**Universidade de Aveiro** Secção Autónoma de Ciências da Saúde
**2012**

**SARA RAQUEL COSTA GUERRA**

# DEMÊNCIA E INTERVENÇÃO FAMILIAR: VISÃO SISTÉMICA E DESENVOLVIMENTAL

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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 Liliana Xavier Marques de Sousa, Professora Auxiliar com Agregação da Universidade de Aveiro e a co-orientação da Doutora Daniela Maria Pias Figueiredo, Professora Adjunta na Escola Superior de Saúde da Universidade de Aveiro.

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Este trabalho é dedicado à memória da Maria Gabriela (Gabi), cuja luz continua a iluminar o meu percurso.

**o júri**

presidente

**Doutora Celeste Oliveira Alves Coelho**
Professora Catedrática do Departamento de Ambiente da Universidade de Aveiro

**Doutora Margarida Maria Baptista Mendes Pedroso de Lima**
Professora Associada da Faculdade de Psicologia e Ciências da Educação da Universidade de Coimbra

**Doutor António Manuel Godinho da Fonseca**
Professor Associado da Universidade Católica Portuguesa

**Doutora Liliana Xavier Marques de Sousa**
Professora Auxiliar com Agregação da Universidade de Aveiro

**Doutora Maria Amália Silveira Botelho**
Professora Auxiliar da Faculdade de Ciências Médicas da Universidade Nova de Lisboa

**Doutora Daniela Maria Pias de Figueiredo**
Professora Adjunta da Universidade de Aveiro

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**palavras-chave**

demência, família, integridade familiar, intervenção psicoeducativa, prestação de cuidados.

**resumo**

A prestação de cuidados familiares, centrada nos desafios colocados ao cuidador principal, particularmente no âmbito das condições demenciais, tem vindo a assumir-se desde a década de 1980 como um tema fulcral no contexto das famílias envelhecidas e da pesquisa gerontológica. Neste contexto, um leque diversificado de intervenções têm sido desenvolvidas para apoiar os cuidadores familiares de pessoas com demência. Estas intervenções têm evidenciado algumas limitações, nomeadamente: a unidade de intervenção é a pessoa com demência ou o cuidador principal, não considerando a família como unidade; a fragmentação do apoio, em que serviços sociais, de saúde, educacionais e de suporte funcionam como estruturas paralelas e independentes; e as abordagens são geralmente centradas na doença, negligenciando os recursos e competências dos participantes (fatores salutogénicos).

Neste estudo procedeu-se ao desenho, implementação e avaliação de um programa integrado, para pessoas com demência e suas famílias, baseado numa abordagem colaborativa e de capacitação: proFamílias-demência. Este programa tem três componentes: (a) sessões psicoeducativas para os familiares da pessoa com demência, num formato de grupo de discussão multifamílias; (b) sessões de ocupação significativa para as pessoas com demência; e (c) serviço de referência pós-intervenção para garantir a continuidade de apoio. O proFamílias-demência envolveu cinco famílias (seis participantes). A avaliação indica que os aspetos estruturais e funcionais são adequados. Em termos de impacto a médio prazo (três meses), as famílias referem que o programa permitiu a consciencialização da importância do autocuidado, melhor gestão emocional e mais união familiar.

Neste estudo também se analisou a influência da prestação de cuidados a um familiar com demência no desenvolvimento do cuidador idoso. Adotou-se a abordagem da integridade familiar (King & Wynne, 2004) como quadro conceptual e o instrumento de recolha de dados foi a entrevista semiestruturada recomendada nesta abordagem. A amostra envolve 26 cuidadores familiares idosos (mais de 64 anos) que nas suas casas cuidam de um familiar com demência.

Os principais resultados sugerem que a prestação de cuidados a um familiar com demência influencia a construção da integridade familiar em termos: (a) concretização de projetos de vida; (b) frequência de contactos com a família; (c) possibilidade de reciprocidade do cuidador; e (d) resolução de conflitos familiares. No entanto, os resultados reforçam que a forma como o cuidador percebe, vivencia e interpreta a prestação de cuidados é fundamental na construção da integridade familiar.

Em geral, a investigação desenvolvida nesta tese permitiu: (a) desenvolver linhas orientadoras para a implementação de programas de apoio psicoeducativo junto de pessoas com demência e suas famílias; e (b) contribuir para o desenvolvimento de modelos teóricos sobre os processos de desenvolvimento individual de cuidadores idosos.

Estudos futuros envolvendo amostras mais alargadas e combinando a utilização de metodologias qualitativas e quantitativas são necessários. A avaliação dos custos e ganhos económicos decorrentes destes programas também se revela primordial.

**keywords** caregiving, dementia, family, family integrity, psychoeducational intervention.

**abstract**

The provision of family care, focusing on the challenges to the primary caregiver, and particularly on dementia scope, has been assumed since the 1980s as a key theme in the context of aging families and gerontological research. In this context, a wide range of interventions has been developed to support family caregivers of people with dementia. These interventions have shown some limitations, namely: the unit of intervention is the person with dementia or the primary caregiver, not considering the family as a unit; the fragmentation of the support, since the health and social services, education and support act as parallel and independent structures; and the approaches are generally focused on disease, neglecting participants' resources and skills (salutogenic factors). In this study we proceeded to the design, implementation and evaluation of an integrated program for people with dementia and their families, based on a collaborative and empowerment approach: proFamilies-dementia. This program has three components: (a) psychoeducative sessions for the relatives of the person with dementia, within a multifamily discussion group format; (b) sessions of meaningful occupation for the people with dementia, and (c) post-intervention referral service to ensure continuity of support. The proFamilies-dementia involved five families (six participants). The evaluation indicates that its structural and functional aspects are suitable. In terms of medium term impact (three months), the families reported that the program allowed the awareness of self-care importance, better emotional management, and more family union.

This study also examined the influence of caring for a relative with dementia in the development of elderly caregivers. We have adopted the family integrity approach (King & Wynne, 2004) as a conceptual framework and the instrument for data collection was the semi-structured interview recommended by this approach. The sample involved 26 family elderly caregivers (over 64) that care for a relative with dementia in their homes. The main results suggest that caring for a relative with dementia influences the construction of family integrity in terms of: (a) realization of life projects, (b) frequency of the contacts with family, (c) caregiver's reciprocity possibility; and (d) resolution of family conflicts. However, the results reinforce that the way the caregiver perceives, experiences and interprets the provision of care is essential in the construction of family integrity.

In general, the research developed in this thesis allowed: (a) to develop guidelines for the implementation of psychoeducational support programs for persons with dementia and their families; (b) to contribute to the development of theoretical models of the processes of elderly caregivers individual development.

Future studies involving more extensive samples and combining the use of qualitative and quantitative methodologies are needed. The assessment of costs and economic gains of these programs also emerges as a paramount issue.

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# INTRODUÇÃO GERAL

# INTRODUÇÃO GERAL

## Demência e Intervenção Familiar: Visão Sistémica e Desenvolvimental

O projeto inicial, submetido e aprovado pela Fundação para a Ciência e a Tecnologia (FCT), centrava-se no desenvolvimento, implementação e avaliação de uma intervenção psicoeducativa para cuidadores familiares de pessoas idosas com demência, num contexto de cuidados de saúde primários. Porém, o plano inicial foi evoluindo, conduzindo a algumas alterações, que decorreram principalmente de: revisão da literatura sobre as temáticas centrais da prestação de cuidados a familiares com doença crónica, particularmente as condições demenciais (nomeadamente o impacto na estrutura familiar e as intervenções que têm sido desenvolvidas); contacto com especialistas da área da psicopatologia e com pessoas com demência e seus familiares, através da observação dos desafios que as especificidades da doença impõem ao funcionamento individual e familiar. Assim, o projeto foi redirecionado em termos de destinatários: a intervenção passou a ser dirigida à família, adotando uma abordagem integrada que abrange a pessoa com demência e os seus familiares mais próximos; e foi introduzido um novo tópico de investigação que visou explorar o impacto da prestação de cuidados a um familiar com demência no processo de construção da integridade familiar do cuidador idoso.

Esta introdução geral enquadra os principais referenciais teóricos da tese e enuncia o seu enfoque e objetivos. Esta tese é composta por um conjunto de estudos, apresentados sob a forma de artigos científicos (publicados, aceites ou submetidos para publicação), por isso esta introdução geral contextualiza teoricamente a sua interligação e evolução.

O enquadramento teórico foca-se no fenómeno de envelhecimento populacional e no subjacente aumento exponencial de casos de demência. Os temas abordados incluem: aspetos clínicos da demência, com um enfoque na doença de Alzheimer, por constituir a principal causa de demência; os desafios e impactos da doença crónica, particularmente da doença de Alzheimer, no desenvolvimento do cuidador principal (integridade familiar) e no contexto familiar; descrição das principais linhas de intervenção nesta área e sua eficácia; importância da continuidade das intervenções. Esta tese foca-se nos pressupostos do modelo biopsicossocial, procurando ultrapassar uma perspetiva estritamente biomédica (Engel, 1977)[1]. Visa, essencialmente, analisar a importância de adotar um novo paradigma na intervenção dirigida a pessoas com demência e suas famílias, sustentando que se baseie nos pressupostos do paradigma biopsicossocial (que inclui a interação dos fatores biomédicos, psicológicos, espirituais e sociais da pessoa e sua família) e do paradigma salutogénico (foca a promoção da

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[1] A referenciação bibliográfica usada respeita os critérios utilizados nas publicações às quais os artigos foram submetidos. Como tal, o leitor encontrará discrepâncias ao longo da tese. Na introdução e conclusões gerais, a referenciação bibliográfica segue o estilo da 6ª Edição da Associação Americana de Psicologia (*American Psychological Association*, APA).

saúde, não a doença, reforçando as competências e os recursos das famílias), numa perspetiva desenvolvimental e sistémica, enquanto "lente" interpretativa do impacto da doença na família (Miller, McDaniel, Rolland, & Feetham, 2006).

## I. Envelhecimento e Demência

O processo de envelhecimento é complexo e pode ser interpretado sob diversas perspetivas. Contudo trata-se de um processo normal, universal, gradual e irreversível de mudanças e de transformações que ocorrem com a passagem do tempo. O envelhecimento é um fenómeno intimamente associado aos processos de diferenciação e crescimento, já que nele concorrem a interação de fatores internos (como o património genético) e externos (como estilo de vida, educação e contexto) (cf. Figueiredo, 2007). Neste sentido, a principal característica do envelhecimento é a variabilidade inter e intra-individual, ou seja, existem padrões de envelhecimento diferentes, tanto em pessoas com a mesma idade cronológica, como nas distintas funções de uma pessoa (e.g., psicológicas, fisiológicas e sociais) (cf. Figueiredo, 2007). O envelhecimento é, assim, um processo complexo que resulta da interação de fatores biológicos, psicológicos e sociais. O envelhecimento é um fenómeno normal que faz parte do desenvolvimento humano, caracterizado pela ocorrência de mudanças adaptativas e influenciado pela exposição a contextos sociais e históricos (cf. Fonseca, 2005). Assim, deverá ser encarado numa perspetiva biopsicossocial que enquadra as mudanças desenvolvimentais nesta fase da vida, mediante a análise de vários domínios.

O envelhecimento populacional é um processo presente à escala mundial enquanto consequência do sucesso dos cuidados de saúde no último século. De acordo com a *Alzheimer Disease International* (ADI, 2009), uma federação de associações mundiais da doença de Alzheimer, as pessoas vivem agora mais tempo e de forma mais saudável, implicando maior proporção de pessoas idosas na população mundial. A população idosa é, atualmente, o grupo etário com maior tendência de crescimento nas estruturas demográficas mundiais. De acordo com a Organização das Nações Unidas (ONU, 2009), em 2009 existiam 737 milhões de pessoas com 60 ou mais anos de idade e estima-se que este número ascenda aos 2 biliões em 2050. Uma característica relevante do crescimento da população idosa é o aumento da esperança de vida após os 65 anos de idade, implicando o crescimento exponencial do número de pessoas idosas com 80 anos e mais (ADI, 1999).

Segundo dados recentes do Instituto Nacional de Estatística (INE, 2011), o cenário de envelhecimento da população mantém esta tendência em Portugal, em particular o duplo envelhecimento (alargamento superior e o estreitamento inferior da pirâmide etária), que denota: aumento da esperança média de vida; baixas taxas de natalidade e fecundidade. Assim, as pessoas vivem até mais tarde, com melhores condições de vida e com acesso a serviços de saúde de melhor qualidade. Neste contexto, o cenário futuro é de uma população com menos jovens e mais idosos, constituindo um desafio à sustentabilidade demográfica dos territórios e à solidariedade entre gerações (INE, 2011). De acordo com as projeções do índice de envelhecimento, de um conjunto de 29 países europeus, Portugal deverá ser o sétimo país mais envelhecido em 2030, com cerca de 175 idosos por 100 jovens (INE, 2011). Para Portugal, estas projeções indicam que, entre 2010 e 2030, a população residente deverá aumentar cerca de 2%, à custa de uma redução transversal de todos os grupos etários quinquenais até aos 44 anos e de ambos os sexos (cf. INE, 2011). Contudo, nas faixas etárias mais elevadas, vai assistir-se ao crescimento do efetivo populacional que nos indivíduos com 65 ou mais anos será de 39% e na faixa dos 85 e mais anos deverá ultrapassar os 80% (cf. INE, 2011).

O aumento da população idosa tem sido acompanhado pelo aumento da prevalência de doenças crónicas, particularmente das condições demenciais. Dados recentes indicam que, em 2010, existiriam cerca de 35,6 milhões de pessoas com demência a nível mundial, com um novo caso a cada sete segundos (ADI, 2010). Prevê-se que estes números dupliquem a cada 20 anos e que o diagnóstico de demência, a nível mundial, ascenda a 65,7 milhões em 2030 e 115,4 milhões em 2050. A Europa enquadra esta tendência, prevendo-se que em 2050 sejam diagnosticadas com demência cerca de 14,5 milhões de pessoas, representando 3,3% da população, sendo 10,1% pessoas com mais de 65 anos (Mura, Dartigues, & Berr, 2010). Em Portugal existem cerca de 153 mil pessoas com demência, sendo que 90 mil estão diagnosticadas com a doença de Alzheimer (Alzheimer Portugal, 2009).

O impacto social da demência é motivo de atenção, pois pode ser considerada uma epidemia a ganhar terreno na população idosa, a nível mundial (ADI, 2009). A demência representa um dos maiores desafios deste século, principalmente para os sistemas de saúde (Kiejna *et al.*, 2010), constituindo um problema de saúde pública significativo pois, para além de ser uma doença comum na velhice, é uma das maiores causas de incapacidade e mortalidade (Ritchie & Lovestone, 2002). Nesse sentido, a ADI (2010) recomendou que a Organização Mundial de Saúde (OMS) e os governos nacionais declarassem a demência como uma prioridade mundial/nacional de saúde, desenvolvendo estratégias de apoio a pessoas com demência e suas famílias. A ADI recomendou ainda o financiamento de pesquisa neste âmbito, incluindo a exploração de tratamentos farmacológicos e não farmacológicos, prevalência, impacto e prevenção. O desenvolvimento de estratégias de apoio a pessoas idosas com demência e suas famílias constitui, assim, o foco desta tese.

## 1. Demência: características

### *1.1. Diagnóstico e etiologia*

O conceito de demência tem variado ao longo do tempo, tendo no início do século XX sido considerada uma deterioração intelectual. Atualmente, a demência associa-se a uma síndrome de etiologia multifatorial, onde são afetadas funções cognitivas como memória, linguagem, atenção e pensamento. Contudo, para que haja um diagnóstico de demência, essas alterações têm de ser persistentes no tempo e comprometer a funcionalidade da pessoa. O Quadro 1 define o conceito de demência proposto pela Associação Americana de Psiquiatria (APA) (DSM-IV-TR), em 2000.

**Quadro 1 -** Diagnóstico de Demência, *Manual de Diagnóstico e Estatística das Perturbações Mentais* (4ª ed) – DSM-IV-TR (adaptado de APA, 2000)

A. Desenvolvimento de défices cognitivos múltiplos manifestados por:

(1) Diminuição da memória (diminuição da capacidade para aprender novas informações ou recordar informação aprendida previamente).

(2) Pelo menos uma das seguintes perturbações cognitivas:

a) Afasia (perturbação da linguagem);
b) Apraxia (diminuição da capacidade para desenvolver atividades motoras, apesar da função motora permanecer intacta);
c) Agnosia (incapacidade em reconhecer ou identificar objetos, ainda que a função sensorial se mantenha intacta);
d) Perturbação do funcionamento executivo (isto é, planeamento, organização, sequenciamento e abstração).

B. Os défices cognitivos indicados nos critérios A1 e A2 têm de causar alterações significativas no funcionamento social e ocupacional da pessoa e representam um declínio significativo em relação a um nível prévio de funcionamento.

C. Tem de existir evidência clara a partir da história clínica ou de exames complementares de que a perturbação é a consequência fisiológica direta de uma afeção médica geral.

D. Os défices não se manifestam exclusivamente durante a evolução de um estado de confusão mental.

A demência pode resultar de um conjunto de perturbações e estados; algumas perturbações são reversíveis (os sintomas podem ser contidos ou anulados em graus diversos com tratamentos específicos) e outras irreversíveis (crónicas e progressivas com as abordagens atualmente disponíveis, como a doença de Alzheimer) (Spar & La Rue, 2005).

As etiologias mais frequentes de demência podem dividir-se em dois grupos: (a) doenças degenerativas (em geral, progressivas e irreversíveis); e (b) doenças não degenerativas (potencialmente reversíveis ou evitáveis). Nas doenças degenerativas destaca-se a doença de Alzheimer, que representa mais de 50% dos casos de demência (Hay, 2001; Lobo *et al.*, 2000; Santana, 2005; Stevens *et al.*, 2005) e algumas perturbações neurológicas (como a demência dos corpos de Lewy, doença de Parkinson, doença de Pick e doença de Huntington). Nas não degenerativas, destaca-se (cf. Santana, 2005; Spar & La Rue, 2005; Stevens *et al.*, 2005): a demência vascular, que representa cerca de 20% da etiologia demencial; a depressão; terapêutica farmacológica (e.g., anti-hipertensivos, digitálicos, opiáceos e narcóticos sintéticos); infeções (por exemplo, Síndrome da Imunodeficiência Adquirida e encefalites); perturbações da nutrição (por exemplo, carência de vitamina B12 e de tiamina); tumores cerebrais. Em geral, a lista de fatores suscetíveis de provocar demência aumenta com a idade, à medida que o declínio da reserva funcional do cérebro reduz a capacidade para tolerar desarranjos fisiológicos (Spar & La Rue, 2005).

## *1.2. Sintomatologia: alterações psicológicas e comportamentais*

As alterações psicológicas não cognitivas são frequentemente excluídas da definição de demência. Estes sintomas encontram-se nas formas mais frequentes de demência, como a doença de Alzheimer, e tendem a ser os primeiros a manifestar-se, constituindo um dos principais desafios para a pessoa com a doença e para o(s) seu(s) cuidador(es). Estes sintomas são designados por sintomas psicológicos e comportamentais da demência (SPCD's), também apelidados de sintomas não cognitivos, neuropsiquiátricos ou comportamentos desafiantes. São identificáveis mediante entrevista com o doente ou seus cuidadores, e incluem alucinações, ansiedade, ideias delirantes, depressão e sintomas comportamentais (como agressão verbal ou física, agitação, gritos, insónias, discurso repetitivo e/ou ofensivo e deambulação) (cf. Jentoft, 2002).

Estes sintomas surgem de forma irregular ao longo do curso da demência, por isso, a sua prevalência é variável em função da causa e fase da demência, bem como do ambiente (Jentoft, 2002). Estima-se que pelo menos dois terços das pessoas com demência apresentem estes sinais e sintomas em algum momento da doença, que tendem a agravar-se ao longo do tempo (cf. Lawlor, 2002). Os sintomas comportamentais são uma das principais causas de *stresse* e sobrecarga nos cuidadores familiares e um forte preditor de institucionalização (Brodaty, Draper, & Low, 2003; Dupuis, Epp, & Smale, 2004; Hope, Keene, Gedling, Fairburn, & Jacoby, 1998).

Os critérios em relação à fase da demência ainda não foram completamente validados para demências não causadas pela doença de Alzheimer (APA, 2007), pelo que serão descritos mais à frente quando se abordar, especificamente, essa doença.

## *1.3. Epidemiologia e fatores de risco*

A possibilidade de ter demência pode ser influenciada por diversos de fatores, mais ou menos conhecidos, que podem interagir; no entanto, nenhum fator é, por si, causador de demência.

A *idade* constitui o principal fator de risco independente de demência. A demência não é consequência do envelhecimento ou da idade; no entanto, a sua prevalência aumenta com a idade, afetando 1 em cada 20 pessoas com 65 ou mais anos, e 1 em cada 5 com mais de 80 anos (Knapp & Prince, 2007), duplicando a cada cinco anos, representando 0,8% no grupo etário entre os 65 e os 69 anos e 28,5% daqueles acima dos 90 anos de idade (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010; Lobo *et al.*, 2000).

