the means to address their own needs. Besides, the intervention was found to have pioneered a few innovations that are considered to significant improve DCWs' wellbeing. For instance, one aged-care facility has implemented weekly relaxation sessions for DCWs after the intervention period. Typically, it is rare for care workers to have a space of their own and to meet and nurture positive relationships at work; this is, therefore, a powerful example that represents an increased recognition and valorisation of DCWs' role.

The findings do not provide complete answers and far more conceptual, empirical and experimental work is required. While conscious that the implementation of an intervention requires attention at all levels, i.e., DCWs, residents and their family, organisational and societal levels to achieve long-lasting, positive changes in the quality of care, results further reinforce the importance of seeing these initiatives as an important stimulus for change. It is hoped that these findings will prove useful in stimulating the debate necessary before genuine progress can be achieved.

4. Directions for future practice and research

The present study showed that a PCC-based PE intervention could positively impact DCWs' level of burnout, but no or only modest positive effects were found for the remaining variables. First, these are explorative results of a single study conducted in Portugal. Also, studies in this field are complex and present inevitable methodological limitations that hinder firm conclusions. Thus, additional studies are needed to settle the discussion. Based on the experiences of this study, more insight is also necessary into the optimisation and implementation of PCC-based PE interventions in aged-care facilities.

4.1. Recommendations for practice

Preconditions

- The preparation of an intervention must not underestimate the time which is needed for care facilities and researchers to familiarise themselves with each other. Preliminary fieldwork undertaken as a visitor to the facility is recommended as a necessary and useful phase. It will increase the understanding of the facility culture, and help to establish support for the study and to gain trust and respect (Luff et al., 2011). Moreover, it is the researcher who needs to be as flexible with their time as possible, rather than the facility. In the current study the assessments were undertaken while DCWs were on duty (sometimes at weekends). The delays, wasted journeys and adjusted timetables may be frustrating, but having flexibility of time is likely to be appreciated and help to build positive relationships.
- It is apparent that little is likely to change unless the practice environment is receptive to change (Nolan et al., 2008). In the absence of a positive working environment, any intervention can be counterproductive and lead to higher DCWs' levels of stress and dissatisfaction. DCWs' motivation is likely to falter if the culture is not ready to accept change and good support structures are not promoted. Thus, commitment and support from the facility need to be assured prior to the intervention (Beeber et al., 2010; Kuske et al., 2009; McCabe et al., 2007). Engaging managers in the implementation process may prevent possible organisations obstacles, and incorporate new knowledge and skills into their ongoing supervision, feedback, and goal-setting with DCWs. In this way, it is possible to move from offering isolated sessions to a strategic development plan.

- It is important that the intervention reflects DCWs' particular needs. Therefore, it is recommended that assessment of participants' expectations, difficulties and needs is conducted prior to the intervention. This not only will reduce resistance and develop a sense of ownership, making clear to participants that the intervention is about them and their work, but will also establish the relevance and appropriateness of the intervention.
- The use of observation methods in aged-care facilities can be a challenge as staff and residents may fear exposure. Therefore, the aims and limits of the project should be made clear and any claims to confidentiality and anonymity made explicit.
- As previously discussed, DCWs have varying levels of education and may have few or no qualifications. Considering this, questionnaires and interviews should be as short as possible and use familiar language. To overcome this, the proposal of Luff, Ferreira and Meyer (2011) to pilot research materials with a few participants to gain feedback and get a realistic understanding of how long completion took is recommended.
- Antecedent information about the persons' background, lifestyle, preferences and current conditions should be collected, as this data can improve DCWs' relationships with the resident and the quality of care provision.

Intervention

- Study findings underscore the need to extending the focus of the intervention beyond the DCWs and permeate the entire organisation, so that a general receptivity and willingness to embrace change could be promoted. Training the management was particularly emphasised during participants' focus-group to establish the continuation of the implementation process. This is an area that has received increased investment, with training courses aiming to enhance managers' awareness of residents and DCWs' needs, and to develop their skills in bringing about the best possible outcomes for both being recently developed (e.g., *The Dementia Leadership Programme* (Loveday, 2011)).
- *Reinforcing* strategies must be incorporated to facilitate change. These include providing regular feedback, supervision and *booster* sessions for the reinforcement of DCWs' learning. Such strategies could be difficult to sustain and so it would be interesting to use *cascade training* (i.e., providing training to staff members who in turn provide the same training to others) to integrate new knowledge and sustainability within the workplace.
- According to participants, the inclusion of only advanced residents' cognitive and functional deterioration was a constraint of the intervention. Thus, expanding the

intervention to residents with mild dementia or with conditions other than dementia may contribute to spreading its benefits. As well, this can potentially lead to care assistants' motivation to improve practice, as it might be easier to perceive benefits in residents without advanced physical and cognitive deterioration.

- Observations can offer unprecedented access to detailed data, which may not be as effectively gleaned from other methods, such as interviews or questionnaires. Based on participants' reports it could be of interest to expand observations to other daily moments (e.g., meals or leisure time) to gather more comprehensive data about the staff/resident interaction.
- The facilitators' conduct and attitude were seen as key to the success of the intervention. While the facilitators should be experts in the field, they should also be able to build positive relationships with participants, by being approachable, able to listen and to empathise and create trust.
- Evidence indicates that family involvement in the care of a relative can be beneficial for residents, family members and staff (Gaugler, 2005; Maas et al., 2004). Therefore, involving the residents' family is highly encouraged. This can be accomplished through several venues, including: being able to clarify any doubt about the project; collecting information about the residents' background, lifestyle and preferences; gaining their views on the impact of the intervention; provide them with handouts about the educational content of the intervention or even provide them with a report of the impact of the intervention.

4.2. Directions for research

A few recommendations for future research emerged from this study.

- Given the small magnitude of change, further randomised, double-blind studies with larger samples of facilities are required to draw final conclusions on the effectiveness of the intervention on DCWs. Although assessing the impact of the intervention on people with dementia, residents' family and organisation was beyond the scope of this thesis, triangulation of data from these different levels would provide more comprehensive data about its effects. Looking at the results, one might argue that such factors possibly reinforce each other, thus, more research is needed to understand this process in detail.
- Future studies are needed to examine which portion of the intervention was responsible for the benefits noticed on participants. The intervention had multiple

components and it was not possible to identify its *active ingredients*. In future research it would be worthwhile to assess whether only psycho-educational sessions are needed or whether it was the combination of the sessions plus the individual assistance which lead to these findings. Related to this, more structured evaluations of the implementation process are required to provide in-depth data about the extent to which the intervention was implemented as intended. In the absence of an accurate assessment of implementation process, conclusions about the outcome measures are difficult to interpret.