A *história familiar e os fatores genéticos* têm sido descritos como fatores de risco, particularmente quando a demência ocorre antes dos 60 anos de idade (cf. Figueiredo, 2007); no entanto, o papel dos fatores genéticos em fases mais avançadas (ou seja, a partir dos 60 anos) ainda não é claro. Adicionalmente, a maior parte das pesquisas relacionadas com o risco genético e outros fatores de risco de demência incide na doença de Alzheimer, reflexo da sua significância enquanto causa de demência (McCullagh, Craig, McIlroy, & Passmore, 2001).

O *género* tem sido descrito como fator de risco, ainda que muitos estudos não revelem diferenças significativas entre homens e mulheres em relação à prevalência da doença. Todavia, outros estudos demonstram que as mulheres têm mais probabilidades de contrair a doença de Alzheimer, pois a sua esperança média de vida é superior (cf. Kawas *et al.*, 1997; Mulnard *et al.*, 2000). Na Europa, em 2010, foram diagnosticadas cerca de seis milhões de pessoas com demência, sendo 74,3% do género feminino (Mura, Dartigues, & Berr, 2010).

Alguns estudos indicam que a demência é menos comum em pessoas com níveis educacionais elevados, que não fumam nem consomem quantidades excessivas álcool (cf. Figueiredo, 2007); no entanto, estes estudos têm incidido, fundamentalmente, na doença de Alzheimer, por constituir a causa mais frequente de demência. A maior parte destes fatores continua em investigação.

### *1.4. Tratamento*

Não existe, atualmente, cura para a demência. Os esforços da investigação têm-se centrado em retardar a evolução dos sintomas. Nesse sentido, podem ser considerados dois tipos de tratamento para a pessoa com demência: psicossocial e somático (APA, 2007).

*O tratamento psicossocial* inclui as intervenções não farmacológicas e encontra-se dividido em quatro grupos (cf. APA, 2007): (a) abordagens orientadas para o comportamento (visam reduzir a frequência dos comportamentos disruptivos, direcionando mudanças que alteram os seus antecedentes e consequências); (b) abordagens orientadas para as emoções (e.g., terapia das reminiscências; terapia da validação; psicoterapia de apoio; integração sensorial; terapia da presença simulada); (c) abordagens orientadas para a cognição (e.g., orientação para a realidade; treino de competências); e (d) abordagens orientadas para a estimulação (e.g., atividades recreativas; terapia da arte; exercício; estimulação multissensorial e motora).

*O tratamento somático* inclui as terapias farmacológicas, nomeadamente (cf. APA, 2007): (a) terapêutica para as perdas cognitivas e funcionais (e.g., inibidores da colinesterase; memantina; vitamina E); (b) terapêutica para a psicose e agitação (e.g., antipsicóticos; benzodiazepinas; anticonvulsantes); (c) terapêutica para a depressão e sintomas relacionados (e.g., antidepressivos; terapia electroconvulsiva); e (d) terapêutica para os distúrbios de sono.

## 2. Doença de Alzheimer

A causa mais comum de demência irreversível é a doença de Alzheimer. Estudos recentes indicam que pode ser responsável por até 80% dos casos de demência (Abbott, 2011; Barnes & Yaffe, 2011). A doença de Alzheimer representa, assim, uma importante preocupação de saúde pública e tem sido identificada como prioridade da investigação (Ballard *et al.*, 2011). Atendendo à relevância da doença de Alzheimer no contexto das demências, passamos a uma breve descrição da doença e suas características clínicas.

### *2.1. Diagnóstico*

O aumento da longevidade nos países industrializados tornou a doença de Alzheimer num dos principais problemas de saúde (Figueiredo, 2007). Por extrapolação linear de estimativas referentes a 2006, pensa-se que existam atualmente cerca de 33.9 milhões de pessoas com a doença no mundo, com tendência para triplicar nos próximos 40 anos (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). A doença de Alzheimer é uma doença cerebral irreversível, que ocorre de forma gradual e leva à perda de memória, a mudanças ao nível do comportamento e de personalidade e deterioração do pensamento (cf. Figueiredo, 2007). O diagnóstico da doença de Alzheimer é habitualmente decidido em duas etapas: i) diagnóstico de síndrome demencial (utilizando os critérios do DSM-IV-TR; APA, 2000) (Quadro 2); ii) classificada como possível, provável ou definitiva, pelos critérios do *National Institute of Neurological and Communicative Disorders and Stroke* e a *Alzheimer's Disease and Related Disorders Association* (NINCDS/ADRDA) (Quadro 3). O diagnóstico definitivo baseia-se em evidências histopatológicas; o diagnóstico provável baseia-se no quadro demencial de início insidioso e progressivo, na ausência de outras doenças cerebrais ou sistémicas que possam justificar os défices cognitivos.

**Quadro 2.** Critérios de Diagnóstico da doença de Alzheimer, *Manual de Diagnóstico e Estatística das Perturbações Mentais* (4ª ed) – DSM-IV-TR (adaptado de APA, 2000).

A. Desenvolvimento de múltiplos défices cognitivos manifestados por:
  1. Défice de memória (prejuízo na habilidade de aprender novas informações ou recuperar informações previamente aprendidas) e
  2. Um (ou mais) dos seguintes distúrbios cognitivos:
    a. Afasia (distúrbio de linguagem);
    b. Apraxia (prejuízo na habilidade de executar atividades motoras apesar de função motora intacta);
    c. Agnosia (falha em reconhecer ou identificar objetos apesar de funções sensitivas intactas);
    d. Distúrbio de funções executivas (por exemplo: planeamento, organização, sequenciamento, abstração).
B. Os défices cognitivos nos critérios A1 e A2 causam um prejuízo significativo no funcionamento social ou ocupacional e representam um declínio significativo em relação a nível prévio de funcionamento.
C. O curso é caracterizado por início gradual e declínio cognitivo continuado.
D. Os défices cognitivos nos critérios A1 e A2 não se devem a:

1. Outras patologias do sistema nervoso que causam défices progressivos na memória e cognição (e.g., doença cerebrovascular, doença de Parkinson, doença de Huntington, hematoma subdural, hidrocefalia de pressão normal, tumor cerebral).
2. Condições sistémicas que causam demência (e.g.,. hipotireoidismo, deficiência de vitamina B12 ou ácido fólico, deficiência de niacina, hipercalcemia, neurossífilis, infeção por HIV).
3. Condições induzidas por substâncias.

E. Os défices não ocorrem exclusivamente durante curso de *delirium*.

F. O distúrbio não é melhor explicado por outra doença do eixo I (e.g.,. transtorno depressivo maior, esquizofrenia).

**Especificar subtipo:**

Com início precoce: se início ocorre em idade ≤ 65 anos.
Com início tardio: se início ocorre em idade > 65 anos.

**Quadro 3.** Critérios de diagnóstico da doença de Alzheimer segundo o NINCDS-ADRDA.

**I. O critério para o diagnóstico clínico de doença de Alzheimer provável inclui:**

a. Demência estabelecida por exame clínico e documentada pelo Mini-Exame do Estado Mental, *Blessed Dementia Scale*, ou exame similar, e confirmada por testes neuropsicológicos;
b. Défice em duas ou mais áreas da cognição;
c. Declínio progressivo da memória e outras funções cognitivas;
d. Ausência de distúrbio da consciência;
e. Início entre 40 e 90 anos, mais frequentemente após 65 anos; e
f. Ausência de doenças sistémicas ou outras doenças cerebrais que poderiam ser responsáveis pelos défices progressivos de memória e cognição.

**II. O diagnóstico de doença de Alzheimer provável tem como características de suporte:**

a. Deterioração progressiva de funções cognitivas específicas como linguagem (afasia), habilidades motoras (apraxia), e perceção (agnosia);
b. Prejuízo em atividades de vida diária e padrões alterados de comportamento;
c. História familiar de distúrbios similares, particularmente se houver confirmação neuropatológica; e
d. Resultados laboratoriais de:
i. Líquido cefalorraquidiano normal por técnicas padrão,
ii. Padrão normal ou alterações inespecíficas no eletroencefalograma, tais como aumento da atividade de ondas lentas,
iii. Evidência de atrofia cerebral na tomografia computadorizada (TC) de crânio com progressão documentada por observação seriada.

**III. Outras características clínicas consistentes com o diagnóstico de doença de Alzheimer provável, após exclusão de outras causas de demência, incluem:**

a. "Planaltos" no curso de progressão da doença;
b. Sintomas associados de depressão, insónia, incontinência, delírios, ilusões, alucinações, surtos catastróficos verbais, emocionais ou físicos, distúrbios sexuais, e perda de peso; outras alterações neurológicas em alguns pacientes, especialmente com doença mais avançada e incluindo sinais motores como aumento de tónus muscular, mioclonias, ou distúrbio da marcha;
c. Crises epiléticas em fase avançada da doença;
d. Tomografia computorizada de crânio normal para idade.

**IV. Características que tornam o diagnóstico de doença de Alzheimer incerto ou improvável incluem:**

a. Início súbito, apoplético;
b. Sinais neurológicos focais como hemiparesia, défice sensitivo, défice em campo visual e incoordenação precoce no curso da doença; e
c. Crises epiléticas ou distúrbios da marcha na instalação ou precocemente no curso da doença.

**V. O diagnóstico clínico de doença de Alzheimer possível:**

a. Pode ser feito com base em síndrome demencial, na ausência de outras doenças neurológicas, psiquiátricas ou sistémicas suficientes para causas demência, e na presença de variações no início, na apresentação ou no curso clínico;
b. Pode ser feito na presença de uma segunda doença cerebral ou sistémica suficiente para produzir demência, que não é considerada causa da demência; e
c. Deve ser utilizado em pesquisa clínica quando défice cognitivo único, grave e gradualmente progressivo é identificado na ausência de outra causa identificável.

**VI. Os critérios para diagnóstico de doença de Alzheimer definitiva são:**
a. Critério clínico para doença de Alzheimer provável e
b. Evidência histopatológica obtida por biópsia ou autópsia.

**VII. A classificação de doença de Alzheimer para fins de pesquisa científica deve especificar características que podem diferenciar subtipos da doença, tais como:**
a. Ocorrência familial;
b. Início antes dos 65 anos;
c. Presença de trissomia 21; e
d. Coexistência de outras condições relevantes como doença de Parkinson.

Em 2007, face às descobertas da fisiopatologia da doença de Alzheimer e de novos métodos diagnósticos, foram propostos novos critérios diagnósticos para a doença de Alzheimer (Dubois *et al.*, 2007). Os novos critérios (Quadro 4) limitaram-se ao diagnóstico de doença de Alzheimer provável e têm como objetivo um diagnóstico mais precoce e fino da doença; o diagnóstico passa a considerar biomarcadores (substâncias utilizadas como indicadores de um estado biológico). O critério central passa a ser a presença de um declínio precoce e significativo da memória episódica durante, pelo menos, seis meses, com evidência objetiva de distúrbio de memória episódica que não melhora com sugestões/orientações ou testes de reconhecimento. O défice de memória pode estar associado a outros défices cognitivos. Essa definição exclui outras apresentações conhecidas, porém menos frequentes da doença de Alzheimer, como a atrofia cortical posterior ou a variante comportamental da doença de Alzheimer (Alladi *et al.*, 2007).

**Quadro 4**. Critérios de diagnóstico da doença de Alzheimer provável revistos (Dubois *et al.*, 2007)

**Doença de Alzheimer provável: critério A e uma ou mais características de suporte (B, C, D ou E)**
**Critério diagnóstico central**
A. Presença de prejuízo significativo e precoce da memória episódica e que inclui as seguintes características:
• Mudança gradual e progressiva na função de memória relatada por pacientes ou informantes por período maior que 6 meses.
• Evidência objetiva de prejuízo significativo de memória episódica à testagem: geralmente consiste em défice em recordação que não melhora significativamente ou não normaliza com dicas ou testes de reconhecimento e após controlo de codificação efetiva da informação.
• O prejuízo da memória episódica pode ser isolado ou associado a outras mudanças cognitivas no início da doença de Alzheimer, ou à medida que a doença avança.

**Características de suporte**
B. Presença de atrofia do lobo temporal medial
• Perda de volume nos hipocampos, córtex entorrinal, amígdala evidenciado na ressonância nuclear magnética (RNM) com avaliação qualitativa (em relação a população bem caracterizada, com regras por idade) ou volumetria quantitativa de regiões de interesse (em relação a população bem caracterizada, com regras por idade).
C. Biomarcadores de líquido cefalorraquidiano anormais.
• Concentração baixa de amiloide ß1-42, aumento na concentração de tau, ou aumento na concentração de fosfotau, ou combinação das três.
• Outros marcadores bem validados a serem descobertos no futuro.
D. Padrão específico em neuroimagem funcional com PET
• Redução do metabolismo de glicose em região temporoparietal bilateral.
• Outros ligantes bem estabelecidos, incluindo aqueles que emergirão, como o *Pittsburg compound B* ou FDDNP.
E. Mutação comprovada de DA autossómica dominante na família imediata

**Critérios de exclusão**
A. História
- Início súbito.
- Ocorrência precoce dos seguintes sintomas: distúrbios da marcha, crises epiléticas, alterações comportamentais.

B. Características clínicas
- Sinais neurológicos focais incluindo hemiparesia, perda sensitiva, defeitos de campo visual.
- Sinais extrapiramidais precoces.

C. Outras condições médicas graves responsáveis pela memória e sinais relacionados
- Demência não-doença de Alzheimer.
- Depressão *major*.
- Doença cerebrovascular.
- Alterações tóxicas e metabólicas, que podem requerer investigação específica.
- Anormalidades no lobo temporal medial na RNM (T2 ou FLAIR) que são consistentes com insultos infeciosos ou vasculares.

**Critério para doença de Alzheimer definitiva**
D. A doença de Alzheimer é considerada definitiva quando os itens seguintes estão presentes:
- Evidência clínica e histopatológica (autópsia ou biópsia cerebral) da doença, conforme requerido pelo critério NIA-Reagan no diagnóstico pós-morte da doença de Alzheimer; os dois critérios devem estar presentes.
- Evidência clínica e genética (mutação no cromossomo 1, 14 ou 21) da doença de Alzheimer; os dois critérios devem estar presentes.

### *2.2. Fases e sintomatologia*

Cada pessoa viverá o progresso da doença de Alzheimer de forma distinta. A fase inicial da doença é muitas vezes interpretada incorretamente pelos profissionais e amigos, pois tende a ser associada ao processo normal de envelhecimento. Como o início da doença é gradual torna-se difícil identificar o momento exato.

Em geral, a Escala de Deterioração Global (*Global Deterioration Scale*, GDS) (Reisberg, Ferris, de Leon, & Crook, 1982) tem sido útil para distinguir as diferentes fases da doença de Alzheimer. Esta escala caracteriza a severidade da doença ao longo de sete fases (cf. APA, 2007): 1ª - “sem declínio cognitivo”, caracteriza-se pela inexistência de queixas subjetivas em relação a défices de memória; 2ª - “declínio cognitivo ligeiro”, encontra-se associada ao processo normal de envelhecimento e caracteriza-se por algumas queixas de défices de memória (e.g., a pessoa começa a esquecer-se do sítio onde guarda os objetos e do nomes das pessoas que conhece e com quem está regularmente); 3ª - “declínio cognitivo leve”, os défices tornam-se mais claros e a pessoa começa a demonstrar desorientação espácio-temporal; o seu desempenho diminui e acentua-se a dificuldade para recordar o nome das pessoas; surgem défices de concentração, normalmente acompanhados por ansiedade; 4ª - “declínio cognitivo moderado”, os défices estendem-se à história pessoal, com dificuldade em recordar o passado; os défices de concentração agravam-se e a capacidade para viajar, lidar com as finanças e realizar tarefas complexas diminui; 5ª - “declínio cognitivo moderadamente grave”, a pessoa necessita de apoio para sobreviver; agrava-se a desorientação espácio-temporal e a incapacidade para recordar acontecimentos recentes; 6ª - “declínio cognitivo grave”, caracteriza-se pela necessidade de assistência considerável ou total nos cuidados pessoais (inclui vestir/despir, tomar banho); 7ª - “declínio cognitivo muito grave”, trata-se da fase terminal, as pessoas ficam acamadas, requerendo cuidado constante.

### *2.3. Fatores etiológicos*

As causas da doença de Alzheimer não são ainda conhecidas com rigor. Seria mais correto falar de um contexto de eclosão das demências, do que de etiologia. Várias causas foram colocadas em evidência pela investigação; contudo, com exceção da tese genética, nenhuma é verdadeiramente explicativa, dado que os sistemas etiológicos identificados não desencadeiam demência sistematicamente (Phaneuf, 2010). Diversos fatores podem ser responsáveis pela doença de Alzheimer.

A *idade* constitui o principal fator e o mais facilmente identificável (cf. Figueiredo, 2007; Phaneuf, 2010). As estatísticas mostram que o seu desenvolvimento aumenta com o acumular dos anos. O início tende a ocorrer após os 65 anos de idade, embora possa manifestar-se em idades anteriores (não é considerada uma consequência do envelhecimento, mas a sua incidência aumenta com a idade).

O *risco genético* da doença de Alzheimer é estimado em cerca de 70% (e.g., história familiar da doença e um gene do cromossoma 19 responsável pela produção de um tipo de proteína associada à doença, a apolipoprotéina E4) (cf. Ballard *et al.*, 2011). O estudo dos antecedentes familiares tem assumido um papel significativo na investigação e tem demonstrado que as pessoas em que um parente (pai ou mãe, irmã ou irmão) teve a doença de Alzheimer estão mais expostas à doença, do que aquelas cujos familiares estão isentos. Isto é particularmente evidente na doença precoce, representando 5 a 10% dos casos diagnosticados (cf. Phaneuf, 2010).

O *nível de escolaridade* também tem sido descrito como fator de risco. Os investigadores têm observado que uma escolaridade inferior a sete anos é fator predisponente da doença de Alzheimer (cf. Phaneuf, 2010). Um nível de instrução elevado aumentaria a rede sináptica e teria efeito protetor. Trata-se, possivelmente, de um efeito de reserva em que a atividade cerebral ligada à leitura, escrita, resolução de problemas e exercícios de memorização permitiria criar múltiplas ligações interneuronais. Um nível menos elevado de instrução também pode estar associado a um período ou a acontecimentos passados que não foram favoráveis ao desenvolvimento cerebral (cf. Phaneuf, 2010).

O *género* tem sido considerado um fator predisponente à doença; contudo, estudos estatísticos mais profundos permitiram estabelecer melhor as *nuances* desta afirmação. Sugere-se que, abaixo dos 80 anos, o número de mulheres afetadas será inferior ao dos homens, mas após esta idade o número tornar-se-á mais significativo (cf. Phaneuf, 2010). Deve considerar-se a longevidade acrescida das mulheres; nos países em que a longevidade feminina e masculina é similar, a diferença de incidência é menos marcada (Dartigues, Berr, Helmer, & Letenneur, 2002).

O *ambiente* constitui outro fator de risco. Segundo um estudo do *Centre de Recherche pour le Développement International* (Centro de Investigação para o Desenvolvimento Internacional, CRDI), os trabalhadores expostos a inseticidas, colas ou fertilizantes têm risco mais elevado de desenvolver a doença de Alzheimer (cf. Phaneuf, 2010). Alguns estudos indicam ainda o alumínio como possível fator etiológico, mas o seu papel tem sido alvo de controvérsia (cf. Kawahara & Kato-Negishi, 2011; Zatta, Lucchini, van Rensburg, & Taylor, 2003).

Alguns *problemas de saúde* criam condições favoráveis à eclosão da doença de Alzheimer. A diabetes, hipertensão, hipercolesterémia, perturbações cardíacas, Acidentes Vasculares Cerebrais (AVC's) e traumatismos cranioencefálicos constituem fatores predisponentes (cf. Ballard *et al.*, 2011; Barnes & Yaffe, 2011). Contudo, a evidência em relação a uma gestão adequada da diabetes ou prevenção do AVC no risco da doença ainda é limitada, sendo necessárias mais pesquisas (cf. Ballard *et al.*, 2011).

### *2.4. Tratamento*

Não existe, atualmente, cura para a doença de Alzheimer. O tratamento visa, essencialmente, retardar a evolução dos sintomas e envolve dois aspetos (cf. Spar & La Rue, 2005; APA, 2007): um inespecífico, a partir de alterações comportamentais como a agitação e a agressividade, alteração do humor como depressão, que deve incluir medicação e tratamentos não farmacológicos; e um específico, efetuado com fármacos que podem corrigir o desequilíbrio químico na atividade cerebral, como os precursores da acetilcolina e os inibidores da acetil-colinesterase.