- Studies on moderators of intervention effects are necessary. For example, it is unreasonable to expect any individual to separate the workplace from their personal lives, and more research is needed to identify how personal circumstances exacerbate workplace stress and how they may possibly be used to reduce stress and job dissatisfaction. Also, residents' characteristics (e.g., age, gender, dependency) should be assessed to understand their impact on final outcomes.

Based on the results of the present thesis and on prior research studies (Hasson, 2006; van Weert, 2004), it is proposed the model below as a possible foundation for the evaluation of future interventions within formal care contexts. According to this model, a PCC-based PE intervention is suggested to be directly related to DCWs' wellbeing and PCC communicative behaviours. However, this relationship may be influenced by DCWs and residents' characteristics, which act as moderators. DCWs' outcomes may have an impact on quality of care, which in turn affects residents' wellbeing and residents' family. Outcomes are suggested to be directly affected by the facility organisation and culture.

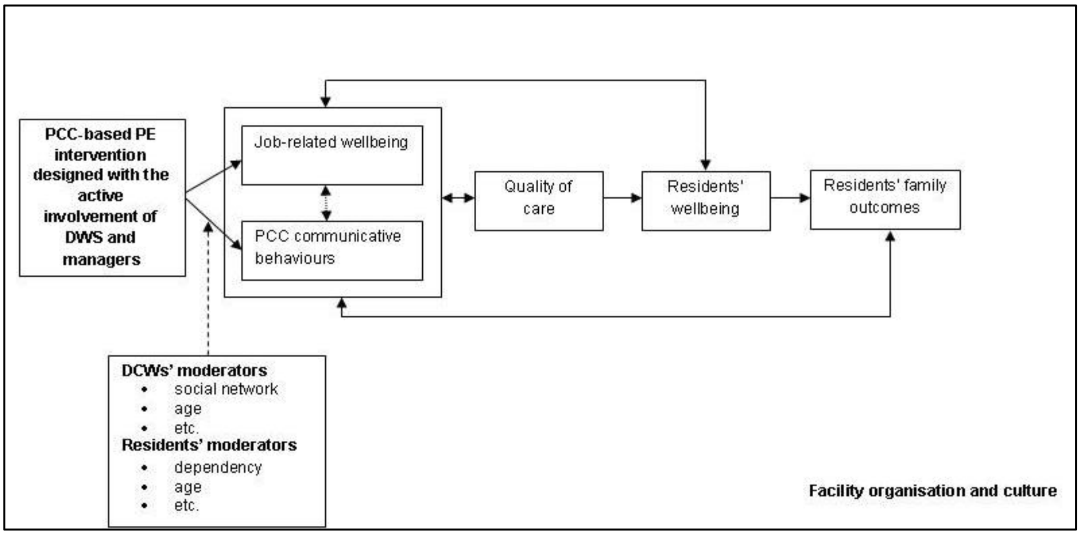

Figure 6. Recommendation model for future interventions

5. References

Barbosa, A., Nolan, M., Sousa, L., & Figueiredo, D. (2014a). Psycho-educational approaches in long-term care homes: Direct care workers and managers' perspectives. *Procedia - Social and Behavioral Sciences, 131*(0), 406-410. doi: 10.1016/j.sbspro.2014.04.138

Barbosa, A., Nolan, M., Sousa, L., & Figueiredo, D. (2014b). Dementia in long-term care homes: Direct care workers' difficulties. *Procedia-Social and Behavioral Sciences, 140*, 172-177. doi: 10.1016/j.sbspro.2014.04.405

Brooker, D. (2005a). Dementia care mapping: a review of the research literature. *The Gerontologist, 45*(suppl 1), 11-18.

Brooker, D. (2005b). Dementia Care Mapping: A review of the research literature. *Gerontologist, 45*(suppl 1), 11-18. doi: 10.1093/geront/45.suppl_1.11

Caris-Verhallen, W., Gruijter, I., Kerkstra, A., & Bensing, J. (1999). Factors related to nurse communication with elderly people. *Journal of Advanced Nursing, 30*(5), 1106-1117. doi: 10.1046/j.1365-2648.1999.01197.x

Caris-Verhallen, W., Kerkstra, A., van der Heijden, P., & Bensing, J. (1998). Nurse-elderly patient communication in home care and institutional care: an explorative study. *International Journal of Nursing Studies, 35*(1-2), 95-108. doi: 10.1016/S0020-7489(97)00039-4

Craft, J., Haviland, S. B., Woodside, M. A., & Konrad, T. R. (2007). Fostering supportive learning environments in long-term care: the case of WIN A STEP UP. *Gerontology and Geriatric Education, 28*(2), 55-75. doi: 10.1300/J021v28n02_05

Department of Health. (2009). Living well with dementia: A National Dementia Strategy. London, UK: Department of Health.

Edvardsson, D., & Innes, A. (2010). Measuring Person-centered Care: A Critical Comparative Review of Published Tools. *Gerontologist, 50*(6), 834-846. doi: 10.1093/geront/gnq047

Elder, J. H. (1999). Videotaped behavioral observations: enhancing validity and reliability. *Applied Nursing Research, 12*(4), 206-209. doi: 10.1016/S0897-1897(99)80273-0

Fagan, R. M. (2003). Pioneer network: Changing the culture of aging in America. *Journal of Social Work in Long-Term Care, 2*(1-2), 125-140. doi: 10.1300/J181v02n01_09

Figueiredo, D., Barbosa, A., Cruz, J., Marques, A., & Sousa, L. (2013). Empowering staff in dementia long-term care: Towards a more supportive approach to interventions. *Educational Gerontology, 39*(6), 413-427. doi: 10.1080/03601277.2012.701105

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health, 9*(2), 105-118. doi: 10.1080/13607860412331310245

Gaugler, J. E., Hobday, J. V., & Savik, K. (2013). The CARES((R)) Observational Tool: A valid and reliable instrument to assess person-centered dementia care. *Geriatric Nursing*. doi: 10.1016/j.gerinurse.2013.01.002

Hahn, S., Puffer, S., Torgerson, D. J., & Watson, J. (2005). Methodological bias in cluster randomised trials. *BMC Medical Research Methodology, 5*(1), 10. doi: 10.1186/1471-2288-5-10

Hasson, H. (2006). *Nursing Staff Competence, Psychosocial Work Environment and Quality of Elderly Care: Impact of an Educational Intervention.* PhD thesis, Uppsala University, Sweden.

Johnson, R., Onwuegbuzie, A., & Turner, L. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112-133. doi: 10.1177/1558689806298224

Kitwood, T. (1997). *Dementia Reconsidered: The person comes first* Buckingham, UK: Open University Press.