No entanto, a doença de Alzheimer é uma patologia complexa que reúne vários agentes determinantes. Conhecer os principais fatores de risco pode ajudar a preveni-la. É possível agir sobre alguns desses fatores de risco, seja pela prevenção ou pelo tratamento. É o caso das *doenças crónicas*, como (cf. Ballard *et al.*, 2011; Phaneuf, 2010): (a) diabetes, face ao papel da resistência celular à insulina, que causa uma sobrecarga desta hormona, aumentando o risco de *stresse* oxidativo e de inflamação; (b) hipertensão, face aos danos nos vasos sanguíneos perante o aumento da tensão sanguínea e consequente influência no circuito nervoso celular; e (c) doenças cardíacas, por se acompanharem, geralmente, de elevação do nível de colesterol. O colesterol tem sido reconhecido como tendo uma influência na doença de Alzheimer; a investigação indica que os medicamentos que concorrem para diminuir o nível de colesterol poderão ter efeito positivo na doença de Alzheimer. Na doença cardíaca, a taxa de homocisteína, um aminoácido reconhecido por atacar os neurónios e perturbar o seu funcionamento, encontra-se elevada. Estas doenças devem ser prevenidas e tratadas.

Revisões sistemáticas e meta-análises fornecem evidências de outros fatores de risco modificáveis: sedentarismo, obesidade na meia-idade, ingestão excessiva de álcool e consumo de tabaco (cf. Ballard *et al.*, 2011; McCullagh *et al.*, 2001). Não existe evidência suficiente para a associação entre dieta, suplementos de antioxidantes ou vitamina B e redução da incidência da doença de Alzheimer; no entanto, estes estudos necessitam de ser examinados de forma sistemática em coortes epidemiológicos mais alargados (cf. Ballard *et al.*, 2011).

## II. Desafios da Doença Crónica no Contexto Familiar – Modelo Normativo Sistémico

As alterações decorrentes de uma doença crónica, como as condições demenciais, têm repercussões a nível físico, psíquico e social e, consequentemente diminuem a qualidade de vida da pessoa que tem a doença, afetando a sua independência e autonomia e levando a que necessite de apoio nas tarefas do quotidiano. Nesse sentido, as intervenções começaram a ser direcionadas à pessoa com doença, já que os impactos da doença começam por ser vistos no doente. Contudo, a doença tem impacto na família e em cada um dos seus membros.

Qualquer doença afeta cada membro da família (não só a pessoa com a doença) e a família como unidade, colocando dificuldades à vida familiar que podem rivalizar em importância e consequências negativas com a condição física da pessoa com doença (cf. Duhamel, 1995; Rolland, 1990). O conceito de família de Sampaio e Gameiro (1992: 9) permite entender melhor esta ideia, definindo-a como " (…) *um sistema, um conjunto de elementos ligados por um conjunto de relações, em contínua relação com o exterior, que mantém o seu equilíbrio ao longo de um processo de desenvolvimento percorrido através de estádios de evolução diversificados*". A família com pessoas que têm uma doença crónica tem sido analisada sob quatro perspectivas (cf. Rolland, 1994; Sousa, 2004; Steinglass & Horan, 1988): recurso, défice, influência e impacto.

A perspetiva mais tradicional olha a família como recurso da pessoa com doença, sendo a fonte primária de apoio social, desempenhando um papel profilático e protetor ao fornecer resistência à doença. Determinados atributos familiares, como a empatia e os recursos de *coping*, associam-se a melhorias da condição médica e aceitação do tratamento. A tradição cultural portuguesa atribui às famílias, particularmente aos membros do género feminino, a responsabilidade de cuidar dos mais idosos (e também dos mais novos e daqueles com necessidades especiais) e com laços mais próximos. Cuidar de parentes idosos emerge como uma extensão dos papéis da família, o que aliado a alguma hostilidade para com as instituições pressiona a família a manter esse papel (Sousa, Figueiredo, & Cerqueira, 2006).

A perspetiva deficitária vê na família um potencial contributo ativo (etiológico) do desenvolvimento da doença, por debilitar os seus membros mediante padrões disfuncionais, rígidos e stressantes, que representam fatores de suscetibilidade à doença. Enquanto estas perspetivas se centram em fatores familiares que aumentam ou diminuem o desenvolvimento da doença, a perspetiva da influência analisa a relação entre o comportamento familiar e as características evolutivas da doença e a forma como essa interação mútua pode ter uma influência positiva ou negativa no curso da doença crónica.

A abordagem mais recente enfatiza o impacto da doença crónica na família, nos níveis emocional, prático e financeiro, ao invés dos fatores familiares que afetam o início e o curso de um problema de saúde. O impacto de uma doença crónica é mais ou menos intenso mediante a sensação de controlo que a família demonstra em relação às exigências doença, que muitas vezes é contraposto pela perceção de impotência. Perante o diagnóstico de uma doença crónica, os papéis familiares são reavaliados, readquiridos e legitimados, implicando a reestruturação de responsabilidades e funções na família (cf. Figueiredo, 2007). Góngora (1996) identifica diversos níveis de impacto de um membro com doença crónica numa família: estruturais; emocionais; e processuais.

O impacto *estrutural* centra-se no isolamento social da família e na potencial rigidez da interação familiar, principalmente entre família e pessoa com doença, mas também entre os serviços assistenciais e a família (Góngora, 1996). Frequentemente, nas famílias com pessoas com uma doença crónica, os padrões de interação tornam-se rígidos, pois a família pode apresentar dificuldade em alterar a sua organização face às exigências da doença. Por exemplo, é comum que a família tenda a substituir a pessoa doente em várias tarefas, mesmo naquelas que ainda pode fazer de forma independente. Assim, instala-se um padrão de proteção familiar que aumenta a incapacidade da pessoa doente e diminui a sua autonomia, elevando a sobrecarga dos familiares e levando à diminuição da possibilidade de normalizar a vida quotidiana. Adicionalmente, perante uma doença crónica num elemento da família, há tendência para o isolamento. Isto ocorre, principalmente, porque as famílias sentem que os outros as tratam de forma diferente quando sabem que um dos seus membros sofre de uma doença crónica grave. O isolamento decorre, igualmente, de a família ter um número elevado de tarefas para desempenhar e, por isso, menos tempo para socializar. A isto acrescem algumas experiências emocionais decorrentes da doença crónica: sentir que para a rede informal é um *peso* relacionar-se com alguém em tal sofrimento; desmotivação por se prestar cuidados à pessoa doente e não se observar melhorias. Há casos em que a incapacidade da pessoa com doença é sentida como um estigma, conduzindo a algum tipo de exclusão social.

Os impactos a *nível emocional* centram-se na resposta emocional da família e, sobretudo, do cuidador principal, designada por complexo emocional (Góngora, 1996). Consiste num conjunto de sentimentos misturados, de natureza diversa, em que uns podem ser respostas a outros, sendo típicos os sentimentos de contrariedade, ressentimento, impotência e depressão como resposta à impossibilidade de resolver a doença. Outros sentimentos incluem: injustiça, medo, desejo de morte da pessoa com doença, ansiedade e culpa face a estes desejos e angústia. Frequentemente, a família acredita que a expressão dos seus sentimentos é incompatível com a situação clínica da pessoa doente e com a estabilidade da família (McDaniel, Hepworth & Doherty, 1992).

Os *impactos processuais* relacionam-se com a coimplicação da evolução da doença crónica, o desenvolvimento da pessoa doente e dos outros membros da família e o ciclo de vida familiar (Góngora, 1996). A família, ao deparar-se com um elemento com uma doença crónica severa, envolve-se no processo de gestão da doença e as restantes tarefas são relegadas para segundo plano (Góngora, 1996). Ou seja, os processos de evolução (da doença) coexistem com as tarefas psicossociais do desenvolvimento individual e familiar. É importante compatibilizar a gestão da doença com os processos evolutivos individuais e familiares.

Assim, as famílias têm necessidades de procedimentos preventivos e psicoeducativos que as ajudem a antecipar as tarefas normativas dos diferentes estádios da doença permitindo-lhes maior domínio na compatibilização da atenção às exigências da doença e às suas vidas. Perante uma doença crónica, as famílias necessitam (cf. Rolland, 1990, 1993): a) compreender a doença, sua evolução e padrão evolutivo expectável dos tratamentos, para especificar as tarefas associadas às diferentes fases da doença; b) conhecer as implicações entre estádios evolutivos das pessoas doentes, da doença e da família, para responder e compatibilizar diferentes necessidades; c) entender as crenças que guiam o sistema de cuidados, incluindo os princípios que definem papéis, regras de comunicação, definições de êxito e de controlo e o *encaixe* com os profissionais de saúde. A compreensão destas áreas permite uma visão geral da doença e da família como um sistema funcional composto pela família e pela saúde-doença que evoluem paralelamente. Neste contexto, e tendo como base as premissas do modelo biopsicossocial de Engel (1977), que defende ser fundamental considerar os aspetos sociais e psicológicos da pessoa para melhor compreensão do processo de doença, emergiu o *Modelo Normativo Sistémico da Doença Crónica*, de Rolland (1990, 1993). Este modelo baseia-se na interação sistémica evolutiva entre a doença crónica e a família e entende que um bom *encaixe* entre as exigências psicossociais da doença crónica e a forma de funcionamento familiar é determinante para o êxito ou fracasso da adaptação da família à doença. Este modelo combina três dimensões (Rolland, 1987, 1990, 1993): tipologia psicossocial da doença; principais fases da história natural; variáveis chave do sistema familiar.

A *tipologia psicossocial da doença* visa a definição das categorias significativas e úteis de exigências psicossociais similares para um conjunto de doenças que afetam os indivíduos ao longo do ciclo vital, permitindo vincular os mundos biológicos e psicossociais, e clarificando as relações entre doença crónica e família. O padrão da doença pode variar com o começo, curso, resultado e nível de incapacitação. O *começo* pode ser agudo (a doença ocorre subitamente, por exemplo um AVC, exigindo mudanças afetivas e práticas num curto espaço de tempo) ou gradual (a doença vai progredindo ao longo do tempo, como a doença de Alzheimer). O *curso* pode ser progressivo (a incapacidade vai aumentando, exigindo adaptação contínua e flexibilidade na reorganização interna e utilização de recursos externos), constante (após um período de recuperação inicial, segue um curso estável) ou em recaídas/episódica (a tensão é motivada pela frequente transição entre períodos de estabilidade e crise e pela incessante incerteza em relação ao próximo momento crítico). O *resultado* pode ser a morte (o fator crucial é se a expectativa inicial é a morte), ser progressivo e fatal ou encurtar a vida. A incapacitação pode ser reduzida, média, moderada ou severa, ocorrer em várias áreas (cognitiva, sensorial, motor, estético) ou resultar na combinação desses componentes. O efeito do grau de incapacidade numa pessoa e/ou na sua família depende da interação entre o tipo de incapacidade, com as exigências anteriores à doença e com a estrutura e flexibilidade familiar (Rolland, 1988).

As condições demenciais são doenças crónicas com início gradual, curso progressivo, fatal e incapacitante (GPF$^+$). O início gradual implica um ajustamento prolongado no tempo, muitas vezes vivido na dúvida (é ou não demência!); ou mesmo se a pessoa estará mesmo doente ou apenas a fazer "chantagem" ou a fingir. Aliás esta situação é relatada com frequência pelos familiares e é acentuada pelas dificuldades de um diagnóstico rigoroso na fase inicial. Além disso, o estigma social associado às demências pode desencadear mecanismos de defesa (negação) na família que impedem a mobilização dos recursos. Esta doença tem um curso progressivo, que no contexto da demência é acentuado pela perda ambígua (Boss, 2009), ou seja, o familiar doente está fisicamente presente, mas psicológica ou emocionalmente ausente (não é o mesmo). Esta ambiguidade gera sentimentos disfuncionais e stressantes, que impossibilitam a reorganização e o enfrentamento familiar diante dessa perda, pois as fronteiras permanecem obscurecidas (Boss, 1988). A ambiguidade vivida pelos familiares é permeada de sentimentos conflituosos, como temer a morte do familiar doente e desejar o fim da situação (Boss, 2009). As demências tendem a encurtar a vida e são incapacitantes, assim as famílias têm de se preparar para prestar cuidados cada vez mais alargados e preparar a morte do seu familiar.

Considerar as *fases da história natural da doença* permite pensar longitudinalmente e entender a doença crónica como um processo evolutivo com marcos normativos, transições e exigência de mudanças. Cada fase de uma doença crónica exige da família diferenças em termos de atitude e mudança. Rolland (1987) conceptualizou três fases da doença: crise (fase inicial), crónica (fase de adaptação) e terminal (fase da perda). Cada fase possui tarefas psicossociais específicas e a transição de fases constitui um momento crítico, à semelhança dos períodos de transição do ciclo de vida familiar. O impacto da doença na família vai depender da fase de desenvolvimento em que a família se encontra quando recebe o diagnóstico da doença, da forma como a dinâmica familiar é afetada e do significado que é atribuído à doença em termos de identidade familiar (Pereira, 2001). Uma boa adaptação da família supõe o cumprimento das tarefas de cada fase da doença.

A *fase de crise* (pré e pós-diagnóstico) exige que a família aprenda a conviver com a dor, a incapacidade e/ou outros sintomas associados à doença e, paralelamente, aprenda a conviver e a lidar com o meio hospitalar e com a equipa médica. Além disso, é relevante que consiga dar um significado à doença que lhes permita uma sensação de competência. A *fase crónica* é caracterizada pela adaptação à doença; nesta fase, as tarefas consistem em: compatibilizar o cuidado à pessoa com doença com a manutenção de uma forma de funcionamento, ou seja, "manter a doença no seu lugar" ("*putting the illness in its place*") (Gonzalez, Steinglass, & Reiss, 1989); prevenir e lidar com os momentos agudos da doença; maximizar o apoio social e reduzir o isolamento; preservar o autoconceito familiar e pessoal; redefinir as relações com os outros; exprimir sentimentos e medos; encontrar sentido para a dor, cronicidade e imprevisibilidade do futuro. A *fase terminal* caracteriza-se por: adaptação aos procedimentos médicos; revisão das estratégias de *coping*; aumento das exigências afetivas; separação da pessoa que irá falecer; luto, preparação da morte e despedida; e necessidade de encontrar sentido para a vida e morte, regressando à vida normal.

Existem diversos momentos de transição que unem as três fases: são momentos em que as famílias reavaliam a adequação da sua estrutura de vida face às novas exigências da doença e tratam de assuntos inacabados das fases anteriores (que podem complicar ou bloquear o movimento de transição, ficando as famílias *presas* a uma estrutura adaptativa que deixou de funcionar) (Penn, 1983). A adequação das respostas de *coping* de uma família nas diferentes fases de adaptação à doença é de extrema importância (Gonzalez *et al*., 1989). Em geral, os tipos de intervenção organizam-se de acordo com a fase da doença. Na fase de crise, os objetivos são resolver as necessidades identificadas pela família, clarificar informação, normalizar os sentimentos e reações e ajudar a família a manter a esperança. Na fase crónica, as estratégias de intervenção consistem em negociar as mudanças e os períodos de "alívio" dos cuidadores familiares, ampliar a rede social da família, por exemplo ligando-a a grupos de autoajuda. Na fase terminal, os objetivos consistem em antecipar os efeitos da morte da pessoa doente, recapitular a sua vida de forma positiva, promover a manutenção do contacto emocional e físico entre a família e a pessoa doente e facilitar a expressão de sentimentos.

As *variáveis chave do sistema familiar* incluem: a história transgeracional de doenças, perdas e crises; a relação entre os ciclos vitais da doença, dos indivíduos e da família; e os sistemas de crenças relacionados com a saúde e doença.

O comportamento atual da família, incluindo a resposta à doença, não se pode compreender sem o recurso à sua história: *história transgeracional de doenças, perdas e crises* (Rolland, 1987). Essa história ajuda a explicar e predizer o comportamento habitual e a adaptação da família a uma situação de crise, permitindo identificar áreas de resiliência e vulnerabilidade. O conhecimento da história da família permite reconhecer padrões de enfrentamento repetitivos, descontinuidades, alterações nas relações (por exemplo, alianças, triângulos ou ruturas) e competências (McGoldrick & Walsh, 1983).

*A relação entre os ciclos vitais da doença, da família e dos seus membros* relaciona três evoluções: doença, família e cada membro (incluindo a pessoa doente). A tipologia psicossocial e as fases da doença facilitam este objetivo ao descrever os padrões psicossociais da doença em termos longitudinais. O ciclo vital é um conceito central, indicando uma sequência do curso da vida no qual acontece a unicidade do indivíduo, família e doença. Os conceitos de estilos familiares centrípetos e centrífugos são úteis para se compreender o desenvolvimento da doença, indivíduos e famílias (Beavers, 1982; Beavers & Voeller, 1983). Rolland adota o modelo de Combrick-Graham (1985) que descreve um modelo de ciclo vital familiar em espiral, contemplando um sistema familiar de três gerações que oscila no tempo entre períodos de elevada coesão familiar (centrípetos) e de baixa coesão (centrífugos). Os períodos centrípetos e centrífugos implicam um encaixe entre tarefas de desenvolvimento familiar e a necessidade dos membros da família canalizarem as suas energias para dentro ou fora da família. Nos centrípetos, a família concentra-se no seu interior; nos momentos centrífugos é enfatizada a relação com o exterior, a estrutura muda para se acomodar às metas que permitem a vida fora da família. Na generalidade, as condições crónicas graves, como a demência, implicam movimentos centrípetos no sistema familiar, semelhantes à chegada de um novo membro. Esta orientação provoca ansiedades normativas diferentes dependendo dos estados de desenvolvimento da família e dos indivíduos.

O *sistema de crenças relacionados com a saúde e a doença* indica que cada pessoa, individualmente e como parte de uma família e de outros sistemas, desenvolve um sistema de crenças, que podem influenciar os comportamentos relativamente aos desafios da vida (Kluckhohn, 1958). Alguns mitos e crenças são utilizados para preencher lacunas ou falhas de informação, desencadeando mal-entendidos (Imber-Black, 1987). Esses defeitos comunicacionais ocorrem porque as formas particulares das famílias processarem informação são ignoradas e os modos de funcionamento do sistema de saúde raramente são explicados. Os mitos e crenças mútuos desenrolam-se, por norma, a partir de incidentes críticos (acontecimentos marcantes) que geram comportamentos de interação repetitivos e estereotipados, que suportam essa ideia. Um padrão comum que conduz ao recurso a mitos e crenças é a pouca informação fornecida pela equipa de saúde à família sobre o diagnóstico, prognóstico e tratamento. Esta lacuna é preenchida pela família usando o seu sistema de crenças como guia cognitivo de decisões e ações. Por exemplo, as pessoas com doença e suas famílias podem construir explicações, produto da combinação da informação médica e mitologia familiar, sobre a causa da doença, o que irá influenciar o seu curso e resultado. Alguns dos mitos incluem: punição por erros prévios, culpa de um outro membro, sentido de injustiça, genética, acaso/azar. As crenças dão sentido e orientação à vida familiar facilitando a continuidade entre passado, presente e futuro. O conjunto de crenças sobre a saúde e a doença que a família desenvolveu influenciam a forma como a doença é gerida, bem como a procura de saúde, por exemplo adotando estilos de vida saudáveis (Rolland, 1987).

## III. Doença Crónica: Intervenções

### 1. Do Modelo Biomédico ao Modelo Biopsicossocial

A última década tem sido caracterizada por uma consciencialização crescente da importância dos cuidados centrados na pessoa e numa abordagem holística aos cuidados na demência (Cheston & Bender, 1999; Woods, 2001). A tradicional conceptualização biomédica da doença em geral e da demência (“dano” neurológico), em particular, levou ao desenvolvimento de terapias farmacológicas para aliviar sintomas e intervenções de reabilitação cognitiva para maximizar as capacidades cognitivas. Contudo, reconhece-se que a manifestação clínica da demência não se explica exclusivamente por défices neurológicos, pois os fatores psicossociais também influenciam as condições demenciais. Por exemplo, a não satisfação das necessidades emocionais e os contextos sociais desfavoráveis têm sido identificados como fatores que contribuem para os transtornos de humor e problemas comportamentais na demência (Kitwood, 1990; Woods, 2001). Além disso, este modelo negligencia as pessoas significativas que rodeiam e cuidam da pessoa com demência, olhando apenas o seu papel enquanto recurso e negligenciando os impactos.

O modelo biomédico decorre da visão cartesiana do mundo, em que o funcionamento das pessoas é comparado a uma máquina e em que a compreensão do universo passa pelo conhecimento detalhado de cada parte. Assim, o corpo humano obedeceria a essas leis, ficando reduzido ao aspeto biológico (Reis, 1998, 1999; Ribeiro, 1998). Neste modelo, a doença é comparável a um defeito mecânico (avaria temporal ou permanente da máquina) localizado numa componente física e/ou bioquímica. Este defeito pode ser reparado através de meios físicos (cirurgia) ou químicos (farmacologia). A parte do corpo doente pode ser tratada isoladamente e o processo de cura associa-se à reparação da máquina (Reis, 1998, 1999). Nesta perspetiva, a saúde corresponde à ausência de doença (Reis, 1998) e as pessoas com doença são consideradas vítimas passivas de agentes externos que provocam a doença, sendo o profissional de saúde responsável pelo tratamento. O papel da pessoa doente consiste na *obediência* aos profissionais de saúde para alcançar a sua cura.