Kuske, B., Hanns, S., Luck, T., Angermeyer, M. C., Behrens, J., & Riedel-Heller, S. G. (2006). Nursing home staff training in dementia care: a systematic review of evaluated programs. *International Psychogeriatrics, 19*(05), 818. doi: 10.1017/s1041610206004352

Latvala, E., Vuokila-Oikkonen, P., & Janhonen, S. (2000). Videotaped recording as a method of participant observation in psychiatric nursing research. *Journal of Advanced Nursing, 31*(5), 1252-1257. doi: 10.1046/j.1365-2648.2000.01383.x

Lopez, S. (2006). Culture change management in long-term care: A shop-floor view. *Politics & Society, 34*(1), 55-80. doi: 10.1177/0032329205284756

Loveday, C. (2011). Dementia training in care homes. In T. Dening & A. Milne (Eds.), *Mental Health and Care Homes* (pp. 327-344). Oxford, UK: Oxford University Press.

Luff, R., Ferreira, Z., & Meyer, J. (2011). Care Homes. London, UK: National Institute for Health Research.

Maas, M. L., Reed, D., Park, M., Specht, J. P., Schutte, D., Kelley, L. S., . . . Buckwalte, K. C. (2004). Outcomes of family involvement in care intervention for caregivers of individuals with dementia. *Nursing Research, 53*(2), 76-86. doi: 10.1097/00006199-200403000-00003

Moher, D., Hopewell, S., Schulz, K. F., Montori, V., Gotzsche, P. C., Devereaux, P. J., . . . Altman, D. G. (2010). CONSORT 2010 Explanation and Elaboration: updated guidelines for reporting parallel group randomised trials. *British Medical Journal, 340*(8), e1-e37. doi: 10.1136/bmj.c869

Moyle, W., Hsu, M. C., Lieff, S., & Vernooij-Dassen, M. (2010). Recommendations for staff education and training for older people with mental illness in long-term aged care. *International Psychogeriatrics, 22*(07), 1097-1106. doi: 10.1017/s1041610210001754

Nolan, M., Davies, S., Brown, J., Wilkinson, A., Warnes, T., McKee, K., . . . Stasi, K. (2008). The role of education and training in achieving change in care homes: a literature review. *Journal of Research in Nursing, 13*(5), 411-433. doi: 10.1177/1744987108095162

Owen, T., & Meyer, J. (2012). *My home life: Promoting quality of life in care homes*.

Powell, B., McMillen, J., Proctor, E., Carpenter, C., Griffey, R., Bunger, A., . . . York, J. (2012). A compilation of strategies for implementing clinical innovations in health and mental health. *Medical Care Research and Review, 69*(2), 123-157. doi: 10.1177/1077558711430690

Powell, B. J., Proctor, E. K., & Glass, J. E. (2014). A Systematic Review of Strategies for Implementing Empirically Supported Mental Health Interventions. *Research on Social Work Practice, 24*(2), 192-212. doi: 10.1177/1049731513505778

Rabig, J., Thomas, W., Kane, R. A., Cutler, L. J., & McAlilly, S. (2006). Radical redesign of nursing homes: applying the green house concept in Tupelo, Mississippi. *Gerontologist, 46*(4), 533-539. doi: 10.1093/geront/46.4.533

Ryan, T., Nolan, M., Enderby, P., & Reid, D. (2004). 'Part of the family': sources of job satisfaction amongst a group of community-based dementia care workers. *Health and Social Care in the Community, 12*(2), 111-118. doi: 10.1111/j.0966-0410.2004.00471.x.

Sanson-Fisher, R. W., Bonevski, B., Green, L. W., & D'Este, C. (2007). Limitations of the randomized controlled trial in evaluating population-based health interventions. *American Journal of Preventive Medicine, 33*(2), 155-161. doi: 10.1016/j.amepre.2007.04.007

Stein-Parbury, J., Chenoweth, L., Jeon, Y. H., Brodaty, H., Haas, M., & Norman, R. (2012). Implementing Person-Centered Care in Residential Dementia Care. *Clinical Gerontologist, 35*(5), 404-424. doi: 10.1080/07317115.2012.702654

Stolee, P., McAiney, C. A., Hillier, L. M., Harris, D., Hamilton, P., Kessler, L., . . . Le Clair, J. K. (2009). Sustained Transfer of Knowledge to Practice in Long-Term Care: Facilitators and Barriers of a Mental Health Learning Initiative. *Gerontology & Geriatrics Education, 30*(1), 1-20. doi: 10.1080/02701960802690233

Stone, R. (2012). The long-term care workforce: From accidental to valued profession. In D. Wolf & N. Folbre (Eds.), *Universal coverage of long-term care in the United States: Can we get there from here?* United States: Russell Sage Foundation.

Stone, R., Reinhard, S. C., Bowers, B., Zimmerman, D., Phillips, C. D., Hawes, C., . . . Jacobson, N. (2002). *Evaluation of the Wellspring model for improving nursing home quality*: Commonwealth Fund, Picker/Commonwealth Program on Quality of Care for Frail Elders.

Stone, R., & Wiener, J. (2001). Who will care for us? Addressing the long-term care workforce crisis. United States of America: The Urban Institute and the American Association of Homes andServices for the Aging.

van Weert, J. (2004). *Multi-Sensory Stimulation in 24-hour Dementia Care: Effects of snoezelen on residents and caregivers.* PhD, University of Utrec, Netherlands.

van Weert, J., Kerkstra, A., Van Dulmen, A., Bensing, J., Peter, J., & Ribbe, M. (2004). The implementation of snoezelen in psychogeriatric care: An evaluation through the eyes of caregivers. *International Journal of Nursing Studies, 41*(4), 397-409. doi: 10.1016/j.ijnurstu.2003.10.011

van Weert, J., Vandulmen, A., Spreeuwenberg, P., Ribbe, M., & Bensing, J. (2005). Effects of snoezelen, integrated in 24h dementia care, on nurse–patient communication during morning care. *Patient Education and Counseling, 58*(3), 312-326. doi: 10.1016/j.pec.2004.07.013

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *Gerontologist, 45 Spec No 1*(1), 96-105. doi: 10.1093/geront/45.suppl_1.96

Appendix 1

Psycho-educational approaches in long term care homes: exploring direct care workers and managers' perspectives[7]

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Abstract

The majority of the Direct Care Workers (DCWs) in long-term care (LTC) facilities have no formal qualifications or training on dementia and experience high levels of stress and burnout as a result of dementia-related symptoms and behaviours. Psycho-educational (PE) approaches can be effective in supporting DCWs, yet, they are underdeveloped within the context of formal care. Therefore, this study aimed to explore the expectations and concerns of care home managers (service managers and top-level managers)and DCWs about PE interventions. A qualitative, cross-sectional study was conducted. Individual interviews with 8 managers (75% female; mean age 45.5 ± 10.26) and 8 focus-group interviews with a total of 58 DCWs (female; mean age of 44.72 ± 9.06) of 4 LTC facilities were performed. All interviews were recorded, transcribed and analysed through thematic analysis by 2 independent judges. Managers' main expectations were related to the opportunity to improve DCWs': understanding and attitudes towards dementia; ability to interact with residents; motivation and job satisfaction. DCWs expected to: acquire knowledge and practical skills to deal with dementia; develop their knowledge about resident's biography; enhance their ability to deal with job strain; share experiences and improve group cohesion. Lack of time and support to translate learning into practice and sustain potential benefits over time were anticipated as the main barriers by both elements. There were coincident expectations and concerns among both managers and DCWs. Findings underscore the importance of targeting both DCWs-level and manager-levels perspectives to the planning of a sustainable PE intervention for DCWs.~

Keywords: dementia, direct care workers, expectations, long-term care facilities

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1. Introduction

Direct care workers (DCWs) provide the majority of daily hands-on care to people with dementia in long-term care (LTC) facilities, therefore they are most likely to influence their quality of life and care [1]. Yet, they have an unquestionable emotionally challenging job [1]. Persistent behaviour and psychological symptoms of dementia (BPSD), as agitation, coupled with a lack of training to handle them, emerge as significant sources of DCWs' stress and burnout [2]. Besides, the lack of teamwork, support and reward from care home managers contribute to overall DCWs' strain [3]. Despite the available evidence suggesting that staff mental well-being can affect the process of caring for people with dementia [4], the provision of emotional support to this workers remains scarce. Psychoeducational (PE) approaches by responding to both educational and emotional needs can be effective in supporting DCWs. PE interventions have been widely used with family carers of people with dementia [5], but are still underdeveloped within the context of formal care. This study sought to explore the expectations and concerns of care home managers (service and top-level managers) and DCWs about PE interventions. By collecting the perception of different grades of staff it is expected to increase knowledge for a better fit of the intervention to the needs of the target population and organizational setting.

2. Methods

2.1. Design

A qualitative cross-sectional study was conducted with DCWs and managers of 4 LTC facilities in the central region of Portugal (Aveiro), between November 2011 and December 2012. Approval to conduct the research was provided by the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra, Portugal.

1.2. Recruitment procedures and participants

Four LTC facilities were contacted and the service managers were informed about the project. All facilities agreed to participate. The manager of each facility was asked to identify staff members that maintained direct contact with people with dementia during care provision and were employed for at least 2 months; temporary workers, trainees, DCWs working only on the night shift and other health or social care practitioners (e.g., nurses) were excluded. A meeting with eligible DCWs, service managers and top-level managers was scheduled in order to explain the project and invite them to participate. Potential participants were clarified about the voluntary nature of their participation and anonymity and confidentiality were assured. Written informed consent was obtained from those who accept to participate.

A total of 66 participants were recruited to participate in the study. These included DCWs (n=58) and managers (n=8). DCWs were all female, mainly married (67.2%) and with an average age of 44.72 (±9.06). Nearly half of the participants (46.4%) had the primary and middle school and 41.3% the high school (Table 1). The average length of employment was 9.61 years (±3.72). The majority of the managers and administrators were female (n=6) with an average age of 45.5 (±10.26).

1.3. Data collection

Data were collected through eight staff focus-group ranging in size from 5 to 12 DCWs, and eight individual interviews with the managers of each facility. The interviews were held by a trained gerontologist (1st author) at workplace. A semi-structured guide was used, including the following questions: *What do you expect from a psychoeducational programme? What barriers or constraints do you anticipate to the development of a PE intervention?* Questions were followed by probes and paraphrasing of content to elicit more detail (e.g., ‘can you explain further?’). Each interview was recorded and transcribed *verbatim*. The average length of the focus-group interviews was 43.21±10.08 minutes; individual interviews had an average duration of 35.66±12.98 minutes.

1.4. Data analysis

Both the individual and the focus-group interviews transcripts were analysed using thematic analysis. The process of creating and testing the categorisation system was gradually refined by two independent judges (1st and 4th authors) as follows: (1) the text was read several times to construct a sense of the text as a whole; (2) a list of preliminary codes was created; (3) the codes were sorted into categories and then integrated into major themes; (4) the categorisation was compared and discussed between the two judges until reach a consensus; (5) a critical feedback was performed by the other authors. Data was managed using a qualitative data analysis software - webQDA (University of Aveiro, Portugal).

Table 1. Background characteristics of DCWs

Outcome	Direct Care Workers (n=58) N	%
Gender		
Female	58	100.0
Age		
19-28	2	3.4
29-38	14	24.1
39-48	20	34.4
49-58	19	32.7
≥59	3	5.1
M (SD)	44.72	9.06
Marital Status		
Married	39	67.2
Widowed	3	5.2
Single	4	6.9
Divorced/separated	9	15.5
Other	3	5.2
Education		
Primary school	15	25.8
Middle school	12	20.6
High school	24	41.3
College degree	1	1.7
Other	6	10.3
Working time (years)		
≤1	4	6.8
2-6	10	17.2
7-11	32	55.1
≥12	12	20.6
M (SD)	9.61	3.72

3. Results

Four unifying themes in both groups of respondents were found: knowledge and skills to improve dementia care; work attitudes and psychological wellbeing; group cohesion and barriers to PE interventions. Themes are described with reference to extracts from the data.

3.1. Knowledge and skills to improve quality of dementia care

Most of the managers expected that DCWs could understand the importance of focusing on the person more than on the task. They would like to see DCWs prepared to provide a more individualised care and to encourage residents' involvement during daily routine, in order to maintain their dignity and highest level of functioning:

> "*My expectation is that they become trained and prepared to deal with residents with dementia (…) obviously it is much easier to grab the spoon and give the soup at once to residents. But this is not beneficial for this kind of residents. They [DCWs] have to grab the spoon and show how the resident should do…and they should be attentive to their reaction. (…) I hope that they could encourage residents' involvement*." [Manager, facility 2]
> "*I want them to improve their daily behavior with the residents (…) the main error is treating every person in the same way. The person is admitted with some limitations and they do nothing to recover them. (…) I want them to acquire competences and to recognize that there is always something that people with dementia can do."* [Administrator, facility 3]

One manager underlined the importance of DCWs to learn effective ways of communicating with people with dementia. The need for staff to adapt their communication to the resident, in order to create an enriched environment between both, was emphasized:

> "*Support for DCWs to have a more accessible language and to understand what the resident wants to express. If they could understand the resident, the relationship between the both would be better."* [Manager, facility 1]

Managers also noted that guidance during care practice would be important to strengthen DCWs' competences, as programs are often more focused on classroom instruction and less on practical training:

> "*If they could put into practice what they have eared, first with your support and then by themselves, I think they will effectively change and learn. The new skills will become part of their routine."* [Manager, facility 1]

As well, DCWs stressed the importance of acquire new information to be used in daily practice and advice on how to manage residents' behaviors. Participants emphasized that a focus on understanding the residents' personal history would facilitate care delivery. Despite feeling competent and confidence about their actual performance, DCWs noted the importance of being trained by *'professionals with specialist knowledge'*:

> "*I'm waiting to learn something new that could help me in my daily practice*." [DCW, LTC facility 4]
> "*(…) I would like to know how to control their behavior". [DCW, LTC facility 2]*
> *"We think that what we do is the correct but there may be other techniques which can help us, and so it would be useful to learn them*". [DCW, facility 1]

3.2. Work attitudes and emotional wellbeing

Managers expected that the intervention could enhance DCWs' attitudes towards their work. They would like to see highly motivated and satisfied staff as this could improve their performance and productivity:

> "*(…) more pleasure, more motivation, more commitment…yes more commitment! (…) If they were more motivated, things would be different."* [Manager, facility 2]

Instead, DCWs reported the need to be recognized by their emotional demanding job. A few participants would like to have the opportunity to share and vent their emotional concerns in a trustful environment. Others called for practical strategies to handle job stress, as relaxation. Time management skills were also mentioned to be required, as this was thought to alleviate feelings of frustration that emerge from the incapacity to provide a better quality of care:

> "*We need to talk, to vent what we have been building up." [DCW, facility 1]*
> *"Here, at the facility, we should have someone that we could trust our concerns."* [DCW, facility 1]
> "*We need support for handling stress, for example by relaxing or receiving massages*." [DCW, facility 4]
> "*Help to create time within time. Sometimes we feel so dissatisfied because we can't do more for them*." [DCW, facility 4]

3.3. Group cohesion

The need to improve peer-relationships was stressed by all respondents. Managers reported the existence of '*highly competiveness'* among DCWs and a '*lack of teamwork'*.

According to their view, staff should be given appropriate methods to handle interactions assertively in order to improve interpersonal relationships. For DCWs there is lack of trust, union or respect between workers. Participants would like to have a space where they could socialize, share their experiences and raise mutual respect:

> "*Staff should learn to be more confident with each other" [Manager, facility 1]*
> *"We need a space where we can be together, help each other or even talk about job issues.*" [DCW, facility 3]

3.4. Barriers to PE interventions

All interviewees noted that time constraints and difficulty in sustaining potential benefits over time were two main barriers to effective PE interventions. Respondents saw managers as a pivotal figure and particularly commented on their ability to change practice. According to DCWs, managers could allow them to have enough time to translate learning into practice. For managers, their role in supervising DCWs post-intervention is fundamental:

> "*My greatest fear is that everything will work well until you leave, but then things will be lost. I believe we will need to be constantly supervising them."* [Administrator, facility 2]
> "*I think the PE intervention will help us if they [managers] enable us to practice… if they give us time to put into practice what we have learnt."* [DCW, facility 1]

4. Discussion

Managers and DCWs identified a range of expectations and barriers regarding the development of PE interventions for DCWs. Both groups stressed the need for knowledge on dementia, skills to deal BPSD and practical guidance to promote and sustain change. Support to improve DCWs' teamwork, workload and time management has also been mentioned as a key-element to be included on a PE intervention. These results strengthen the need of DCWs to be provided with education as well as with tools for stress and emotional management as this can be critical to promote practice change and performance improvement. Moreover, findings are consistent with the available evidence, which identifies limited time and difficulty in sustaining potential benefits over time as barriers to interventions in LTC facilities [6]. This means that, irrespective of the content of the programme, it is important that managers support and encourage change, by allowing, for example, DCWs to practise and maintain any skills they have learned.

The present study underscores the importance of engaging different grades of staff in the design of interventions. Both DCWs-level and manager-levels perspectives are fundamental to plan sustainable PE interventions and tailor them to the culture and particularities of the facilities in which they are to be implemented.

References

1. Stone, R. (2012). The Long-Term Care Workforce: From Accidental to Valued Profession. In D. Wolf and N. Folbre (Eds.), *Universal Coverage of Long-Term Care in the United States: Can We Get There from Here?* United States: Russell Sage Foundation.
2. Miyamoto, Y., H. Tachimori, &H. Ito. (2010). Formal caregiver burden in dementia: impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatr Nurs, 31*(4), 246-53. doi: 10.1016/j.gerinurse.2010.01.002
3. Edvardsson, D., P. Sandman, R. Nay, &S. Karlsson. (2009). Predictors of job strain in residential dementia care nursing staff. *J Nurs Manag, 17*(1), 59-65. doi: 10.1111/j.1365-2834.2008.00891.x
4. Hannan, S., I.J. Norman, &S.J. Redfern. (2001). Care work and quality of care for older people: A review of the research literature. *Reviews in clinical Gerontology, 11*(2), 189-203.
5. Pinquart, M., &S. Sörensen. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics, 18*(04), 577-595. doi: doi:10.1017/S1041610206003462
6. Beer, C., B. Horner, O.P. Almeida, S. Scherer, N.T. Lautenschlager, N. Bretland, . . . L. Flicker. (2009). Current experiences and educational preferences of general practitioners and staff caring for people with dementia living in residential facilities. *BMC Geriatrics, 9*(1), 36. doi: 10.1186/1471-2318-9-36

Appendix 2

Dementia in long-term care homes: direct care workers' difficulties[8]

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Abstract

Increasing numbers of people with dementia are being admitted to long-term care facilities. Behavioural and psychological symptoms of dementia (BPSD) are particularly challenging to care homes which are commonly characterised by a low-skilled workforce. The increasing demand for higher quality dementia care emphasizes the need to address the Direct Care Workers' (DCWs) difficulties, as this can inform the development of effective training interventions. This study aimed to explore the difficulties faced by DCWs caring for people with dementia in long term care homes. A qualitative cross-sectional study was conducted with 58 DCWs (female; mean age 44.63 ± 2.32). Eight focus-group interviews were performed to collect data. All interviews were video-recorded, transcribed and submitted to thematic analysis by two independent judges. Main difficulties faced by DCWs were related to: i) lack of time to provide personalised care and interact with residents, particularly during morning care; ii) management of the BPSD (e.g., agitation); iii) lack of knowledge about dementia and its symptoms, evolution and available treatments; iv) communication with residents; and v) stress and burnout related to BPSD. The findings underline the importance of training programmes for DCWs that provide both information and skills for dementia care that can be implemented during personal care tasks, and support to deal with stress and burnout. This is essential as training interventions are usually targeted on DCWs' care knowledge and skills, neglecting the psychological pressure experienced by these workers.