Os pressupostos do modelo biomédico são (cf. Bilton *et al.*, 2002): (a) a doença é uma condição orgânica, logo os fatores não orgânicos não são importantes e tendem a ser ignorados; (b) a doença é um estado orgânico temporário que pode ser erradicado (curado) através da intervenção médica; (c) a doença é vivida por uma pessoa doente que se torna objeto de tratamento; (d) a doença é tratada após a manifestação dos sintomas (a aplicação da medicina consiste num processo de cura reativo); (e) a doença deve ser tratada num ambiente médico (e.g., cirurgia ou um hospital), longe do contexto onde os sintomas surgiram. Esta visão redutora e mecanicista tem sido incorporada em intervenções desenvolvidas junto de pessoas com demência e seus familiares (particularmente do cuidador principal), o que tem vindo a ser criticado. Engel (1977) foi um dos autores que criticou os pressupostos do modelo biomédico, propondo o “modelo biopsicossocial”, como foi referido anteriormente. Este modelo é caracterizado pelos pressupostos que se seguem (cf. Engel, 1977): (a) a saúde e a doença são estados determinados por fatores biológicos, psicológicos e sociais; (b) a importância relativa destes fatores pode variar com a doença e o doente, mas a contribuição dos fatores biológicos, psicológicos e sociais deve ser considerada para avaliar aspetos como a etiologia, diagnóstico, prognóstico e prevenção; (c) os cuidados de saúde adequados requerem o tratamento, não apenas da doença, mas da pessoa que tem a doença. Ao considerar aquelas três dimensões, este modelo afasta a definição de saúde como sinónimo de ausência de doença e permite abandonar o reducionismo biológico. O modelo biopsicossocial é multifatorial, contemplando a interação entre aspetos biológicos, sociais, cognitivos, emocionais e motivacionais; inclui ainda o ambiente sociocultural com as regras e crenças sobre o que é ser saudável ou doente.

O modelo biomédico coloca ainda o profissional como o *expert* que toma as decisões pela pessoa doente. A pessoa doente é uma figura passiva no tratamento, esperando-se a sua cooperação na adesão e cumprimento (Wade & Halligan, 2004). A saúde tem sido uma atividade intimamente associada ao exercício do poder profissional (Stacey, 1988), pois o controlo da saúde e da doença é colocado nos profissionais de saúde. Já no modelo biospsicossocial (cf. Engel, 1977) existe um equilíbrio de poder entre o profissional de saúde e a pessoa com doença (conhecimento partilhado), permitindo maximizar o funcionamento e competências de *coping* da pessoa com doença e sua família.

Outra crítica que tem vindo a ser apontada ao modelo biomédico reside na sua perspetiva deficitária, já que foca a doença (modelo patologizante) (Wade & Halligan, 2004). Ou seja, não dá atenção às componentes salutogénicas que promovem a saúde e competências das pessoas. A World Health Organization (WHO) afirmava que era necessário desenvolver uma abordagem da doença mental mais positiva: "*In today's society no one can avoid confronting stressful situations and setbacks, and the way in which people react to such stress is a decisive factor for their mental health. A more positive approach to mental health should therefore be developed.*" (1997: 67). Essa abordagem tinha suscitado a atenção de Antonovsky (1987) quando se interessou pelos fatores de saúde e não pelas causas da doença. Neste contexto emergiu o modelo salutogénico, centrado e orientado para as condições e fatores que favorecem a saúde. Os recursos salutogénicos promovem a autoestima e a capacidade de *coping*, eventualmente fomentando menor dependência dos serviços e profissionais (Morgan & Ziglio, 2010). Esta orientação como fundamento da promoção da saúde dirige os esforços de investigação e ação a todas as pessoas, para potenciar os fatores salutogénicos. A finalidade é o desenvolvimento dos indivíduos, aumentando os fatores protetores (recursos de resistência), facilitando recursos e permitindo que se envolvam na resolução dos problemas. Assim, responsabilizam-se pela sua saúde, das suas famílias e comunidade. Antonovsky utilizava a metáfora do *rio* para descrever a salutogénese e comparar o pensamento e ação predominantes na área clínica com a perspetiva salutogénica. O *rio* simboliza a vida e a pessoa encontra-se sempre a nadar num rio mais ou menos perigoso. A orientação patogénica do modelo biomédico procura retirar as pessoas do rio perigoso, enquanto a salutogénica aposta na capacidade das pessoas como nadadores (defesa contra a perigosidade do rio). Ou seja, é essencial que as pessoas criem recursos e competências para se poderem debater com os agentes de perturbação. As intervenções devem considerar os fatores salutogénicos no confronto com a doença.

Por outro lado, o modelo biomédico tende a isolar a pessoa do seu contexto (perspetiva individualista) familiar, social e cultural. Trata-se de um modelo reducionista (cf. Wade & Halligan, 2004), pois reduz a explicação da patologia ao elemento mais básico: a biologia. Em consequência, fomenta uma visão fragmentada da pessoa (um corpo, com defeito em alguma parte), impedindo perspetivá-la como um complexo sistema dinâmico de componentes físicas, intelectuais, sociais, espirituais e emocionais (Fleisher *et al.*, 2006). Canguilhem (1990: 42) colocou a seguinte questão: "*O que é um sintoma sem um contexto ou pano de fundo*?". Para o autor, a "doença do médico" só poderia ser entendida considerando a experiência das pessoas na relação com o seu contexto. Kleinman (1992: 252) refere que: "*No paradigma biomédico ocidental, patologia significa mau funcionamento ou má adaptação de processos biológicos e psicológicos no indivíduo; enquanto enfermidade (estar doente), representa reações pessoais* *interpessoais e culturais perante a doença e o desconforto, imbuídos em complexos nexos familiares, sociais e culturais. Dado que a doença e a experiência de doença fazem parte do sistema social de significações e regras de conduta, são fortemente influenciadas pela cultura e por isso socialmente construídas.*" Assim, uma intervenção deverá ser capaz de perspetivar a pessoa como um todo, considerando o seu contexto familiar, social e cultural.

É importante realçar que o modelo biomédico é eficaz, principalmente, perante doenças agudas. A partir do modelo biomédico desenvolveram-se várias terapêuticas farmacológicas e outras terapias biológicas, oferecendo ajuda significativa para lidar com diversas doenças. Mas, principalmente no contexto da doença crónica, é necessário ressignificar a doença e as pessoas envolvidas na doença; ou seja, o modelo biomédico permite que as famílias recebam explicações biológicas (geralmente, apreciado pelas famílias); no entanto, essas explicações são efetuadas num contexto psicossocial vago ou inexistente. Assim, é primordial que, além dos cuidados médicos, as intervenções considerem a vertente emocional, social e educativa, seguindo as premissas do modelo biopsicossocial proposto por Engel, em 1977.

## 2. Intervenções no Contexto da Demência

Apesar dos pressupostos analisados, onde é reconhecido o impacto da doença crónica na família como unidade (especificamente nas condições demenciais), as intervenções mais atuais em contexto demencial são dirigidas ou à pessoa idosa com demência ou à sua família, perspetivando a pessoa com doença e a família como entidades individualizadas (Nolan, Ingram, & Watson, 2002; Sousa, Mendes, & Relvas, 2007). Fundamentalmente, as intervenções dirigidas à pessoa idosa com demência compreendem as farmacológicas e as não-farmacológicas (APA, 2007). Os modelos de intervenção com familiares têm como objetivo ajudá-los a enfrentar os desafios impostos pela condição demencial. As intervenções com cuidadores familiares visam facilitar a adaptação da família à doença e atrasar a institucionalização, podendo dividir-se (Sörensen, Pinquart, & Duberstein, 2002): (a) nas que pretendem reduzir a sobrecarga objetiva ou a quantidade de cuidados prestados, como os serviços de "alívio" ("*respite*"); e (b) nas que procuram melhorar o bem-estar dos cuidadores e otimizar as suas competências e estratégias de *coping*, normalmente designadas por intervenções psicossociais.

As intervenções que pretendem reduzir a sobrecarga objetiva ou a quantidade de cuidados prestados oferecem serviços que permitem uma retirada temporária do cuidador principal das tarefas de cuidado, através de grupos de cuidados diários, serviços de alívio domiciliário ("*in-home respite*") ou a nível institucional (cf. Gottlieb & Johnson, 2000; Zarit, Stephens, Townsend, & Grenne, 1998). Os serviços de alívio encontram-se mais desenvolvidos em países como o Reino Unido, Noruega, Dinamarca, Suécia, Holanda, França e Bélgica, contrariamente aos países do sul da Europa, incluindo Portugal.

As intervenções psicossociais visam apoiar a família da pessoa com demência (particularmente o cuidador principal) através do recurso a serviços comunitários para fomentar a construção de uma rede de apoio. Este tipo de intervenção é o que mais se aproxima e incorpora os pressupostos do paradigma biopsicossocial.

## 2.1. Intervenções Psicossociais

As intervenções psicossociais dirigidas a familiares de pessoas com doença crónica, particularmente com demência, têm vindo a proliferar de forma rápida e pretendem promover uma adaptação salutogénica aos desafios que advêm da evolução da doença, contribuindo para a aquisição de informação e melhorarando o *stresse* emocional que ocorre após o diagnóstico de uma doença crónica. Uma intervenção psicossocial pode ser definida como um conjunto de técnicas para utilizar mecanismos de ação cognitiva, comportamental ou social focados na melhoria do bem-estar psicológico e/ou social, para ajudar as famílias de pessoas com demência a lidar melhor com os desafios associados ao desenvolvimento da doença (Andrén & Elmstahl, 2008). A maior parte das intervenções compreende diversas componentes: aconselhamento, educação, informação e suporte emocional ao cuidador familiar (cf. Andrade & Margarita, 2009; Andrén & Elmstahl, 2008; Chien & Lee, 2008; Gelmini, Morabito, & Braidi, 2009; Wolff *et al.*, 2009). Este tipo de apoio tem demonstrado diminuir a sobrecarga dos cuidadores familiares, diminuir os sintomas neuropsiquiátricos do doente e adiar/prevenir a sua institucionalização (Ponciano, Cavalcanti, & Féres-Caneiro, 2010). As intervenções psicossociais que têm vindo a ser desenvolvidas no contexto da demência incluem: grupos de suporte; aconselhamento ("*counselling"*); intervenções psicoterapêuticas; e, particularmente, intervenções psicoeducativas, que tiveram origem nos pressupostos do paradigma biopsicossocial (Nichols & Schwartz, 2000).

### *2.1.1. Grupos de Suporte*

Os grupos de suporte tendem a ser não estruturados, conduzidos por profissionais ou orientados por pares e focados no desenvolvimento de relações entre participantes, criando um espaço de discussão de problemas, sucessos e sentimentos associados à prestação de cuidados (cf. Scharlach, 1987; Gonyea & Silverstein, 1991). Os grupos de suporte ajudam a reconhecer que existem pessoas com problemas semelhantes, fomentando uma perspetiva normalizante das vivências, proporcionando oportunidades para partilhar sentimentos e estratégias para lidar com as dificuldades (Kaye & Applegate, 1993). Os resultados de um recente estudo de meta-análise de Chien e colaboradores (2011) indicam que os grupos de suporte têm impacto positivo significativo no bem-estar psicológico dos cuidadores, favorecendo uma diminuição da sintomatologia depressiva. Contudo, a literatura ainda é limitada e os resultados inconsistentes (Chien *et al.*, 2011; Dupuis *et al.*, 2004). É necessária uma compreensão mais abrangente da eficácia destas intervenções, nomeadamente quanto às variáveis avaliadas (Chien *et al.*, 2011).

Os grupos de suporte são, normalmente, conduzidos ou financiados por organizações nacionais; em Portugal, essa organização é a Alzheimer Portugal, uma Instituição Particular de Solidariedade Social fundada em 1988 e sediada em Lisboa, com três delegações (Norte, Centro e na Madeira). Do nosso conhecimento, é a única organização em Portugal, de âmbito nacional, especificamente constituída para promover a qualidade de vida das pessoas com demência, seus familiares e outros cuidadores. Os grupos de suporte apoiados pela Alzheimer Portugal incluem: (a) Grupo de Ajuda Mútua no núcleo do Ribatejo; (b) Grupo de Suporte da Delegação Norte (Hospital de São João); (c) Grupo de Ajuda Mútua no Centro de Saúde de Pombal; (d) Grupo de Entreajuda no Funchal; (e) Grupo de Ajuda Mútua da Santa Casa da Misericórdia de Aveiro. Para além da Alzheimer Portugal, existem duas instituições de relevo nesta área de intervenção: Associação Humanitária de Doentes de Parkinson e Alzheimer (AHDPA), com sede no Algarve, que presta apoio social e de saúde a pessoas com a doença de Alzheimer e de Parkinson e seus familiares; e a Associação Alzheimer, nos Açores.

### *2.1.2. Aconselhamento ("counselling")*

O aconselhamento revela-se importante na consciencialização das estratégias de autocuidado nas famílias com pessoas com demência, visando reduzir ou facilitar a gestão dos stressores associados à prestação de cuidados (Dupuis *et al.*, 2004). Os serviços de aconselhamento, para além de fornecerem informações relevantes às famílias, podem incluir treino de competências, técnicas de gestão do *stresse*, resolução de problemas, informação sobre a doença e planeamento do dia-a-dia (Brannstrom, Tibblin, & Lowenborg, 2000; Gallagher-Thompson & Coon, 2007; Mittelman, 2000; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). O aconselhamento demonstra efeitos no cuidador, tais como diminuição da sobrecarga e dos sintomas psiquiátricos, melhoria no apoio social recebido e na relação com a pessoa com demência (Dupuis *et al.*, 2004). Estudos de meta-análise revelam que o aconselhamento a cuidadores de pessoas com demência é eficaz na redução da sobrecarga subjetiva e na sintomatologia depressiva (cf. Gallagher-Thompson & Coon, 2007; Pinquart & Sörensen, 2006). Contudo, alguns estudos questionam a eficácia deste tipo de intervenção. Haley, Brown e Levine (1987), por exemplo, verificaram que a participação em serviços de aconselhamento não teve efeito na diminuição da sintomatologia depressiva do cuidador, nem contribuiu para a satisfação com a vida, melhoria no apoio social ou utilização eficaz de estratégias de *coping*. Todavia, são poucos os cuidadores que recorrem a este tipo de apoio, talvez por as famílias ainda não reconhecerem as suas vantagens (Gräßel, Luttenberger, Trilling, & Donath, 2010). Em Portugal, alguns dos serviços oferecidos pela Alzheimer Portugal, como a terapia ocupacional e a fisioterapia, estão disponíveis sob a forma de aconselhamento (e.g., conselhos para adaptação do espaço físico do domicílio; seleção de ajudas técnicas; exercícios para retardar o declínio da capacidade física da pessoa com demência).

### *2.1.3. Intervenções Psicoterapêuticas*

As intervenções psicoterapêuticas podem ocorrer em grupo, individuais ou com as famílias da pessoa idosa com demência, utilizando (cf. Akkerman & Ostwald, 2004; Gonyea, O'Connor, & Boyle, 2006; Márquez-González, Losada, Izal, Pérez-Rojo, & Montorio, 2007): (a) modelos de capacitação para lidar com o *stresse* (cf. Mariott, Donaldson, Tarrier, & Burns, 2000); (b) intervenções focadas no luto familiar face às perdas associadas ao agravamento da condição da pessoa com demência (cf. Kwak, Salmon, Acquaviva, Brandt, & Egan, 2007); e, fundamentalmente, (c) a terapia cognitivo-comportamental, para capacitar as famílias no desenvolvimento de competências cognitivas (e.g., pensamentos disfuncionais desafiantes) e comportamentais (e.g., aumento de atividades prazerosas) e a lidar com situações difíceis e stressantes (Beck, Rush, Shaw, & Emery, 1979). A terapia cognitivo-comportamental é utilizada através da reestruturação cognitiva, para detetar e modificar crenças e pensamentos que funcionem como barreiras para lidar com os desafios associados à prestação de cuidados (Márquez-González *et al.*, 2007). As intervenções baseadas nesse modelo costumam ser organizadas junto de grupos pequenos (cinco a dez participantes), podendo ser individuais, entre cinco a nove sessões semanais com a duração de aproximadamente 90 a 120 minutos (cf. Akkerman & Ostwald, 2004; Gonyea *et al.*, 2006; Kwak *et al.*, 2007; Márquez-González *et al.*, 2007; Mariott *et al.*, 2000). Este tipo de intervenção tem tido sucesso em reduzir os níveis de sintomatologia depressiva, os pensamentos disfuncionais e os níveis de ansiedade do cuidador principal (cf. Akkerman & Ostwald., 2004; Gonyea *et al.*, 2006; Mariott *et al.*, 2000; Márquez-González *et al.*, 2007); alguns estudos referem que este tipo de intervenção tem efeitos significativos na redução dos comportamentos desafiantes da pessoa idosa com demência (cf. Mariott *et al.*, 2000).

### *2.1.4. Intervenções Psicoeducativas*

Mais recentemente têm sido desenvolvidas intervenções psicoeducativas que se afirmam como uma metodologia de intervenção que congrega o modelo biomédico e a intervenção familiar sistémica. Este tipo de intervenção apresenta objetivos comuns ao paradigma biopsicossocial (Andersen, 1986): (a) aumentar o sentido de eficácia das famílias e das pessoas doentes para lidar com a doença e outros aspetos da vida; (b) atender às necessidades comunicacionais e emocionais reclamadas pela doença; (c) colocar terapeutas familiares, profissionais de saúde, famílias e pessoas com doença a trabalhar em conjunto (perspetiva multidisciplinar e colaborativa). Assim, enfatiza-se como a doença pode ter desgastado os recursos familiares (Kaslow, 2000).

A intervenção psicoeducativa visa facilitar o reenquadramento da doença, desenvolvendo sentimentos de competência. Baseia-se num paradigma de *stresse e coping*, encorajando um clima de normalização, ausência da culpabilização e facilitação da exploração de novas estratégias, bem como de promoção e identificação das gratificações e aspetos positivos do cuidar, possibilitando explorar novas estratégias. Este tipo de intervenção caracteriza-se por integrar apoio educativo e emocional, em programas estruturados, breves e multidisciplinares (cf. McDaniel *et al.*, 1992; McDaniel *et al.*, 2005; Rolland, 2003; Steinglass, 1998). A vertente educativa visa fornecer informação sobre a doença (etiologia, sintomas, curso, prevenção, condições que facilitam a qualidade de vida), permitindo às pessoas com doença e à família: antecipar disrupções e mudanças no estilo de vida requeridas pela doença, aumentando a sua capacidade de lidar com essas transições; esclarecer sobre cuidados a ter em casa, ajudando a lidar com alguns comportamentos perturbados; receber informação sobre recursos comunitários, ajudando a reenquadrar a doença, desenvolvendo sentimentos de competência e controlo. A vertente de suporte (ou psicológica) tem como função fornecer orientações para: reduzir o *stresse* resultante do impacto da doença, otimizando as estratégias de *coping*; ajudar a gerir emoções e a usar estratégias eficazes de resolução de problemas; facilitar a comunicação na família e com os serviços de apoio; evitar o isolamento social e manter redes de apoio (cf. Boise, Congleton, & Shannon, 2005; Schultz, Smyrnios, Schultz, & Grbich, 1994; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

Diversos estudos sugerem a eficácia da intervenção psicoeducativa em contexto de demência. Chien e Lee (2008) desenvolveram um grupo com 12 sessões quinzenais, de duas horas cada, durante seis meses; a intervenção favoreceu uma diminuição significativa nas medidas de sobrecarga nos cuidadores. Devor e Renvall (2008) também obtiveram resultados comparáveis no estudo com 300 cuidadores que participaram numa intervenção psicoeducativa, e ainda melhoria significativa no sentido de competência do cuidador. Andrade e Margarita (2009) desenvolveram um programa desenhado com base em técnicas colaborativas, com 10 sessões semanais; verificaram diminuição significativa em problemas psicológicos dos cuidadores (e.g., sentimentos de fúria, medo). Au e colaboradores (2009) desenvolveram um programa com 13 sessões semanais, de duas horas cada, onde foram exploradas estratégias comportamentais e cognitivas de gestão do *stresse*; os cuidadores que participaram no programa demonstraram um aumento significativo na autoeficácia para controlar sentimentos negativos e para lidar com o comportamento disruptivo da pessoa com demência (cf. Ostwald *et al.*, 1999). Ducharme, Lévesque, Gendron e Legault (2001) observaram melhoria nas estratégias de *coping* dos cuidadores, bem como diferenças significativas na relação com os profissionais em relação à perceção de apoio, na sequência da sua participação num programa psicoeducativo com sete sessões individuais, cujo objetivo consistia em promover os conhecimentos e as competências do cuidador. Morano e Bravo

(2002) desenvolveram um programa psicoeducativo e verificaram que os participantes aumentaram o conhecimento sobre serviços comunitários e motivação para frequentar grupos de suporte. Em suma, este tipo de intervenção tem demonstrado aumentar os conhecimentos e competências do cuidador, reduzir a sobrecarga e depressão, aumentar o bem-estar subjetivo e adiar a institucionalização do familiar com demência (Kennet, Burgio, & Schulz, 2000; Sörensen, Pinquart, & Duberstein, 2002).

Pauta-se por ter duração breve, normalmente entre 6 a 8 sessões semanais/quinzenais, para não sobrecarregar a família com mais tarefas (Sousa *et al.*, 2007). Qualquer programa de intervenção tem uma delimitação temporal e, portanto, não responde aos desafios associados ao curso progressivo da doença/demência e da trajetória da prestação de cuidados. Esta duração breve e o facto de a doença evoluir poderá ter como principal implicação uma curta duração dos impactos após participação nestas intervenções, que se tem verificado durar até cerca de sete meses (Söerensen *et al.*, 2002; Sörensen, Duberstein, Gill, & Pinquart, 2006). Este aspeto exige que se pondere a importância da continuidade do apoio, que se revela essencial para a manutenção dos benefícios alcançados e para acompanhar a evolução da doença (Larsen & Thorpe, 2006).

No contexto demencial, esta continuidade é particularmente relevante, face ao curso da demência e da trajetória da prestação de cuidados, sendo reforçada pela dificuldade das famílias em “navegar” pela complexa rede de respostas e sistemas de suporte comunitário. A continuidade de apoio pós-intervenção oferece a possibilidade de planear os cuidados, através do desenvolvimento de planos de cuidados individualizados (Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010).

## 3. Foco dos Impactos no Cuidador Principal

Apesar destes pressupostos, a literatura relacionada com as condições demenciais tem focado o impacto da prestação de cuidados no cuidador principal, negligenciando o impacto na família como um sistema. Isto torna-se relevante, considerando que cuidar de uma pessoa com demência tem sido reconhecido como uma das maiores fontes de *stresse* para as famílias (Parks & Novielli, 2003), mais difícil do que cuidar de uma pessoa idosa com dependência física (Clipp & George, 1993), pois trata-se de uma tarefa que exige conhecimentos técnicos, competências e disponibilidade a tempo inteiro.

A literatura sobre o impacto da demência no cuidador principal tem descrito, em particular, impactos ao nível de saúde (cf. Martire & Hall, 2002; Schulz & Martire, 2004; Sörensen *et al.*, 2006; Vitaliano, Zhang, & Scanlan, 2003): (a) física (fraca perceção do estado de saúde, pouca disponibilidade para exercício físico, insuficiente tempo de descanso que acarreta exaustão física, distúrbios de sono e envolvimento em comportamentos adversos para a saúde, como fumar e beber álcool em excesso); (b) mental (sintomatologia depressiva, ansiedade, depressão clínica, irritação, sobrecarga e utilização abusiva de farmacologia psicotrópica). Além disso, o tempo livre e de lazer tornam-se muito reduzidos (cf. Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999), levando ao isolamento social e emocional, pois cuidar de alguém com demência requer supervisão constante (cf. Schulz & Martire, 2004; Sörensen *et al.*, 2006; Vitaliano *et al.*, 2003). Estes fatores resultam, frequentemente, numa diminuição da autoeficácia, bem-estar subjetivo e qualidade de vida (Baumgarten *et al.*, 1994; Bodnar & Kiecolt-Glaser, 1994; Cohen & Eisdorfer, 2001; Dunkin & Anderson- Hanley, 1998; Rose-Rego, Strauss, & Smyth, 1998; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Vitaliano, Russo, Young, Becker, & Maiuro, 1991). Alguns estudos indicam mesmo que a prestação de cuidados pode levar à morte prematura do cuidador principal (cf. Schulz & Beach, 1999). Alguns fatores potenciam estes efeitos negativos (Figueiredo, 2007; Brodaty & Green, 2002), nomeadamente: maior frequência de comportamentos desafiantes por parte da pessoa com demência (como gritos e agressão); coabitação; pouco suporte da família alargada e amigos; maior número de horas de cuidados. Paralelamente, outros fatores diminuem o impacto dos efeitos negativos: perceção de suporte adequado por parte da família alargada, amigos e outras pessoas próximas; uso de estratégias de *coping* focadas nas emoções.

Neste contexto, os cuidadores familiares de pessoas com demência têm sido apelidados de pacientes ocultos ("*hidden patients*") (Parks & Novielli, 2003), pois necessitam de ajuda externa e apoio para melhorar a sua saúde e bem-estar; alguns cuidadores familiares obtêm benefícios, ou conseguem identificar aspetos positivos no seu papel (cf. Kramer, 1997), mas a maioria necessita intervenções que lhes forneçam apoio instrumental e psicossocial.

### *3.1. Importância de compreender o impacto da prestação de cuidados no desenvolvimento do cuidador*

As doenças crónicas tendem a aumentar e a ocorrer com mais frequência na fase final da vida. Desta forma, cuidar de um familiar mais velho tem sido considerado um evento de vida normativo (Cavanaugh, 1998). A par do aumento da esperança de vida tem-se assistido a um aumento significativo da proporção de cuidadores que são, eles próprios, mais velhos (Spillman & Pezzin, 2000). A literatura sobre a prestação de cuidados em famílias envelhecidas tem incidido (Barbosa, Figueiredo, Sousa, & Demain, 2011): nas características do cuidador (e.g., género, idade, relação com o recetor de cuidados); e nos impactos negativos da prestação de cuidados na saúde física e mental do cuidador e em outras esferas da vida (e.g., trabalho, vida social e financeira), geralmente descritos ao nível do *stresse* e da sobrecarga; estratégias de coping; e utilização dos serviços comunitários. A influência da prestação de cuidados no desenvolvimento do cuidador e nos processos familiares tem sido raramente considerada (Sousa, Silva, Marques, & Santos, 2009). Por outras palavras, os estudos dos impactos da prestação de cuidados a uma pessoa com demência no cuidador têm focado uma perspetiva patológica, negligenciando os efeitos no desenvolvimento da pessoa que cuida e o contexto familiar.

Atualmente ainda existem poucos modelos teóricos sobre os processos de desenvolvimento e evolução familiar na velhice (King & Wynne, 2004). No entanto, as pessoas idosas e suas famílias são confrontadas com tarefas, desafios e conflitos tão complexos e ricos quanto as gerações mais jovens. Para que a família se desenvolva e evolua de forma saudável é necessário que resolva e integre estes desafios; caso contrário, podem surgir problemas, dificuldades de *coping* e de adaptação. Alguns dos desafios mais referidos para esta fase da vida (individual e familiar) incluem: reforma, ser avô, doença crónica e dependência, suporte e cuidados familiares e viuvez. Carter e McGoldrick (1999) consideram que os processos-chave nesta fase estão relacionados com a aceitação da mudança e transformação dos papéis geracionais. As autoras definem um conjunto de mudanças de segunda ordem (implicam alterações qualitativas e não apenas ajustes funcionais) no funcionamento familiar decisivas para o desenvolvimento: (a) adaptar-se ao declínio físico (mantendo os interesses e o funcionamento individual e de casal) e explorar novas opções para os papéis familiares e sociais; (b) apoiar o papel central da geração intermédia; (c) criar espaço para a sabedoria e experiência da geração idosa, apoiando-a sem a sobreproteger; (d) lidar com a perda do cônjuge, irmãos e outros pares/pessoas significativas e preparar/enfrentar a própria. As pessoas são reconhecidas como evolutivas e em transformação, num processo simultâneo de mudança, desenvolvimento e continuidade; as famílias estão preparadas para manter a organização que as define como família, mas alterando o seu funcionamento e estrutura. O desenvolvimento familiar remete para a mudança/evolução da família enquanto grupo e para as alterações nos seus membros individuais.

Para compreender a relação entre o desenvolvimento individual e familiar na fase final da vida (ou família envelhecida), King e Wynne (2004) associaram a construção da identidade do ego (Erikson, 1950) a um processo mais vasto de construção de significado e sentido: a integridade familiar, que representa o resultado positivo do esforço da pessoa idosa para a construção de sentido, ligação e continuidade com a sua família multigeracional. No entanto, este processo pode evoluir num sentido negativo: desconexão familiar, caraterizado por contactos familiares pouco frequentes, ausência de comunicação e sentimentos de isolamento; ou alienação familiar, pautada pela ausência de partilha de valores, crenças e sentimento de identidade familiar. A presença de uma doença crónica pode ter implicações na construção da integridade familiar, pois a prestação de cuidados assume um papel crucial na velhice.

## ENFOQUE DA INVESTIGAÇÃO

O desenvolvimento de modelos eficazes de intervenção familiar no contexto demencial coloca questões e desafios. Perseguindo as premissas do paradigma sistémico da saúde-doença (Rolland, 1994), esta investigação tem como finalidade contribuir para o desenvolvimento de um modelo de intervenção familiar no contexto da demência que responda a alguns pressupostos e desafios: integrado (porque envolve apoio social e de saúde, educacional e psicológico, combinando apoio à pessoa doente com suporte para a sua família, a curto e médio prazo); capacitador (baseado numa perspetiva salutogénica); multidisciplinar (envolve profissionais de várias áreas, nomeadamente, psicólogos, médicos, enfermeiros, técnicos de serviço social, fisioterapeutas e gerontólogos); e horizontal (promove uma relação de igualdade entre profissionais, pessoa doente e sua família, em que cada um contribui com as suas competências). Adicionalmente, neste estudo analisa-se como este modelo pode ser incorporado nos cuidados de saúde primários. Os objetivos específicos são: (a) desenvolver, implementar e avaliar uma intervenção psicoeducativa multifamiliar em contexto demencial; e (b) analisar o impacto da prestação de cuidados a uma pessoa com demência no cuidador principal idoso em termos de desenvolvimento (estudo da integridade familiar).

Na prossecução destes objetivos foram utilizadas metodologias qualitativas de recolha (entrevistas semi-estruturadas e *photovoice*, em *focus group*) e análise de dados. Esta investigação procurou desvelar caminhos científicos relevantes e potenciar formas de atuação e colaboração entre domínios com impacto direto na qualidade de vida das populações em estudo. A investigação incluiu o desenvolvimento de estudos interligados, que se apresentam organizados em dois capítulos.

## Capítulo 1. Intervenção em Contexto de Demência: proFamílias-demência

O primeiro capítulo abrange quatro estudos e descreve o desenvolvimento, implementação e avaliação de uma intervenção integrada de apoio a pessoas com demência e seus familiares: *ProFamilies-dementia: A programme for elderly people with dementia and their families; Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance; Being a volunteer: motivations, fears and benefits of volunteering in an intervention program for people with dementia and their families; Post- intervention referral service (PIRS): Supporting families of people with dementia after a psycho-educational program.*

Foi implementada, num contexto de cuidados de saúde primários, uma intervenção integrada no contexto da demência (proFamílias-demência), com vista a apoiar um grupo de cinco famílias (num total de seis participantes) com familiares com demência. O proFamílias-demência engloba três componentes: (a) grupo psicoeducativo, dirigido aos familiares de pessoas com demência (6 sessões semanais, 90 minutos cada), onde se providencia informação sobre a doença (e.g., aspetos clínicos da doença, recursos comunitários disponíveis, aspetos legais e financeiros) e suporte emocional (e.g., gestão do *stresse* e das emoções); (b) ocupação significativa (inclui estimulação cognitiva e motora) para os familiares com demência (esta componente ocorre em paralelo com a anterior, pois foi criada no sentido de facilitar a presença dos familiares no grupo psicoeducativo, sendo da responsabilidade de um grupo de voluntários com formação em saúde); (c) serviço de referência pós-intervenção, providenciado por técnicas de serviço social, para acompanhar estas famílias após a sua participação no programa, no sentido de prevenir uma quebra abrupta de apoio.

Os aspetos estruturais e funcionais do programa, assim como os principais benefícios individuais e familiares, foram avaliados duas semanas após a sua finalização, através da técnica de entrevista de *focus group*, junto dos participantes e dos profissionais envolvidos, para recolher sugestões de melhoria da intervenção (impacto a curto-prazo). O impacto a médio-prazo foi avaliado três meses depois, através de um método de recolha de dados participativo e qualitativo (photovoice), em que os participantes identificam a sua vivência pela fotografia (imagem) e discutem-na em grupo (voz).

O serviço de referência pós-intervenção foi implementando durante seis meses, o tempo considerado razoável para proceder à sua avaliação e restruturação. A avaliação incidiu, fundamentalmente, na sua utilidade junto das famílias, tendo também analisado as perspetivas das técnicas de serviço social em relação aos benefícios e possíveis riscos.

Paralelamente são descritas perspetivas de pesquisa e apontadas recomendações práticas para a provisão de apoio psicoeducativo junto de famílias que cuidam de um familiar com demência.

## Capítulo 2. Construção da Integridade Familiar: A Influência da Prestação de Cuidados em Contexto de Demência no Cuidador Principal

O segundo capítulo engloba um estudo cujo objetivo é contribuir para melhor compreender a influência da prestação de cuidados na construção do sentido de integridade familiar: *Constructing family integrity in later life: The case of older caregivers of relatives with dementia*. King e Wynne (2004) consideram que a integridade familiar é um processo emocional caracterizado por sentimentos de conexão, continuidade e pertença na família, fundamental para o bem-estar da pessoa idosa. A perceção pessoal das oportunidades de adaptação às mudanças que advêm do envelhecimento e condições associadas, nomeadamente a prestação de cuidados a um familiar com demência, constitui um elemento-chave na construção da integridade familiar. A recolha de dados efetuou-se através de uma entrevista semiestruturada (baseada em King & Wynne, 2004) com 26 cuidadores familiares de pessoas com demência (em contexto familiar), com idade superior a 64 anos.

Os resultados incidem nas principais competências ou funções familiares que são afetadas pela prestação de cuidados, nomeadamente ao nível da integridade geral, da transformação das relações familiares, na resolução ou aceitação de perdas e na criação de sentido e legado. Os principais resultados sugerem que a prestação de cuidados a um familiar com demência influencia a construção da integridade familiar na fase final da vida, nomeadamente ao nível de: (a) concretização de projetos de vida; (b) frequência de contactos com a família; (c) reciprocidade do cuidador; e (d) resolução de conflitos familiares. No entanto, os resultados reforçam que a forma como o cuidador percebe e vivencia a prestação de cuidados (significações) exerce um papel fundamental na construção da integridade familiar.

São igualmente descritas as implicações, as limitações do estudo e as recomendações para futuras investigações.

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# CAPÍTULO 1

## INTERVENÇÃO EM CONTEXTO DE DEMÊNCIA: PROFAMÍLIAS-DEMÊNCIA

## 1.1. PROFAMILIES-DEMENTIA: A PROGRAMME FOR ELDERLY PEOPLE WITH DEMENTIA AND THEIR FAMILIES[2]

Sara Guerra*[1], Álvaro Mendes[1], Daniela Figueiredo[2,3] & Liliana Sousa[1,3]

[1]Department of Health Sciences, University of Aveiro, 3810-193 Aveiro, Portugal
[2]Higher School of Health, University of Aveiro, 3810-193 Aveiro, Portugal
[3]Member of the research unit UniFAI (Unidade de Investigação e Formação sobre Adultos e Idosos), University of Porto, Portugal
*E.mail: sara.guerra@ua.pt

### Abstract

In this paper we describe the development and pilot implementation, in a primary care context, of a programme for helping families adapt to living with a person with dementia (proFamilies-dementia). This programme aims to promote the healthy adaptation of the family to the presence of an elderly member with dementia living in their homes. It comprises three components: a psycho-educational, multi-family discussion group for the families; cognitive stimulation for the elderly person with dementia; and a mediation service to support the families after participation in the first two components. ProFamilies-dementia was implemented with one group involving five families. The main benefits mentioned by families include: an opportunity to share experiences with others who are living through similar circumstances; the development of an improved sense of competency; and the improvement of family relationships. ProFamilies-dementia reveals potential for promoting the provision of integrated support from health and social services, which usually function as independent and parallel support structures.

**Keywords:** dementia, elderly, families, psycho-educational support.

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## 1. Introduction

Dementia is not just one person's illness: it affects the family and its members. Patients and their families need to adjust socially, emotionally and on a daily basis to the *presence* of the disease in order to prevent problems in their functioning and development. However, programmes in this field tend to target the elderly person with dementia (including pharmacological and non-pharmacological strategies) and/or target the family carer (such as, support groups, respite care, education and home care services). Therefore, the development of effective models of caring for individuals with dementia and their families is of paramount importance. In addition, the literature suggests that effective support programmes should entail a multi-component approach which combines psychological and educational dimensions (Zarit & Femia, 2008; Acton & Kang, 2001). Considering these principles, we developed a programme entitled proFamilies-dementia, which aims to promote the healthy adaptation of the family to the dementia in one of its members, improving their quality of life and well-being and facilitating the connection between family and support systems (social and health). This programme was developed to support families that care for an elderly person with dementia in their homes.

## 2. Construction and implementation

ProFamilies-dementia has its roots in proFamilies-cancer and stroke (Sousa, Mendes, Chiquelho, Neves & Relvas, 2009), which aims to promote a healthy adjustment of the family to a chronic illness, increasing the quality of life and well-being of all family members. It is also inspired in the literature and in other programmes for older people with dementia and their families, namely in Klein, 1998, and Boise, Congleton & Shannon, 2005. Furthermore, it incorporates the needs of families which are expressed during the recruitment process. In short, the families involved reported that they were joining this programme because they *hoped* to improve their emotional self-efficacy (e.g. enhancing emotions-management), to improve care delivery, to learn more about the disease and to share experiences.

## 3. Procedures and recruitment

This project was approved by the Ethics Committee of the Health Administration of the Centre Region, and authorized by the Health Centre of Ílhavo (Portugal). Participating families were recruited according to the following procedure: i) the Director of the Health Centre met the medical team and requested their collaboration in the identification of recent diagnoses of dementia (1 to 2 years following diagnosis); ii) family doctors identified dementia cases and made available to the research team the families' contacts (address and phone number); iii) families were contacted by telephone and informed about the purpose of the project and were invited to participate; iv) an interview was scheduled for interested families (i.e. involving all the available elements of the household); v) the researcher (first author) went to the families' home and presented the objectives and organization of the programme - for those who declined to participate, the interview ended here (6 families declined, reporting discomfort at having to leave the care receiver and lack of time); for those who continued to be interested, the interview continued with the collection of information related to their psycho-social situation (socio-demographic data, health status, expectations, needs and fears concerning their participation); vi) anonymity and confidentiality were guaranteed and authorization to record the sessions was requested; all participants signed the informed consent form; vii) the researcher informed the participants that they would be contacted soon to schedule the sessions. ProFamilies-dementia started with 6 families, but 1 family dropped out, on the grounds that they did not feel the need for support since their relative with dementia was *merely in a phase of memory loss*.

### 3.1. Participants

One group was established, involving 5 families, with 1 family being represented by 2 non-patient family members. The average age of non-patients was 56.17 years (SD = 15.42) and 5 were female; 1 participant worked full time and 4 were retired; 4 were married. Three participants have been caring for the elderly person with dementia for about 1-2 years, and the others have been doing so for more than 2 years. As for academic qualifications: 1 never attended school; 2 have 4 years of schooling; 2 have up to 9 years of schooling; and 2 attended higher education. The kinship of the participants with the elderly dementia sufferer was as follows: 2 - spouses; 2 - children; 1 – niece; 1 - son-in-law. Only 1 family used formal support services (home care).

The 5 elderly persons with dementia had an average age of 79.6 years (SD = 5.77) and 3 were male. They all had primary school education and 4 were married. Regarding the time between the diagnosis and the initiation of the programme, it was observed that in one case, this was up to 2 months; in the other 4, more than one year has passed.

## 4. Components: structure and description

The programme was coordinated by a gerontologist (the first author). ProFamilies-dementia comprises three components: *A*. psycho-educational multi-family groups; *B*. stimulation for elderly persons with dementia; *C*. mediation service. The first two components take place concurrently, while the mediation stage follows on after the other two components.

### 4.1. Component A. Psycho-educational multi-family groups

This component is developed in 6 sessions (one per week, 90 minutes each) in multi-family discussion groups. The sessions took place in the Ílhavo Health Centre and are coordinated by a psychologist and a gerontologist who combine experience and training in psycho-educational and family intervention with caring for elderly persons with dementia. However, the programme involves a multi-disciplinary approach, requiring the participation of a family doctor, nurse and social worker. Professionals should assume an active and empathic attitude, and are responsible for normalizing the experience of certain feelings, reinforcing the competences and resources of families. Each session is organized in four parts: educational, supportive, relaxation and task assignment. In each session participants receive handouts summarizing the main topics of the session.