Keywords: dementia, difficulties, direct care workers, long-term care facilities

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1. Introduction

Dementia is a leading cause for admission of older people to long-term care (LTC) facilities [1] affecting at least 80% of the residents [2]. The majority of the individuals are institutionalised during the later stages of dementia, when behavioural and psychological symptoms of dementia (BPSD) (e.g., agitation or apathy) are more significant [1]. Consequently, BPSD are highly prevalent in care homes, imposing major demands on Direct Care Workers (DCWs) who provide the most hands-on care to these residents. Yet, DCWs are often under-prepared for effectively managing the care required, revealing low educational attainment and inadequate training on dementia [3].

The growing demand for high-quality care to an increasingly number of people with dementia, underscores the need for training interventions to deal with the shortage of competent DCWs [3]. In order to enrich the development of effective training interventions, previous knowledge about potential participants' experiences should be acquired. Thus, the present study sought to understand the difficulties faced by DCWs' caring for people with dementia in LTC facilities.

2. Methods

2.1. Design

A qualitative cross-sectional study was conducted with DCWs of 4 LTC facilities of the central region of Portugal, between November 2011 and December 2012. Ethical approval was previously obtained by the Ethics Committee of the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra, Portugal.

2.2. Procedures and participants

Four LTC facilities were contacted and the service managers were informed about the study plan. All facilities agreed to participate. The service managers were asked to identify DCWs who met the following inclusion criteria to: i) provide regular personal care to people with dementia (e.g., bathing, dressing and toileting); ii) work at the facility for at least 2 months. Temporary workers, trainees, DCWs working only on the night shift, other health and social care practitioners (physicians, nurses and social workers) were excluded, as they spend short periods of time with the residents. After this procedure, potential participants were clarified about the purpose of the study and the voluntary nature of their participation. All the 58 DCWs agreed to participate. Written informed consent was obtained prior to any data collection. Demographic data about the DCWs (Table 1) shows that participants were all female, mainly married (67.2%) and with an average age of 44.72±9.06. Nearly half of the participants (46.4%) had the primary and middle school and 41.3% the high school. The average length of employment was 9.61±3.72 years.

2.3. Data collection

Data were collected through eight focus groups interviews (two in each LCT facility), ranging in size from 5 to 12 participants. The interviews were conducted by a trained gerontologist in a quiet room of each facility, so that DCWs felt that they could speak freely without being interrupted. A semi-structured interview guide was developed to explore DCWs' perspectives. The following questions were considered: *How do you feel about taking care of residents with dementia? What are your main difficulties/concerns?* The role of the moderator was to encourage participants' reflection, using probes to clarify or elaborate their responses (e.g., 'can you explain further?') while keeping a friendly and non-judgemental attitude. Interviews were video-recorded and had an average duration of 43.21±10.08 minutes.

2.4. Data analysis

Focus-group interviews were transcribed *verbatim* and submitted to thematic analysis by two independent judges (1st and 4th authors), as follows: (1) the text was read several times to construct a sense of the text as a whole; (2) preliminary codes were created, closely reflecting the interview questions; (3) codes were organized into categories and then integrated into major themes; (4) the categorization was compared and discussed between the two judges until reach a consensus; (5) a critical feedback was performed by the other authors. Data was processed using computerized qualitative data analysis software - webQDA (University of Aveiro, Portugal).

Table 1. Background characteristics of DCWs

Outcome	Direct Care Workers (n=58)	
	N	%
Gender		
Female	58	100.0
Age		
19-28	2	3.4
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M (SD)	44.72	9.06
Marital Status		
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Single	4	6.9
Divorced/separated	9	15.5
Other	3	5.2
Education		
Primary school	15	25.8
Middle school	12	20.6
High school	24	41.3
College degree	1	1.7
Other	6	10.3
Working time (years)		
≤1	4	6.8
2-6	10	17.2
7-11	32	55.1
≥12	12	20.6
M (SD)	9.61	3.72

3. Results

Seven categories have emerged and were clustered into two key-themes: inability to provide the ideal care and manage residents’ behaviours. Five subthemes - under time pressure and workload; lack of emotional support; lack of knowledge about residents’ profile; lack of information about dementia and difficulties in communicate – were linked to inability to provide the ideal care. Emotional and physical exhaustion were related to manage residents’ behaviour. Results will be discussed regarding the key-themes and supported by reference to illustrative extracts from the data. All names have been changed to protect participants’ anonymity.

3.1. Failure to provide the ideal care

A major difficulty faced by DCWs was related to the inability to perform the care they wished to perform: less instrumental and more individualized. According to several participants, this was a consequence of the time pressure and workload that emerge from the *‘increased number of dependent residents’* and the *‘shortage of staff’*. The DCWs wished to be able to foster the residents' autonomy, communicate and promote their active participation during care routines, and feel frustrated when they had no opportunity to achieve this. Some interviewees noted that the morning care, contemplating basic daily activities (e.g., bathing or dressing), was the most difficult moment '*to be completely committed to the resident'.*

> "*I regret not having more time to talk with them [residents with dementia]. We take care for their hygiene, we feed them, lay them and I feel that they wish to talk with us, they want to tell us something and we don't have a bit of time to be with them and to hear them*." [Maria]
> "*We should have more time to properly care for them... without any stress or rush, with enough time to talk with them, to encourage them to do something.*" [Luciana]

A second threat to the quality level of care was related to DCWs' need of being *'recognised'* and *'valued'* by their emotional demanding work. Many participants missed acknowledgment from their managers and feel that their work is unappreciated. They reported that if their emotional needs were attended they were more likely to be in a state of better well-being which could lead to better care:

> "*It's more mental exhausting being in that floor [a floor predominantly occupied by residents with dementia]…makes you laugh and cry. If you don't feel healthy, if you don't feel well (…) even here if you are not encouraged, valued and respected by the work you perform, it becomes harder. We should have psychological support."* [Ana]
> "*Sometimes I show to others that I'm strong, but in other days I don't feel so well… and if I'm not well I can't care of them as it should be (…)*" [Teresa]

Antecedent information about the person's background, lifestyle, preferences and current conditions was also pointed out as being required, with a few participants recognizing that if this information was available they would improve their relationship with the resident and the quality of care provision. Overall, it was through *experience* and '*working time'* that DCWs became more aware of the residents' characteristics, preferences and values:

> "*I think we don't know our residents. (…) We do not know what their preferences were before their admission to this care home. (…) If we some more information about them perhaps things would be done differently. We involve them all in the same kind of recreational tasks and only through time we realize what they like and dislike. If we were informed from the moment of their admission about their story it would be easier...we could start talking of what they liked.*" [Luisa]

Similarly, participants were acutely aware that they lack information about dementia, dementia-related behaviours and how to manage them. DCWs noted that such information would impact care provision and mitigate feelings of uncertainty about their skills:

> "*Why the resident becomes so aggressive? Why he cries all day long? If we are caring for him or her… well why are they reacting aggressively? If they have the same disease why they react so differently? These are the questions that we don't know how to answer.*" [Paula]
>
> "*We are aware to be short of some skills that prevent us from caring as we should*." [Manuela]
>
> "*(…) we don't know if the things we are doing are hurting them.*" [Luciana]

Finally, the ability to provide a better care was compromised by communication problems with residents. Overall, DCWs emphasised that they are less likely to interact with dementia residents than with the non-cognitively impaired ones. This was related to the fact that residents with dementia '*barely speak'* and with DCWs' doubts to realize if their speech is being understood:

> "*We provide better care for people with intact cognitive capacities because we can talk to them*." [Sonia]
>
> "*Mrs. F. when we say "let's go" maybe she does not understand anything of what we are saying. That's why it is so difficult*." [Palmira]

3.2. Residents' behaviour

Several DCWs felt that their physical and psychological well-being was negatively affected by the strain of caring for people with dementia. According to participants caring for people with dementia was more difficult than caring for residents with other conditions. Terms like '*exhaustion'* or '*stress'* were frequently reported.

BPSD were relatively common and poorly tolerated by participants. Wandering has been seen as a particularly challenging behaviour to be stopped. DCWs reported great difficulty in coping with this symptom, feeling often forced to proceed against their or residents' will. Physical restrictions were seen as adverse but often realized as the only alternative to '*get the work done'* and the '*residents' safety'*:

> "*It is difficult when they are wandering, when they want to go outside and we have to be after them all the time. We ended up having to restrict them, or otherwise we can't do anything*." [Mariana]

Yelling, stealing accusations, agitation or repetitions were also described as challenging behaviours. DCWs stressed their daily struggle to manage these symptoms and the impact of this in their family life:

> "*It's exhausting hearing for 200 times the same things and trying to explain ... and then we know at what time they will start. One resident wants to see the mother … we do not say 'your mother is not here' we put the receptionist saying 'I've already called your mother, she told you to start eating'. Being emotionally well to succeed, to manage all this, it's complicated*." [Ana]
>
> "*It is easier to distract a person without dementia that remains noiseless while watching TV. He is certainly not demanding as a person who is yelling all day (...) You have a person with dementia that yells all day long, another one that cries,...it becomes psychologically exhausting. It exhausts us. You arrive home to be with your family and you are exhausted*." [Gabriela]

Some respondents also felt that caring for residents with dementia has a considerable cost to their own physical health:

> "*It is physically exhausting. Even when they can put their feet on the floor they do not facilitate our work."* [Luísa]

4. Discussion and conclusion

The results provide relevant knowledge about the difficulties faced by DCWs when caring for people with dementia. These were related to the lack of ability to perform the ideal care given the time-pressure, lack of emotional support and absence of information and preparation to deal with dementia. Additionally, feelings of emotional and physical exhaustion that emerge from residents' behaviours were emphasised. These findings are of great significance as they provide important insights to design effective training interventions.

Providing DCWs with information about dementia and competences to deal with BPSD, as well as ways to cope with frustration, stress and burnout might be an important lever to deliver better care. Psycho-educational interventions, albeit underdeveloped in the context of formal care, can be helpful for DCWs as they add to the traditional training programmes (training alone) a supportive component that addresses their emotional needs. Supporting DCWs to cope effectively with stress and burnout is of paramount importance, as it has been shown that staff strain is associated with less willingness to help residents, low optimism and negative emotional responses to residents' behaviour [4]. Organisationally, the present study suggests that the availability of adequate support managers is a key factor in improving the quality of care to residents with dementia. Managers can, for example, hold open channels of communication (e.g., by maintaining DCWs informed about residents' biography), certify that DCWs have enough time to maximize the use of residents' abilities during personal care tasks or encourage and give feedback on care practice. Findings reflect the hierarchical management structure of LTC facilities and the emphasis they placed on organisational needs rather than emotional issues. This 'culture' had determined a dearth of adequate training and support for DCWs. Thus, extending the focus of interventions to all levels of staff might be necessary in order to raise awareness across the entire organization.

References

1. Luppa, M., T. Luck, E. Brahler, H.H. Konig, &S.G. Riedel-Heller. (2008). Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord, 26*(1), 65-78. doi: 10.1159/000144027

2. Alzheimer's Society. (2013). Low expectations: Attitudes on choice, care and community for people with dementia in care homes. United Kingdom: Alzheimer's Society.

3. Stone, R. (2012). The Long-Term Care Workforce: From Accidental to Valued Profession. In D. Wolf and N. Folbre (Eds.), *Universal Coverage of Long-Term Care in the United States: Can We Get There from Here?* United States: Russell Sage Foundation.
4. Duffy, B., J.R. Oyebode, &J. Allen. (2009). Burnout among care staff for older adults with dementia: The role of reciprocity, self-efficacy and organizational factors. *Dementia, 8*(4), 515-541. doi: 10.1177/1471301209350285.

Annex 1

Inventário de Burnout de Maslach

(Maslach & Jackson, 1996)

Versão Portuguesa: IPSSO – Instituto de Prevenção do *Stress* e Saúde Ocupacional, 1999 (adaptado)

Instruções

Responda em função do que tem sentido acerca do seu trabalho. Por favor, assinale com um círculo a opção que melhor corresponde ao seu caso pessoal.

Para cada pergunta escolha uma das seguintes opções:

0	**1**	**2**	**3**	**4**	**5**	**6**
Nunca	**Algumas vezes por ano ou menos**	**Uma vez por mês ou menos**	**Algumas vezes por mês**	**Uma vez por semana**	**Algumas vezes por semana**	**Todos os dias**

Afirmações	*Com que frequência*						
1. Sinto-me vazio emocionalmente, por causa do meu trabalho	0	1	2	3	4	5	6
2. No fim do dia de trabalho, sinto-me exausto	0	1	2	3	4	5	6
3.Sinto-me fatigado quando acordo de manhã e tenho que enfrentar mais um dia de trabalho	0	1	2	3	4	5	6
4. Consigo compreender facilmente como os utentes se sentem acerca das coisas	0	1	2	3	4	5	6
5.Sinto que trato alguns utentes como se fossem objetos impessoais	0	1	2	3	4	5	6
6. Trabalhar com pessoas o dia todo é, de facto, um esforço para mim	0	1	2	3	4	5	6
7. Lido muito eficazmente com os problemas dos utentes	0	1	2	3	4	5	6
8. Sinto-me esgotado devido ao meu trabalho	0	1	2	3	4	5	6
9. Sinto que estou a influenciar positivamente a vida de outras pessoas com o meu trabalho	0	1	2	3	4	5	6
10. Tornei-me mais insensível em relação às pessoas, desde que comecei este trabalho	0	1	2	3	4	5	6
11. Preocupo-me que este trabalho me esteja a “endurecer” emocionalmente	0	1	2	3	4	5	6
12. Sinto-me muito enérgico	0	1	2	3	4	5	6