*Session 1*

This session begins with the introduction of the group facilitators, the families and the objectives and format of the programme.

The educational goal consists in giving the participants basic information about dementia. This starts with a presentation, delivered by a family doctor (with training on dementia), and then participants may ask questions. Some queries are frequent, namely: illness heredity, mechanisms that lead to deterioration, reasons for the disturbed behaviors.

Another goal (support) is to help families to normalize the experience of dementia. Participants identify the positive and negative impacts of the dementia diagnosis on their family life. It is emphasized that the illness did not convey *anything good*; however, when considering family functioning, it is possible to give value to some aspects. The most common positive aspects mentioned are family unity, and avoiding the institutionalization of the elderly relative. Negative impacts include isolation and dealing with the loss of memory.

A further objective is to develop effective ways of dealing with stress, so a moment of relaxation is created in all sessions. In this session, the participants practice diaphragmatic breathing. At the end, participants are given the task of contacting a friend during the week as a way of reducing the feeling of isolation.

*Session 2*

Beginning with the second session, all remaining sessions start with group members discussing their degree of success with the task of the previous week.

This session aims mainly at helping participants improve their self-care. This topic is discussed using scaling (White & Epston, 1990). Participants are asked to answer the following question, using a scale ranging from 0 (not important) to 10 (highly important): *How much do you think you need to care for yourself?* Participants report that the importance of self-care was about 3 to 5 points (*we can't think about self-care while our demented relative is alive*). After a brief explanation, they recognized that they could promote their self-care by: *being more patient with the care receiver, and accepting and finding more support*. Participants are then invited to engage in cognitive relaxation. The task of this session requires the organization of a self-care plan.

*Session 3*

The educational objectives are centred on caring for an elderly person with dementia, and involve the collaboration of a nurse who provides information on relevant topics (such as, nutrition, sleep and rest, personal care) and answers the participants' questions. Participants' queries usually focus on *what to do when the elderly have cold feet or chilblains, how to be sure whether a complaint is true or not.*

The supportive part aims to help the participants develop more efficient strategies of stress-management. Each participant is asked to identify how stress is felt in his/her life); then, they identify the most functional strategies they have used in such situations, which include: seeking the support of friends or looking for information. Participants are then invited to take part in a moment of cognitive relaxation. The task to be done during the week entails the practice of this relaxation technique.

*Session 4*

This session is centred on communication. Participants discuss how to communicate their feelings and concerns more effectively. Facilitators address the topic of different forms of communication (passive, aggressive, manipulative and assertive) emphasizing that assertiveness is, in general, the most efficient way to communicate. How to communicate in an assertive way using the DESC technique is explained (based on Bower & Bower, 2004): describe the facts; express feelings; specify the desired changes; explain the consequences. Subsequently, the group is asked to think about situations in which it is difficult for them to be assertive and role-playing exercises are put into practice. The task for the next session requires the participants to use the assertive training in a situation.

*Session 5*

This session begins with a presentation, made by a social worker, about available community resources (educative). Some queries emerged: *the acquisition of technical aids and available social benefits.*

The supportive part aims to help families improve their emotion-management strategies. The use of the game "six colours to think" (based on Bono, 1985) is recommended. In this game, each colour has a thought associated to it: black - negative; red - emotive; white - neutral; yellow - optimistic; green - creative; blue – meta-thinking (*thinking about thinking*). The group chooses a challenging situation and uses this game to test how different thoughts induce different emotional tones and are associated to varied levels of (dis)comfort.

At the end of the session, two tasks are handed out: participants have to pay attention to the moments when they feel negative emotions and apply the game; as the next session is the last one, they are asked to bring something to eat or drink to celebrate the end of the group.

*Session 6*

Participants are asked to think and share their desires for the future (to maintain significant goals for their individual and family lives). Facilitators also provide information on legal support and social welfare and highlight the need to plan the future of the elderly person with dementia.

The group should end with special events to ensure that families can remember their participation as positive. The end of the group also includes the presence of the volunteers and the mediators. Finally, a celebration (a party with food and drinks) takes place in an informal environment; photographs are taken of each family and of the whole group; three months later, the photos are sent by mail to each family, with a personalized message.

### 4.2. Component B. Elderly people with dementia stimulation

During the first contact with families, researchers asked them about their interest in having a volunteer group service, and this component was available for the families who were interested in it (3 families). A volunteers' training programme was created and implemented at the University of Aveiro. The training programme was advertised among health professionals and students of health professions; it was made clear that participants should be available to commit themselves to developing activities with elderly people with dementia during a 6 week period. Six people signed up (all female): 4 gerontologists, 1 student of gerontology, and 1 nurse. The average age of volunteers was 27.16 years, ranging from 19 to 51 years.

The main objectives of this component are as follows: to delay the progression of the disease (through cognitive stimulation); to allow families to participate in the psycho-educational sessions; and to provide families with concrete information about what they can do (strategies) with their relative with dementia.

Before the start of the stimulation programme, the volunteers visit the family twice; first, to be introduced to the family members, in particular, to the person with dementia; second, to evaluate the needs and potential of the elderly person with dementia. Sessions are developed in the elderly person's home since it is the context to which the person is adjusted and where they feel comfortable. The sessions are organized as follows: in the 1st session, information is gathered about the elderly person (their interests and preferences); in the 2nd to 6th sessions - cognitive stimulation activities are undertaken, such as memory stimulation, attention and language stimulation and reality orientation therapy. Volunteers also encourage the elderly person with dementia to practice self-care, including functional stimulation (e.g. accompanying the elderly in a walk; using a ball to stimulate dexterity).

### 4.3. Component C. Post-programme support (mediation)

Mediation is a supportive component that aims to respond to the needs of families in the medium term. The mediator is a social worker who, on a voluntary basis, facilitates the coordination between families and the formal support services. The mediator fulfils tasks which are usually highly valued by families (Dupuis, Epp & Smale, 2004): giving precise and current information about community resources; facilitating the families' contact with and access to health services and social support. ProFamilies-dementia provides one professional for each family, for a minimum period of 6 months (the time considered reasonable for assessing this service and then proceeding to its reformulation). Mediators were recruited using the snow ball technique, starting with the social worker from the Health Centre where the programme took place. Five mediators were recruited, all female and with an average age of 41 years (ranging from 31 to 54).

## 5. ProFamilies-dementia assessment

The programme was evaluated in order to collect suggestions from the participants as to how to adjust the programme better to their needs and to identify its benefits for individuals and families. The methodology used was focus group interviews involving the participants 2 weeks after the end of the programme. The interview focused participants' opinion around 3 topics: structural and functional aspects of the programme; volunteers and mediators role; individual and family benefits. The focus group interview (duration of 70 minutes) was led by the psychologist and the gerontologist who coordinated the group. The interview was taped, transcribed and submitted to content analysis. The sample is identical to the participants, since all of them agreed to cooperate.

### 5.1. Results

Concerning the structural aspects of the programme, participants' opinions suggest that the number of sessions, their duration and frequency were adequate. About the group's composition, participants stated that a group of 6 people is ideal.

*"Being in a group of 6 persons was great; it was like group therapy, where we can talk without fears."* [Anabela, 60 years]

Participants consider beneficial the presence in the group of families facing different stages of the illness, since it allows the sharing of experiences and the anticipation of future difficulties.

About the functional aspects, participants consider adequate the facilitator's role and the methodologies used. They emphasized the benefits of having professionals that didn't *just teach*, but also listened. Moreover, participants appreciated the absence of new technologies (e.g. PC, data show).

*"There was a lot of interaction! The use of the flipchart also helped! It was also good that you did not use the new technologies!"* [Anabela, 60 years]

Participants point out that the topic on self-care was the most important:

*"When I took a little more time in the coffee shop I felt bad with myself, because I thought "I'm here while my father* [patient] *needs me". Now I think: take your time, you need to care for yourself!"* [Manuela, 39 years]

On the other hand, legal and financial issues were assessed as the less useful topic.

On the role of the volunteers, the families mentioned that it had been quite useful for them and that they even created friendship bonds. Participants still do not have an opinion about how helpful the mediators might be.

The main benefits were centered on the sharing of experiences which attenuated emotional and social isolation and normalized some feelings and thoughts. The participants mentioned the importance of meeting other persons living through "*the same situation*", because it lessened the feeling of "*being on your own*".

Concerning the changes felt by the family, participants stated that they learned more about how to deal with emotions and how to communicate better, which improves the quality of family life and well-being. Participants mentioned that the severity of the dementia was a factor that influenced their decision to participate; however, now they recognized the potential benefits of an earlier participation.

*"If it was 2 years ago I wouldn't have agreed to participate because I felt no need. We need someone with experience to tell us, at an early stage: "this is the ideal time to participate!"* [Teodoro*,* 62 years]

## 6. Discussion

ProFamilies-dementia seems to respond to the needs of families caring for an elderly relative with dementia at home. Families considered that this support should be available immediately after the diagnosis of the dementia. However, the literature and our experience during this programme indicate that those recently confronted with the diagnosis of dementia in a relative are not receptive to this type of support (Morgan, Semchuk, Stewart & D'Arcy, 2002). In fact, they still hope that the disease is not that severe.

The programme targets families caring for an elderly (over 64 years) relative with dementia. Future research should expand the age of the person with dementia and look to understand if it is more appropriate to develop different programmes for younger as opposed to older sufferers, or if all families can participate together. There is also a challenge and a need to develop integrated programmes in an institutionalized context, which should integrate support for older people with dementia, their formal carers and their families.

At least in Portugal, health and social care tend to be developed independently. During the last decade, a lot of effort has been dedicated to articulating these two crucial types of support and much has been achieved; however, there is still a long way to go. This programme integrates both types of support and shows how this articulation can be achieved in an easy and simple way.

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## 1.2. EVALUATING PROFAMILIES-DEMENTIA: ADOPTING PHOTOVOICE TO CAPTURE CLINICAL SIGNIFICANCE[3]

Sara Guerra*[1], Sofia Rodrigues[1], Sara Demain[2], Daniela Figueiredo[3,4] & Liliana Sousa[1,4]

[1]Department of Health Sciences, University of Aveiro, 3810-193 Aveiro, Portugal
[2]School of Health Sciences, University of Southampton. SO17 1BJ, United Kingdom.
[3]Higher School of Health, University of Aveiro, 3810-193 Aveiro, Portugal
[4]Member of the research unit UniFAI (Unidade de Investigação e Formação sobre Adultos e Idosos), University of Porto, Portugal
*E.mail: sara.guerra@ua.pt

### Abstract

Dementia is a challenging chronic illness which affects the patients and their family. Families often perform a full-time, specialized role, which requires expert knowledge and skills. This paper describes the evaluation of proFamilies-dementia (a programme developed to support families that care for a relative with dementia) using an innovative participatory methodology: photovoice, a qualitative method of research which uses *photography* and *voice* to access people's experiences. The programme was evaluated in order to identify the positive and negative impacts of the intervention on individuals and families; the advantages and disadvantages of photovoice as a participatory tool were also captured. The sample consisted of 6 people from 5 families. Participants identified only positive impacts of the programme, including: better emotional management, normalisation of feelings, and increased focus on self-care. Photovoice facilitated access to the process of change initiated by proFamilies-dementia, described by a process of going beyond illness, negativity and loneliness.

**Key words** *chronic illness; clinical significance; participatory evaluation; photovoice; proFamilies-dementia.*

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## 1. Introduction

Dementia is a particular challenging chronic illness which affects not only the patient, but all the family members (Clipp & George, 1993; Parks & Novielli, 2003). Living with and/or caring for a person with dementia is often considered a more difficult and stressful experience than caring for a frail person who is not cognitively impaired and who can understand and co-operate with carers in the caregiving process. Families often perform a full-time, highly specialised role, which requires expert knowledge, skills and attitudes.

In recent years, there have been significant advances in the development of interventions for people with dementia and their families. The psychosocial interventions, like psychotherapy or psychoeducational programmes, have the strongest evidence of benefit (Losada, 2007). Recent meta-analysis studies (cf. Sörensen, Duberstein, Gill, & Pinquart, 2006; Sörensen, Pinquart & Duberstein, 2002) suggested that these types of interventions have the most consistent short-term effects on a wide range of outcomes measures (e.g., burden, depression, and coping abilities).

Psychoeducational interventions are considered particularly effective at improving carer knowledge, reducing burden and depression symptoms, and increasing subjective wellbeing and satisfaction (Sörensen et al., 2006). Research also suggests that psychoeducational interventions have moderate effects in terms of delaying the institutionalisation of those receiving care by improving the psychological well-being of the carer (Kennet, Burgio, & Schulz, 2000). Recent interventional studies found a significant reduction in health-risk behaviour and improvements in self-care and self-efficacy in family carers following a psychoeducational intervention (Andrén & Elmstal, 2008; Boise, Congleton, & Shannon, 2005; Kennet et al, 2000; Won et al., 2008).

### 1.1. Determining the effectiveness of interventions

Overall, psychoeducational interventions have been reported as effective (Sörensen et al., 2006). This effectiveness has been established using traditional approaches assessed by the amount of improvement identified in outcomes (e.g., burden, anxiety, depression, subjective well-being, coping abilities) determined by researchers before the intervention (Sörensen et al, 2002). However, the dominance of researchers in the design of both interventions and evaluation methods has been criticised by those, such as Fraenkel (2006), who advocate participatory research methods.

Firstly, the use of apriori measures (Mirin & Namerow, 1991; Jacobson & Truax, 1991) has been criticised for underestimating the impact of interventions on issues of importance to participants. Interventions are focused on reaching predefined objectives, typically associated with achieving normative levels of functioning: reducing, eliminating or easing symptoms, solving problems and/or modifying risk behaviours (Sousa & Rodrigues, 2008). This process, based on a biomedical approach, fails to analyse the process of change, or to consider other positive and/or negative changes besides those previously defined for the intervention.

Participants may experience clinically significant changes which improve or worsen their quality of life, but which do not coincide with the initial intentions of the intervention and which, therefore, are often not captured (Jacobson & Truax, 1991; Mirin & Namerow, 1991). Evaluations need to capture the clinical significance and practical importance of interventions, specifically, the degree to which the intervention makes a practical, genuine and valuable difference to the life of the client and those with whom he/she interacts (Kazdin, 1999).

Secondly, traditional models of evaluation rarely involve families in the design of the programmes which are created to help them (Fraenkel, 2006). Franekel suggests that this lack of family involvement, alongside an absence of organisational commitment to implement family-focused programmes, contributes to the under utilisation of family intervention programmes. Fraenkel (2006) also argues that there needs to be a more collaborative stance between services/professionals and families, with families viewed as experts on their life circumstances, recognised for their coping and resilience and asked about what services might help them. Such participatory approaches require participatory evaluation methods; that is, an educational process through which participants produce action-oriented knowledge about their reality and clarify and articulate their norms and values (Brunner & Guzman, 1989). Participatory methods involve evaluators working in a collaborative partnership with families/users to facilitate and support them in owning and understanding the evaluation (Keast & Waterhouse, 2006). The objectives of participatory evaluation are to promote programme enhancement, encourage self-evaluation and self-determination, and promote the contribution of all involved, including clients, who have traditionally been excluded from evaluation (Patton, 2002). The active involvement of participants in the evaluation process has afforded enhanced programmatic outcomes as well as contributing to capacity building around evaluation and broader participation roles (Keast & Waterhouse, 2006).

### 1.2. Photovoice: a tool for participatory evaluation

Photovoice, a qualitative method of research and action which uses *photography* and *voice* to access the lives and personal experiences of a community or privileged informants, and aims to make these accessible to others (Rodrigues, Carvalhal, & Alarcão, 2008) is advocated as a highly flexible tool for participatory evaluation (Wang & Burris, 1994). Photovoice is becoming more common in interventional research, and has been described as *an empowering process* since it offers an opportunity for action and reflection that fosters the progressive development of participatory skills (Jason et al., 2004; Zimmerman, 1998). Photovoice entrusts photographic cameras to the hands of individuals and captures their voices and visions about their lives, community, and concerns, so they can act as recorders of their own story or lived experience (Fleury, 2002; Wang, Burris, & Xiang, 1996). By sharing and talking about their photographs, they use the power of the visual image to communicate their life experiences, expertise and knowledge.

Promoting a participatory evaluation advocates a more collaborative approach to the intervention. Listening to and learning from programme beneficiaries, field staff, and other stakeholders who know why a programme is or is not working is critical to making improvements. Also, the more these insiders are involved in identifying evaluation questions and in gathering and analysing data, the more likely they are to use the information to improve performance. Participatory evaluation empowers programme providers and beneficiaries to act on the knowledge gained.

This exploratory study aims to use photovoice to evaluate the clinical relevance and benefits of a psychoeducational programme developed to support families that care for an older person with dementia in their homes (proFamilies-dementia). Additionally, it aims at understanding the relevance and the contributions of this participatory methodology in the evaluation of these types of programmes. This study makes an important contribution to understanding the impact of psychoeducational interventions on the dementia–family-care context that goes beyond that traditionally assessed by standardised outcome measures and, as well, contributes to understanding the suitability of other evaluation methodologies to capture these effects.

## 2. Methodology

### 2.1. Design and setting

Researchers employed a qualitative method of research and participative action (photovoice) to evaluate an exploratory psychoeducational intervention (proFamilies-dementia), developed to support families that care for an older person with dementia in their homes. This study was developed at the Health Care Centre of Ílhavo (Portugal), i.e., in a primary care context. The study was approved by the Ethics Committee of the Health Administration of the Centre Region.

### 2.2. Participants

The sample consisted of 6 people from 5 families who participated in proFamilies-dementia (Table 1). One family was represented by 2 family members and the other 4 were represented by the main caregiver of the person with dementia. The average age of non-patients was 56.2 years (SD = 15.42) and 5 were female. Regarding the kinship to the person with dementia, there were 2 spouses, 2 children, 1 niece and 1 son-in-low. The 5 persons with dementia had an average age of 79.6 years (SD = 5.77) and 3 were male; all of them were retired. One participant had been diagnosed for only 2 months when commencing the programme but the other 4 had been diagnosed for more than 1 year.

Prior to intervention, participants were informed about the study objectives, design and methods and the right to freely participate or withdraw at any time during the study. Anonymity and confidentiality were guaranteed and authorisation to video-record the sessions was requested; written informed consent from each participant was obtained.

**Table 1** Characteristics of Participants

| **Older person with dementia (n=5)** | | |
|---|---|---|
| *Gender* | Female | 2 |
| | Male | 3 |
| *Mean age in years* | | 79.6±5.77 |
| *Dependence level* [Barthel Index, 1965] | Total | 1 |
| | Moderate | 1 |
| | Mild | 3 |
| | | |
| **Family members (n=6)** | | |
| *Gender* | Female | 5 |
| | Male | 1 |
| *Mean age in years* | | 56.2±15.42 |
| *Professional status* | Work at full time | 1 |
| | Retired | 5 |
| *Kinship with the older person with dementia* | Spouse | 2 |
| | Daughter | 1 |
| | Niece | 1 |
| | Son-in-law | 1 |

### 2.3. Intervention

ProFamilies-dementia is a psychoeducational intervention programme based on a participatory approach (Guerra, Mendes, Figueiredo, & Sousa, 2011). The name “proFamilies” was adopted to reflect three aspects – pro is an abbreviation of programme; pro is also used as a term meaning in “favour of” reflecting the aim of supporting families caring for people with dementia; finally pro can also be used to reflect the positive aspects or strength of something (i.e pros and cons) hence the term aims to acknowledge and utilise family strengths in supporting people with dementia. ProFamilies dementia adopts the following principles: (a) family-centred, since it considers family potential as a fundamental social support resource for elderly people with dementia; (b) integrated, that is, it involves social, health, educational and psychological support, combining support for the patient and for the non-patient family members and offering short and medium-term support; (c) and uses a empowering approach, which shifts the emphasis of the intervention from what went wrong, to what can be done to enhance functionality, and builds on family strengths and resources that enable them to overcome life’s challenges and support the healthy development of all the family (Egan, 1998; Saleebey, 2001). ProFamilies-dementia was developed to support families that care for an older person with dementia in their homes. It aims to promote family and community care, and to facilitate the connection between family and formal support systems (social and health).

The programme consisted of six sessions of 90 minutes, one per week. A multi-family discussion group format was adopted and followed a highly structured protocol, consisting of two components: educational and supportive. A psychologist and a gerontologist, who combine experience and training in psychoeducational and family interventions for families caring for older people with dementia, facilitated the sessions. The programme used a multi-disciplinary approach with additional input from a family general practitioner, nurse and social worker.

Table 2 briefly describes the programme sessions. In addition, the participants: i) participated in relaxation at the end of each session in order to learn relaxation techniques and to develop effective ways of dealing with stress; ii) received handouts summarising the main topics of each session; iii) and received a ‘home work’ assignment at the end of each session, putting into practice some of the activities they learnt during the group.

**Table 2.** Description of the sessions

| Session | Components | Description |
|---|---|---|
| 1 | Presentations | Introduction of the group facilitators, the families and the programme. |
|  | Information about the disease | A doctor provides basic information about dementia and answer participants’ queries. |
|  | Impact of the disease in family life | Participants identify the positive and negative impacts of the dementia diagnosis on their family life, in order to normalize the experience of dementia and to establish unity among group members. |
| 2 | Self-care | Families are encouraged to improve their self-care, giving special attention to the principal caregiver. |
|  | Introduction of relaxation techniques | The benefits of the relaxation techniques are introduced. Participants are invited to engage in a cognitive relaxation. |
| 3 | Caring for the older person with dementia | A nurse provides information on relevant topics (such as, nutrition, personal care, and the administration of medicines) and answers the participants’ queries. |
|  | Stress management | Participants are encouraged to develop more efficient strategies of stress-management. |
| 4 | Communicating feelings | Participants discuss how to communicate their feelings, needs, and concerns more effectively, preventing misunderstandings and promoting positive interaction. |
|  | Communication and dementia | Participants identify how they might change their behaviour or manipulate the environment in order to maximise communication with their relatives with dementia |
|  | Social networks | The role of in/formal social networks as sources of emotional and practical support is discussed. |
| 5 | Community resources | A social worker presents the available community resources. |
|  | Emotion-management | Families are encouraged to improve their emotion-management strategies. The debate is centred upon the emotions experienced by the members of the group since “*the arrival”* of the illness. |
| 6 | Mastering caregiving decisions | Projects for the future are discussed in order to allow participants to maintain significant goals for their individual and family lives. |
|  | Legal and financial issues | Information on legal support and social welfare are provided; and the need to plan the future of the older person with dementia is underlined. |
|  | Ritualise and finalisation of the group | This final meeting includes a celebration/party, which takes place in an informal environment. |

### 2.4. Evaluation Procedures

At the end of the last psycho-educative session, the facilitators introduced the importance of images as privileged vehicles of communication. They explained that each family would receive a photographic camera with the aim of exploring, through images, the positive and negative impacts of the programme on their lives. They were encouraged to take as many pictures as they wished, during the following 3 months, with the aim of selecting 6 photographs: 3 to represent positive impacts and 3 to represent negative impacts of the programme. Ethical considerations, such as the need to get prior consent of those being photographed, were carefully highlighted and explained.

Data was collected at a post-intervention stage, 3 months after the intervention. Two weeks before the evaluation session, the cameras were collected so that the photographs could be developed. The printed photographs were then returned to the families who selected those they wished to discuss at the evaluation session; 3 families selected 4 photographs, the other 2 families selected 6 images.

The evaluation session aimed at encouraging participants to share their interpretations and thoughts about the meaning and significance of their own selected images. It lasted 90 minutes, was video-recorded and coordinated by the programme facilitators. After the participants had been welcomed, the facilitators encouraged informal discussion about their experiences during the 3 months since the end of the programme (this part lasted 15 minutes). Participants were then asked to present the 6 photos they had selected to the rest of the group; as none of the families had selected any photographs portraying negative impacts of the programme, facilitators allowed them to share up to 6 photos concerning the positive aspects. Each photograph was explored individually and then discussed among the participants. The researchers used a script with semi-structured questions and encouraged the participants to take a critical stance by framing their stories in terms of questions spelling the acronym SHOWeD (Wallerstein, 1987): What do you See here? What's really Happening here? How does this relate to Our lives? Why does this problem or this strength exist? What can we Do about this? The participants were also asked to reflect on their experiences of using photovoice including what difficulties they experienced, how they felt, and whether they found it an interesting experience. At the end of the evaluation session the participants were thanked for sharing their thoughts and feelings and encouraged to contact the team whenever they needed to.

### 2.5. Data analysis

The evaluation session was video-recorded, with the prior consent of the participants, and later transcribed and submitted to thematic analysis. The process of categorisation was based on the visual data (which provided information on non-verbal behaviours), the transcripts and photographs. The researchers used an inductive approach, refraining from conducting a formal review of the literature prior to data analysis as doing so may “bias the researcher’s thinking and reduce openness to whatever emerges in the field” (Patton, 2002, pp. 226). The analytical procedures recommended by Foster-Fishman et al. (2005) were adopted: i) all of the researchers read the transcript and independently identified major themes; ii) the themes were compared and discussed by the team until agreement was reached; iii) then the transcription was coded by two of the authors; iv) resulting themes were discussed again and areas of disagreement were identified and resolved, creating a final coding scheme for the transcriptions. For each emergent theme, the authors selected one verbatim extract and identified the photograph that triggered most dialogue among participants as an exemplar of that theme. All of the participants authorised, with written consent, the publication of their photos.

## 3. Results

All families only selected photos representing positive impacts of the programme stating that it only brought them *good things*. Each participant presented his/her own perceptions of the positive impacts of the programme. However, all other participants agreed with each of these benefits, even when they had not identified them previously. Lively discussions took place about each photograph with participants asking questions about each image in order to get a better understanding (e.g. "Who is this?"; "What is this?").

All photos (with the exception of one, which was taken in a coffee shop) were taken in the participants' homes. This may have been because ProFamilies-dementia is centred on the family and participants tried to capture a more familiar environment or because participants had difficulty in leaving their homes, since they had to provide care for their relatives with dementia.

The reported positive impacts were organized into seven major themes: better emotional management; family union and quality of life; increased awareness of self-care; better understanding of the disease; normalisation of feelings; ability to perceive positive aspects; and increased capacity to seek, ask and receive help.

### (a) *Better emotional management*

Five families (6 photos) (see Figure 1) reported "better emotional management", stating that they *learned more about how to deal with emotions*, since they now had *more patience*, *more tolerance*, and *a greater capacity for understanding*, which made each of them experience *increased self-control*.

"*I used to grumble a lot with my father* [patient] *when I was upset, because I need to find relief. Now I act normally, I don't show him I'm angry*." [Family Dias[4]]

*"I was never a patient person, but now I'm more patient with my husband* [patient]. *I've learned how to deal with situations that bother me."* [Family Rodrigues]

*"The programme helped me to be more patient and more indulgent. I've acquired the ability to control myself in difficult situations."* [Family Costa]

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[4] All names were altered to protect the participants' identity.

Participants mentioned that they are now using some of the emotion-management strategies they had learnt during the programme, and not only in situations related to the disease, but in other situations of their lives.

*"I learned how to deal better with some situations: now, when I feel upset, I can calm down easily and I try to understand the situation and reflect on it."* [Family Santos]

**Figure 1**. "Dealing with it"[5]

(b) *Family union and quality of life*

Three families (4 photos) (see Figure 2) reported improved "*family unity and quality of life*" mentioning that they now: i) spend more quality time with the patient and also with other relatives (in particular their children and grandchildren); ii) are more appreciative of the support they received from their friends and relatives.

*"My family is closer now. My daughter and my grandson spend more time with me and go more often to my house."* [Family Rodrigues]

*"Our family became more united."* [Family Costa]

*"Now I spend more time with my husband* [patient] *and I try to make him feel good."* [Family Dias]

*"I took this picture to my mother to show her that she's important to me. I tell her that she gives me a lot of work and, by taking this photo, I wanted to show her that she helps me and that I need her."* [Family Santos]

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[5] The title of each image reflects the designation given by the participants.

**Figure 2.** "Family unity"

(c) *Increased awareness of self-care*

Although only 2 families pre-selected photos (3) (see Figure 3) concerning the *increased awareness of self-care*, all the participants agreed with this impact during the photovoice discussion and highlighted how important it was for them to be able to enjoy their free time without guilt. This was promoted by the encouragement received in the proFamilies-dementia group where they could understand the relevance of self-care (*if we take care of ourselves, we'll have more capacity to care for the others). "This picture represents a moment of relaxation and peace. My son was painting his sister's nails and my mother was watching television. We were all together, enjoying our time. I've realized that self-care is very important."* [Family Santos]

*"I've realized that the meetings with my sisters are very helpful for me. Our meetings are our "party recreation": they are not too much, but they have quality, we can relax and enjoy our time."* [Family Dias]

**Figure 3.** "A moment of relaxation and peace"

(d) *Better understanding of the disease*

Two families (3 photos) (see Figure 4) reported receiving information that had helped them to understand the disease better, in particular they gained an understanding of: i) the patients' behaviour (such as forgetfulness or aggressiveness) and realised that no one was to blame; ii) how to communicate with the person with dementia, especially using touch because they realised the importance of communication using the senses; iii) the importance of stimulation, and, as a consequence they now encouraged the family member with dementia to maintain their hobbies and past-times and tried to do these activities *with* them. Participants stressed the importance of having a medical doctor explaining what dementia is and how it is manifested. As a result, they had developed an improved sense of competence.

*"Now I touch my husband* [patient] *plenty of times, because I've learned that touch is very important. I also learned that stimulation is important. Now I encourage my husband to walk. I know that he needs to move. I understand the disease better!"* [Family Costa]

*"I understand now how to communicate with people with dementia. The folder I've photographed symbolises the information I've acquired."* [Family Dias]

**Figure 4.** "The touch"

(e) *Normalisation of feelings*

Two families (2 photos) (see Figure 5) emphasised the "normalisation of feelings" which they associated with the sharing of experiences in the psychoeducational group. In the group they had the unique opportunity to share *things* they had never previously shared, for fear of being misunderstood, even by their closest relatives and friends. The feelings they felt were most important to share, and as a consequence, to feel relief from were: *feeling tired with their situation; ticking off the person with dementia and then feeling guilty; feeling frustrated at not having free time*. The participants realised the importance of meeting other people who were living through *the same situation*, because it reduced the feeling of "*being on your own*" and made them aware that "*everyone has problems*".

"*We shared our feelings with no constraints and without fear of not being understood. The group was sympathetic and gave me strength.*" [Family Dias]

“*Now I know that all of us have problems and it feels good to share them*.” [Family Rodrigues]

**Figure 5.** “The sharing”

(f) *Ability to perceive positive aspects*

One family (2 photos) (see Figure 6) reported an increased ability to “perceive the positive aspects” of the caregiving circumstances they were going through. The family mentioned that it was almost impossible for them to find something positive before their participation in proFamilies-dementia; afterward, they realised that finding the positive aspects made them feel stronger and more able to cope with the situation. For instance because one family who was caring for two parents with dementia, identified that they received more visits from other family members.

“*It was very difficult to find something positive concerning my situation. It’s hard to take care of two people with dementia and it is even harder when those people are our parents, since we watch them suffering. But now, I try to focus on something positive, such as the time I spend with my sisters.”* [Family Dias]

**Figure 6.** “The positive aspects”

(g) *Increased capacity to seek, ask and receive formal support*

One family (1 photo) (see Figure 7) mentioned an increased capacity to seek, ask for and receive formal support, which reduced their stress level. Before the participation in proFamilies-dementia this family thought that it was their obligation to care for the older relative with dementia without any help. Now they felt comfortable asking for help, especially because they were encouraged by the social worker, who explained the benefits of having formal support. In addition, they now placed greater value on the support they received from relatives.

*"I've realised that seeking help is not a bad thing. I think that I'll ask for some formal support to help me, such as home care services."* [Family Rodrigues]

**Figure 7.** "Seeking help"

*Photovoice experience*

Participants reported that they were initially surprised and curious about the proposal to evaluate the ProFamilies-dementia programme through photographs. At the beginning, they were concerned about the difficulty of transforming abstract ideas into photographs. However, after starting, they found this easier and saw it as a positive experience for the following reasons: it enabled them to reflect on their caregiving situation and the implications on their family life; it facilitated the sharing of testimonials among participants; it allowed them to explore, interpret and communicate their feelings; it *forced* them to leave their "*self-indulgence" and* "*self-pity*"; it encouraged them to adopt a more active role in representing themselves and the others and it gave them something to recall as they saw the photographs as a memory and a tribute of what they lived, felt, and learned during proFamilies-dementia.

"*When I was asked to photograph the impact of the programme, I had many doubts. But then it was easy, I only had to think and shoot. Also, my sisters helped me. It was good to use this method since it forced us to think and to leave our self-indulgence and self-pity, by encouraging us to analyse our situation.*" [Family Dias]

*"It is so good to have these photographs with us… Every time I'll look at them, I will remember all of you and everything that we have shared here."* [Family Santos]

Photovoice also offered participants an opportunity to dialogue about dementia in ways they never had. Families reported that they had been constrained in talking about dementia in their family before participating in proFamilies-dementia and that taking and looking at pictures together effortlessly led to discussion about dementia within the family.

*"This is a good way to communicate to the others what we feel… it makes me feel good to look at a photo and explore all the meanings it has to me. I even feel more comfortable to share talk about some issues regarding dementia with my relatives."* [Family Rodrigues]

Families clearly showed intentions to act, which is the most advanced stage of critical consciousness (Freire, 2005). They were willing to help and share information with other families who were in the same situation and they also expressed the intention of keeping in contact with the families who participated in the programme.

*"This is my second family. I want to keep the contact with all of you."* [Family Dias]

## 4. Discussion

### 4.1. Clinical significance of proFamilies-dementia

The evaluation of proFamilies-dementia using photovoice revealed only positive impacts of the programme that seemed to describe its clinical significance in terms of the process of going beyond illness, negativity and loneliness.

Living and caring at home for a relative with dementia turns family members' focus onto the illness (e.g., Rolland, 2009). The impacts revealed by the proFamilies-dementia participants indicated that they could now go beyond an illness-focus. For instance, they were able to apply their enhanced emotional management skills to other areas of their lives, revealing that the experience of the illness in the family could be used positively. They also reported enhanced family unity and quality of life, appreciating the time they spent with their family and with the person with dementia. In this way the illness was no longer an obstacle to the quality of relationships within the family. Increased awareness of the importance of self-care can be viewed as putting the illness in its place (Gonzalez, Steinglass & Reiss, 1989), because life is not only focused on the demand of the illness but also on the family's own well-being.

When a severe chronic disease arrives in a family's life, negativity often results (Steinglass, 1998). Dementia is one of the most disturbing diseases in family life. This is due to the ambiguous loss involved where the person with dementia is physically present but cognitively and emotionally lost (Boss, 2007). In addition, caregiving tends to be more demanding in dementia, involving daily 24 hour care with a person who may not be cooperative. It is undeniable that some negativity will be involved, but relatives need to gain some sense of competence in order to cope with the circumstances, and maintain a sense of well-being (Steinglass, 1998). It seems that the participation in proFamilies-dementia allowed family members to be more positive. For instance the ability to apply the emotional management skills to all areas of life was an example of one way in which people reported that good *things* had come because the disease had occurred; and participants directly mentioned ability to perceive positive aspects, meaning they now feel stronger and more able to cope with the situation.

When a severe disease, such as dementia, happens to a family there is a tendency for the family to focus all of their attention inward (Rolland, 2003; Combrick-Graham, 1985), reducing or avoiding contact with the outside world, which may reinforce feelings of loneliness and lack of support. This internal focus is, to some extent necessary, as high family demands come to the fore. However balance is required to prevent the family from becoming too closed and isolated. It seems that the participation in proFamilies-dementia allowed families to move beyond loneliness. Participants stated that proFamilies-dementia allowed them to view their feelings as normal. By sharing their feelings they found that they were not ”alone”, and they gained increased capacity to seek, ask for and receive support, which reduced their stress levels and their isolation.

It seems that understanding the disease is the first step toward all the other gains. This has been reported as relevant in most severe chronic diseases (e.g., Chiquelho et al., 2006), but it seems to be even more relevant in dementia which is emotionally and relationally more difficult to deal with, and which often goes unrecognised and undiagnosed (e.g., we still listen to family members wondering if the relative with dementia actually has a disease or is just being unkind) and socially stigmatising.

Using photovoice to focus on the clinical significance of ProFamilies-dementia allowed us to capture the processes established in and by participants as a result of the programme. This process involves a change of perspective and attitudes that transforms the way the family and its members view themselves, their relative with dementia and others. It seems to be a process of becoming individuals and families who are living with a stressful situation as are many other people and families.

### 4.2. Photovoice: relevance and the contributions

Photovoice was used as an evaluation method for capturing the clinical significance participants gave to the proFamilies-dementia intervention. However, it proved to be more than this, becoming an extension of the intervention itself as it encouraged participants to remember and reflect on what the programme had meant to them. This happens because photovoice is simultaneously a reflexive methodology (since it gives time for people to think) and spontaneous (since it allows families to capture their ideas as they arise). In this sense it empowers and serves both researchers’ and participants’ interests. In particular, the photographs enabled researchers to view the world through the eyes of the participants. This facilitated deeper knowledge of them and their reality, and enabled researchers to capture insights which may not have been revealed through other means (Palibroda, Krieg, Murdock, & Havelock, 2009). In contrast, traditional quantitative evaluation methodologies are focused on specific predetermined outcomes (e.g., depression, anxiety). This limits access to participants’ experiences beyond those considered relevant by the researchers.

Photovoice may be considered a more person-centred approach because it allows families to specify what components of the intervention and which outcomes have been most important to them. The use of group discussion allowed participants to identify impacts that neither they nor the researchers had previously defined or anticipated. The increased awareness the importance of self-care is an example; although only two families pre-selected photos regarding its importance, all the participants agreed with this impact during the discussion and emphasised how important it was for them. The impact of photovoice went beyond those which are usually anticipated. For instance, families reported they were using some of what they had learned in other spheres of their lives, beside the provision of care. Photovoice also forced participants to undertake a deeper analysis of the significance of the programme, going beyond reporting the extent of improvements (such as better stress management) and accounting for changes and adjustment in their daily lives. Finally, photovoice enabled people to make their reflections and emotional processing more concrete. The photographic images embodied something of the intra-individual and familiar processes, allowing participants to see "themselves from the outside", and therefore to learn more about themselves.

Other advantages of using photovoice as a participatory tool to evaluate the clinical significance of these type of programmes were noted: (a) it facilitated participants' ability to express their feelings and thoughts, since photos served as stimulators, promoting the dialogue and the expression and sharing of ideas; (b) it encouraged discussion as participants always wanted to know more about each photo; (c) it provided common ground amongst a group of people who were heterogeneous in terms of socioeconomic background, helping all members to share and gain valuable insights and understanding of important issues; (d) it reinforced the bond between participants, as they shared intimate topics in a supportive environment which made them feel safe and comfortable; (e) it improved their interactions with other family members since they were involved in the process of taking photos (e.g., participants asked them for help to take the pictures); (f) it promoted the search for positive meanings and behaviours, giving continuity to the competences promoted by the programme. This is especially relevant when it is anticipated that the care recipients' clinical situation will worsen and because palliative coping, which is focused on the emotions and on reformulating the process, is known to be more effective than trying to solve a situation that has no solution (Belsky, 1999; Nolan, Grant, & Keady, 1998).

This methodology also has some disadvantages and difficulties. The use of this method did not lead to the identification of any negative impacts. This may be due to several factors: (a) participation in proFamilies-dementia was a unique experience in the participants' lives. It was the first time they had received any special attention centred on their role as caregivers of a relative with dementia and this may have encouraged participants to focus only on the positive elements; (b) the photography is a tool for self-expression and photographing can constitute a "therapeutic" experience *per se*; (c) people may be culturally biased toward taking photographs which highlight positive aspects that are worth celebrating and memorialising in photographs;

(d) there may also be a memory bias, such that certain aspects of the programme lend themselves more to being photographed than others.

The main limitation of this method seems to be with data analysis that, as in most qualitative methods, is a lengthy process which requires thorough attention to detail. Researchers must be very attentive to every detail of the participants' photos, conversations and behaviours, in order to interpret what they intend to convey. Some authors suggest that it is relevant to involve participants in data analysis (Sousa, Silva, Marques, & Santos, 2009), which did not occur in our research, but may be a relevant addition to future studies.

### 4.3. The contributions of this research to the development of programmes in the field of dementia caregiving

Our experiences with proFamilies-dementia and the use of photovoice to evaluate its clinical significance leads us to make recommendations for the design of future programmes and evaluations: (a) families may benefit from using the photovoice method during the programme (for instance, introducing it as an exercise early in the programme), to help them get used to the method and develop their skills in using photography to convey meaning; (b) families should be specifically encouraged to take pictures in all contexts, to capture the *spontaneity* of thought and to acknowledge the wider impact; (c) facilitators can explore the impact of the programme on the non-participant family members in order to evaluate the indirect impact.

## 5. Conclusion

ProFamilies-dementia responds to the needs of families caring at home for a relative with dementia, in particular by facilitating the process of going beyond a focus on illness, negativity and loneliness. Photovoice appears to be a useful method for capturing and extending this process, by facilitating participants' engagement in an ongoing reflection process about their experiences. This empowered participants, and contributed to the development and strengthening of positive behaviours and thoughts. As an evaluation research method, photovoice provides in-depth data and the potential for bringing out additional information that might not emerge during traditional interviews or focus group discussions. Overall, this methodology is an excellent tool for examining the impact of participatory methods on participants as it combines a variety of techniques which engage participants in ongoing reflection about their world (Foster-Fishman et al., 2005). These results underline the relevance of integrating new research approaches in clinical settings to increase our understanding of the contextual processes related to expected outcomes (Baum, 1995).