0	**1**	**2**	**3**	**4**	**5**	**6**
Nunca	**Algumas vezes por ano ou menos**	**Uma vez por mês ou menos**	**Algumas vezes por mês**	**Uma vez por semana**	**Algumas vezes por semana**	**Todos os dias**

13. Sinto-me muito frustrado com o meu trabalho	0	1	2	3	4	5	6
14. Sinto que estou a trabalhar demasiado no meu trabalho	0	1	2	3	4	5	6
15. De facto, não me interessa o que acontece a alguns utentes	0	1	2	3	4	5	6
16. Trabalhar diretamente com pessoas coloca-me sob demasiada tensão	0	1	2	3	4	5	6
17. Consigo facilmente criar uma atmosfera relaxada com os utentes	0	1	2	3	4	5	6
18. Sinto-me entusiasmado depois de trabalhar de perto com os utentes	0	1	2	3	4	5	6
19. Consegui realizar muitas coisas importantes nesta profissão	0	1	2	3	4	5	6
20. Sinto que estou no meu limite (“no fim da linha”)	0	1	2	3	4	5	6
21. No meu trabalho, lido com os problemas emocionais com muita calma	0	1	2	3	4	5	6
22. Sinto que os utentes me culpam por alguns dos seus problemas	0	1	2	3	4	5	6

Annex 2

Escala de *Stress* Percebido

(Cohen, Kamarck & Mermelstein, 1983)

Versão Portuguesa - Moreira (2002)

Instruções

As questões seguintes referem-se ao modo como se sentiu ao longo do **<u>último mês</u>**. Para cada pergunta deve indicar com que frequência pensou ou se sentiu dessa forma (pode colocar um círculo em volta do algarismo que melhor representar a sua resposta). Para cada pergunta escolha uma das seguintes alternativas:

Nunca	**Quase nunca**	**Às vezes**	**Com alguma frequência**	**Com muita frequência**
0	**1**	**2**	**3**	**4**

1. No último mês com que frequência se sentiu aborrecido com algo que ocorreu inesperadamente?	0	1	2	3	4
2. No último mês com que frequência se sentiu que era incapaz de controlar as coisas que são importantes na sua vida?	0	1	2	3	4
3. No último mês com que frequência se sentiu nervoso ou “stressado”?	0	1	2	3	4
4. No último mês com que frequência enfrentou com sucesso coisas aborrecidas e chatas?	0	1	2	3	4
5. No último mês com que frequência sentiu que estava a enfrentar com eficiência mudanças importantes que estavam a ocorrer na sua vida?	0	1	2	3	4
6. No último mês com que frequência se sentiu confiante na sua capacidade para lidar com os seus problemas pessoais?	0	1	2	3	4
7. No último mês com que frequência sentiu que as coisas estavam a correr como queria?	0	1	2	3	4
8. No último mês com que frequência reparou que não conseguia fazer todas as coisas que tinha que fazer?	0	1	2	3	4
9. No último mês com que frequência se sentiu capaz de controlar as suas irritações?	0	1	2	3	4
10. No último mês com que frequência sentiu que as coisas lhe estavam a correr pelo melhor?	0	1	2	3	4
11. No último mês com que frequência se sentiu irritado com coisas que aconteceram e que estavam fora do seu controlo?	0	1	2	3	4
12. No último mês com que frequência foi capaz de controlar o seu tempo?	0	1	2	3	4
13. No último mês com que frequência sentiu que as dificuldades se acumulavam ao ponto de não ser capaz de as ultrapassar?	0	1	2	3	4

Annex 3

Questionário de Satisfação de Minnesota: versão reduzida

(Weis *et al.*,1967)
Versão portuguesa - Ferreira *et al.* (2009)

O objetivo deste questionário é perceber como se sente em relação ao seu atual trabalho, o que o/a faz satisfeito/a ou insatisfeito/a.

Para cada afirmação escolha uma das seguintes alternativas:

Muito insatisfeito 1	Insatisfeito 2	Nem insatisfeito nem satisfeito 3	Satisfeito 4	Muito satisfeito 5

1. Ser capaz de me manter ocupado(a) durante todo o tempo	1	2	3	4	5
2. Possibilidade de trabalhar de modo independente no meu cargo	1	2	3	4	5
3. Oportunidade fazer coisas diferentes de tempos a tempos	1	2	3	4	5
4. Oportunidade de “ser alguém na vida”	1	2	3	4	5
5. Modo como o meu superior lida com os seus subordinados (as)	1	2	3	4	5
6. Competência do meu supervisor na tomada de decisões	1	2	3	4	5
7. Possibilidade de fazer coisas que não vão contra a minha consciência/valores	1	2	3	4	5
8. Segurança/estabilidade que o meu emprego me fornece	1	2	3	4	5
9. Possibilidade de ajudar outras pessoas	1	2	3	4	5
10.Possibilidade de dizer às pessoas o que fazer	1	2	3	4	5
11.Possibilidade de fazer algo em que faça uso das minhas competências	1	2	3	4	5
12.Forma como as políticas da instituição são implementadas	1	2	3	4	5
13.Meu salário e da quantidade de trabalho que realizo	1	2	3	4	5
14.Possibilidade de progressão profissional	1	2	3	4	5
15.Possibilidade de tomada de decisões por mim próprio	1	2	3	4	5
16.Possibilidade de utilização dos meus próprios métodos para a realização do meu trabalho	1	2	3	4	5
17.Condições de trabalho	1	2	3	4	5
18.Modo como os meus colegas se relacionam entre si	1	2	3	4	5
19.Reconhecimento por fazer um bom trabalho	1	2	3	4	5
20.Sentimento de realização pessoal que obtenho no trabalho	1	2	3	4	5

ERRATA

Barbosa, A. Apoio a cuidadores formais de pessoas com demência: Os efeitos de uma intervenção psico-educativa. Tese de doutoramento em Gerontologia e Geriatria apresentada à Secção Autónoma de Ciências da Saúde da Universidade de Aveiro.

Pag.	Texto anterior	Texto atual
40	Given the lack of research in this area, Certified Nursing Assistants/Ails were also considered eligible in order to obtain a large number of studies.	Certified Nursing Assistants/Aids (CNAs) were also considered eligible in order to obtain a large number of studies. As DCWs, CNAs are responsible to assist residents with activities of daily living, such as bathing, dressing, grooming and eating, however, they are required to be certified after complete a specialized training.