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## 1.3. BEING A VOLUNTEER: MOTIVATIONS, FEARS AND BENEFITS OF VOLUNTEERING IN AN INTERVENTIOS PROGRAM FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES[6]

Sara Raquel Costa Guerra
University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago 3810-193 Aveiro, Portugal
sara.guerra@ua.pt

Sara Demain
University of Southampton, School of Health Sciences, Building 45, Highfield, Southampton, SO17 1BJ, United Kingdom

Daniela Maria Pias Figueiredo
University of Aveiro, Health School, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal
Unidade de Investigação e Formação em Adultos e Idosos, University of Porto, Portugal

Liliana Xavier Marques de Sousa
University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal
Unidade de Investigação e Formação em Adultos e Idosos, University of Porto, Portugal

### Abstract

ProFamilies-dementia, a program designed to support families caring for a person with dementia, included a component of Meaningful Occupation (MO), provided by volunteers. This study aimed to explore the volunteers' motivations and fears and evaluate the benefits of their involvement. MO involved 6 volunteers, 3 people with dementia and their families. Data were gathered through semi-structured interviews. Main findings suggest that: volunteers were motivated by altruistic values, while fearful of inadequate performance; they perceived an increased sense of competence, but reported some disappointment about the limited professional growth; families reported that they wanted greater opportunities for interaction with the volunteer.

**Key-words**: dementia, fears, meaningful occupation, motivations, volunteers.

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## 1. Introduction

Volunteering incorporates any activity in which time is given freely to benefit another person, group or cause. Volunteering is part of a general cluster of helping activities; unlike the spontaneous help given to the victim of an assault, where it is necessary to decide rapidly whether or not to take action and the encounter is brief and often chaotic, volunteerism is typically proactive rather than reactive and entails some commitment of time and effort (Wilson, 2000).

Under Portuguese legislation (*Decree-Law nº 71/98 of November 3*), a volunteer is an individual that, in a free and responsible way, commits to perform voluntary activities within an organization, according to his/her skills and time available, without the expectation for payment (Association of Voluntary Service Organizations, 2005). In Portugal, civil society (which includes the Non-Governmental Organizations) requires almost a quarter of a million full time equivalent employees; about 70% are in paid positions and the remaining 30% work as volunteers (Franco, Sokolowski, Hairel & Salamon, 2005). These numbers represent about 4.2% of the working-age population. In recent years, volunteering and the critical role it plays supporting non-profit organizations, has gained increasing attention from the general public and researchers (Parboteeah, Cullen & Lim, 2004; Dekker & Halman, 2003). The value of volunteers to society is unquestioned, since they are often key to the provision of many social and community programs (Wilcox et al., 2004). Therefore, identifying, recruiting and engaging volunteers has become both a priority and a challenge for many service agencies (Dutta-Bergman, 2004).

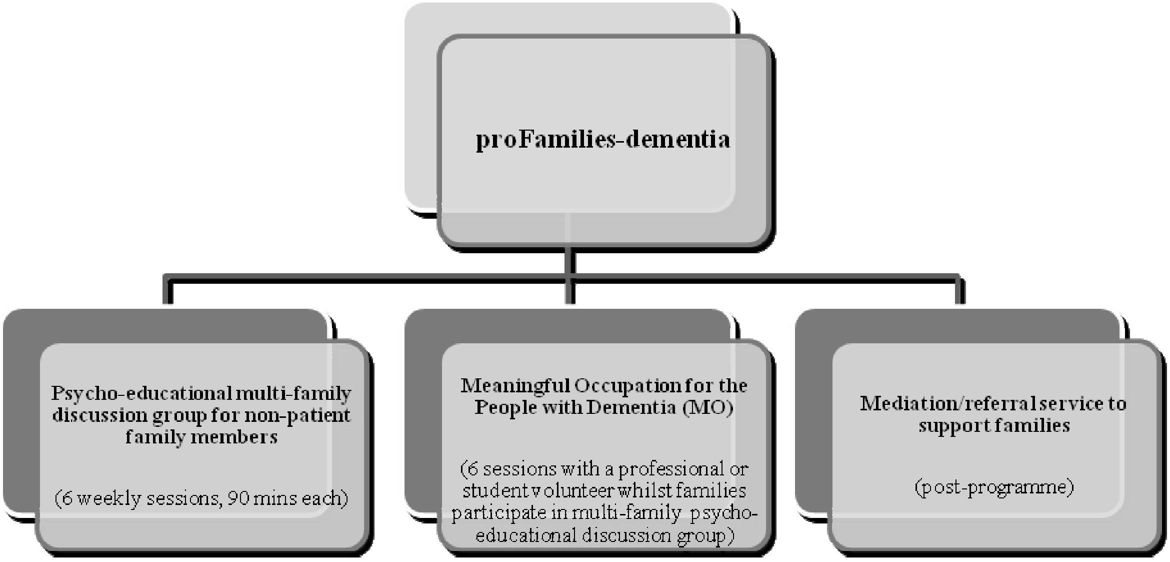
The motivational drives of those who volunteer have been a recurring theme in literature (e.g., Esmond & Dunlop, 2004). Knowing volunteers' motivations, fears, and what they gain from volunteering may help researchers, practitioners and agencies to adjust volunteering programs to maintain volunteers' satisfaction and maintain their commitment. Shye (2009) suggests that the opportunity to develop friendships and gain a sense of community belonging are the most important motivations for volunteering, while Esmond and Dunlop (2004) found that deeply held values about the importance of helping others, were the most important motivations. Altruism is a motivator in many types of volunteering (Bussell & Forbes 2002); however intrapsychic motivations are also often simultaneously present (Cnaan & Goldberg-Glen, 1991): volunteers want to help others and, simultaneously, they need to experience personal development.

This paper aims to: i) describe the development and implementation of a volunteer led intervention for people with dementia, as part of a larger program designed to support families caring for a person with dementia at home; ii) explore the motivations and fears of the potential volunteers; (iii) evaluate volunteers' perceptions of the benefits of taking part and the suggestions of both families and volunteers about how the volunteers' role could be improved.

## 2. Use of volunteers in proFamilies-dementia

Living with and/or caring for an older person with dementia is usually a more difficult task than caring for a frail older person who is not cognitively impaired and who can understand and co-operate with what carers are trying to do. Families often perform a full-time, highly specialized role, which requires expert knowledge, skills and attitudes. A broad range of intervention programs have been developed to help people involved in caring for people with dementia, including individual or family counselling, case management, skills training (Schulz, Martire & Klinger, 2005); but mostly psycho-educational approaches (Brown, 2004). Interventions that take a psycho-educational approach have a greater effect than those that use education alone (Pinquart & Sorensen, 2006; Sorensen et al., 2002), since they enable carers to actively apply the general information received to their specific situation (Zarit & Femia, 2008). ProFamilies-dementia (Guerra et al., 2010) is an intervention program with the purpose of promoting healthy adaptation and improving the quality of life and well-being for families who have a relative with dementia. It is based on a participatory approach that adopts the following principles: family-centred, integrated and empowering. Pro-families comprises three components (Figure 8): a) *psycho-educational support* provided in a multi-family group setting to families of people with dementia, where they receive information and psychosocial support; b) a mediation service to facilitate links between families and community social and health services; c) Meaningful Occupation (MO) for the people with dementia.

**Figure 8.** Components of proFamilies-dementia



The MO component was developed because during the recruitment to the psycho-educational component it became apparent that some family carers were keen to participate but unable to do so because they had no-one to care for their relative with dementia while they attended the group (Brodaty et al., 2005). To facilitate adherence, our research team decided to organize a group of volunteers who could be with the person with dementia while their relatives attended the psycho-educational sessions. As these volunteers would also provide motor and cognitive stimulation to the person with dementia, qualified and student health professionals with appropriate knowledge and skills for working with people with dementia were deemed appropriate. This decision enabled the development of a low cost program, which would be easy to replicate and disseminate and which fosters a culture of solidarity with the population, increasing their participation level.

This component of proFamilies-dementia, which was named MO, aims to: i) allow families to participate in the psycho-educational sessions; ii) perform meaningful activities with the person with dementia, in order to rediscover and maximise their potential; and iii) provide families with concrete information about suitable cognitive stimulation tasks they could do with their relative with dementia. The components of proFamilies-dementia are summarised in Figure 8.

The following ground-rules were established for the volunteering element of the program: i) in order to establish and maintain a rapport with the person with dementia and their family the same volunteer would remain with each family during the program; ii) the volunteer would provide meaningful activities while supervising the person with dementia; iii) in order to maintain dignity and prevent confusion the person with dementia would be informed about the presence of the volunteer. Given the variability in lucidity that occurs in dementia, it was anticipated that this explanation would need to be tailored to the needs of the person with dementia and repeated throughout the program; iv) the volunteer needed to be available on the same day of each week; v) the volunteer would document the activities performed and the degree of collaboration and participation gained from the person with dementia at the end of each session.

The development of MO also followed the Guiding Principles of Volunteering contained in the Portuguese Decree-Law nº 71/98 of November 3: participation, cooperation, complementarity, convergence, gratuity and responsibility. The law recognizes that voluntary action is one of the basic instruments for the participation of citizens in society and acknowledges the freedom and flexibility inherent in volunteer activities.

## 3. Development and implementation of the MO

### 3.1. Procedures and recruitment

This project was approved by the Ethics Committee of the Health Administration of the Central Region, and authorized by the Health Care Centre of Ílhavo (Portugal). In order to implement this component, the researchers requested the support of an occupational therapist with expertise in dementia and cognitive and multi-sensorial stimulation to develop a dementia caregiving training plan for the volunteers.

The volunteer scheme and training plan were widely advertised through flyers and posters (distributed at the Department of Health Sciences of University of Aveiro and at the Portuguese Red Cross), among health professionals and healthcare students who had experience or training in gerontology, geriatrics and/or dementia care. It was made clear that participants should be available to commit themselves to develop activities with people with dementia once per week, over a 6 week period; 6 people volunteered by expressing to the first author their interest in participating in the training and their commitment to the activities once a week with people with dementia.

Before the training, all the volunteers provided socio-demographic data and then completed a brief individual semi-structured interview around two topics: (a) *"Why are you considering joining the program*?" (motivations); (b) "*What are your main concerns/fears about your participation as a volunteer*? (fears). This was conducted by the first author (SG) at the University of Aveiro (average duration of 15 minutes). The interviews were taped, transcribed and submitted to thematic analysis. All of the researchers read the transcripts and independently identified major themes; the themes were then compared and discussed by the team until agreement was reached; the transcription was coded by one of the authors; resulting themes were discussed again and areas of disagreement were identified and resolved, creating a final coding scheme for the transcriptions.

Volunteers reported that their motivations to join the program related to: altruistic values; learning; personal growth; sharing of experiences. The volunteers' were fearful about: inadequate performance; inadequate relationships; and taking on a big responsibility. Table 3 provides verbatim quotes to illustrate these themes.

**Table 3**. Motivations and fears of the volunteers

| **MOTIVATIONS (number of reports identified)** | **VOLUNTEERS' REPORTS** |
|---|---|
| VALUES: ALTRUISTIC BELIEFS (n=5) | "This is voluntary, civic-spirited and humanitarian work and I really need to have an unpaid occupation. I think it's important that people participate in these projects because if I was developing a program like this one, I would also need people to be available." (L., 51 years)<br>"This is an interesting and needed program for the families, who are currently helpless. I want to contribute, as a citizen, to the volunteering and I want to feel good about myself for helping those in need." (C., 24 years)<br>"I see this as an opportunity to provide moments of relief and distraction to the families and I want to give them an opportunity to participate in the program while I'm with their relative." (R., 23 years)<br>"This project is an asset to the person with dementia and his/her caregivers. I really want to help." (I., 19 years)<br>"I would like to help these families. I truly believe in these projects and I recognize that families need this type of support." (L., 23 years) |
| LEARNING: KNOWLEDGE & SKILLS (n=5) | "This is a learning experience for me. I know it will help me know how to intervene with a person with dementia, that is, I consider my participation as a huge opportunity for my training as a gerontologist." (R., 23 years) |

| | |
|---|---|
| | “I want to gain knowledge and to improve my skills and attitudes in this area, namely: become more aware of dementia symptoms and learn how to communicate with a person with dementia.” (I., 19 years)<br>“I want to improve my communication (verbal and nonverbal) with people with dementia.” (L., 51 years)<br>“I want to learn how to deal with a person with dementia and to apply appropriate intervention strategies.” (C., 24 years)<br>“This program will help me to realize what kind of support these families need.” (L., 23 years) |
| PERSONAL GROWTH AND REALIZATION (n=2) | “I hope I’ll get some accomplishments at a person level.” (I., 19 years)<br>“I see this as an opportunity for self-fulfillment.” (C., 24 years) |
| SHARING OF EXPERIENCES (n=2) | “I feel motivated to share experiences with the other volunteers.” (I., 19 years)<br>“I would like to socialize with people who share my interest in dementia.” (J., 24 years) |
| **FEARS** | |
| INADEQUATE PERFORMANCE (n=5) | “I am afraid of acting or behaving inappropriately.” (L., 51 years)<br>“I’m afraid of not knowing how to deal with the person’s behavior.” (L., 23 years)<br>“I’m afraid of not being capable of delivering the intervention adequately to the person with dementia.” (J., 24 years)<br>“I'm afraid of not knowing how to deal with aggressive behaviors”. (I., 19 years)<br>“I'm afraid of rebuke the person with dementia.” (R., 23 years) |
| INADEQUATE RELATIONSHIP (n=3) | “I’m afraid of not being well received or understood by the families of the person with dementia.” (C., 24 years)<br>“I’m afraid of not being capable of establishing an empathetic relationship with the person with dementia.” (J., 24 years)<br>“I'm afraid that the person with dementia won’t feel comfortable with me.” (R., 23 years) |
| HUGE RESPONSABILITY (n=1) | “I’m afraid of being alone with the person. I feel that it is a huge responsibility.” (L., 23 years) |

The interview feedback was used to adjust the training to better meet the volunteers’ needs and to address their fears, as described below:

(i) Communication Skills: Volunteers feared an inadequate relationship and wanted to learn more about how to communicate with the person with dementia. The training therefore emphasized skills for communicating with people with dementia: different methods of verbal and non-verbal communication, the use of physical contact, and interpreting non-verbal signals, behaviors and images. They were also taught formal communicational strategies such as: (a) *Reality Orientation*, which aims to disrupt cognitive decline by stimulating the person with dementia with repetitive orientating activities such as reinforcing names, date, place and time (Scanland and Emmershaw, 1993); (b) *Validation Therapy,* which is based on the general principle of validation, the acceptance of the reality and personal truth of another's experience (Neal and Barton, 2003); (c) *Reminiscence Therapy*, which involves the discussion of past activities, events and experiences usually with the aid of tangible prompts such as photographs, music, household items and other familiar objects from the past (Woods et al., 2005).

To address participants' fear of an inadequate relationship with the family, two 'pre-contact' sessions with the person with dementia and his/her family were incorporated.

(ii) Sharing experiences: The volunteers reported a need to share experiences and to socialize with families. The volunteers attended the last psycho-educational session, for 1 hour. The families were asked to ensure someone else was available to stay with their relative during this time. The volunteers discussed their experiences of working with the families. They explored the activities and communication strategies they had used with the people with dementia, and shared how to deal better with the behavioral and psychological symptoms.

A focus group was also organized at the end of the program to formally assess volunteers' experiences; enabling them to share their views, feelings, thoughts and experiences. A dinner with the volunteers and research team was also arranged to provide an informal setting to share experiences and to thank the volunteers.

(iii) The fear of performing inadequately was also taken in consideration: the training plan focused on how to identify, understand and deal with major cognitive impairments of dementia.

(iv) To address concerns about the level of responsibility, volunteers were advised that they could call the family and/or the research team if there was a problem. In the event of an emergency they should also contact the Emergency services. The volunteers reported this helped them to feel more relaxed.

### 3.2. Training the volunteers

The volunteer training plan was developed around the following topics (Table 4): (i) the main changes in dementia, (ii) communicating with the person with dementia, (iii) the benefits of creative activities, movement and sensory stimulation, (iv) cognitive stimulation exercises, (v) engaging with the person with dementia and their families. The training plan was conducted over two sessions, each one lasting approximately 3 hours and 30 minutes. It was held in the Department of Health Sciences, at the University of Aveiro, Portugal. Volunteers received a certificate of participation. The occupational therapist offered to be available to support volunteers and answer any questions. Volunteers provided weekly feedback about the MO sessions to the research team.

**Table 4**. The volunteers' training plan

| **Module duration**: 7 hours | **Duration of each session:** 3h30 minutes | |
|---|---|---|
| **Educational Objectives** | | **Duration** (minutes) |
| **General** | **Specific** | |
| A. Contextualising dementia | A.1. Aging and dementia;<br>A.2. Identifying the main symptoms of dementia;<br>A.3. Identifying the early warning signs of dementia. | 27 |
| B. The major changes in Alzheimer's disease | B.1. Knowing the development of three stages of Alzheimer's disease;<br>B.2. Identifying and understanding how to deal with major cognitive impairment;<br>B.3. Identifying and understanding how to deal with the major changes in Activities of Daily Living<br>B.4. Identifying and understanding how to deal with behavior changes. | 90 |
| C. Recognizing the importance of communication with the person with dementia | C.1. Different types of communication;<br>C.2. Techniques and strategies to improve communication (e.g., validation therapy, reminiscence therapy, Reality Orientation Therapy). | 60 |
| D. Creative activities, movement and sensory stimulation | D.1. Identifying creative activities, movement and sensory stimulation and discussion about its impact. | 20 |
| E. Examples of cognitive stimulation | E.1. Examples of exercises to stimulate memory, praxis and executive functions;<br>E.2. Examples of attention and language stimulation exercises. | 30 |
| F. Planning the volunteers involvement and intervention with the person with dementia and their family | F.1. Planning the 1st contact with the family and the person with dementia:<br>F.1.2. Understanding the level of activity and expertise of the person with dementia;<br>F.1.3. Understanding interests, significant activities and routines of the person with dementia;<br>F.1.4. Understanding the persons' life history<br>F.2. Exploring the stage of dementia:<br>F.2.1. Identifying the major cognitive impairments in the Activities of Daily Living (ADLs), in the Instrumental Activities of Daily Living (IADLs), and in the behavior;<br>F.2.2. Selecting techniques and communication strategies;<br>F.2.3. Suggesting meaningful and motivating activities to develop to the person with dementia. | 100 |

### 3.3. Engaging the families

Families were contacted by telephone, informed about the purpose of the project and invited to participate. Researchers asked potential participants whether they would value using the volunteer service: 3 families (from 5 recruited) used the service; the remaining 2 had relatives who could stay with the person with dementia. 6 volunteers were involved, 2 for each family. This enabled all volunteers to contribute and reduced their anxiety by enabling them to share responsibility with another volunteer.

## 3.4. Participants

There were 3 groups of participants: volunteers, people with dementia and their relatives. The volunteers (n=6) were all female, 5 single, with a mean age of 27.16 years old (ranging from 19 to 51). The people with dementia (n=3), were all male and diagnosed with Alzheimer disease - 2 at a middle stage (case 1 and case 3) and 1 at the late stage (case 2). This classification was based on family members' reports regarding current symptomatology, and on their medical diagnosis, provided by their general practitioner (GP) from the Health Care Centre. The relatives of the people with dementia (n=4), consisted of 3 families, with 1 family being represented by 2 non-patient family members. The relatives had a mean age of 56 (SD: 19.69) and 3 were male (Table 5).

**Table 5**. Characteristics of participants

| | | |
|---|---|---|
| **Volunteers (n=6)** | | |
| *Gender* | Female | 6 |
| *Mean age in years* | | 27.16±11.82 |
| *Marital status* | Single | 5 |
| | Married | 1 |
| *Occupation* | Gerontologist | 4 |
| | Nurse | 1 |
| | Student in gerontology | 1 |
| *Area of residence* | Rural | 2 |
| | Urban | 4 |
| **People with dementia (n=3)** | | |
| *Gender* | Male | 3 |
| *Mean age in years* | | 77.66±6.80 |
| *Marital status* | Married | 3 |
| *Academic qualifications* | 4 years of school | 3 |
| *Dependence level* [Barthel Index, 1965] | Mild | 2 |
| | Total | 1 |
| *Diagnose* | Alzheimer disease | 3 |
| **Relatives of the people with Dementia (n=4)** | | |
| *Gender* | Female | 3 |
| | Male | 1 |
| *Mean age in years* | | 56±19.69 |
| *Marital status* | Married | 4 |
| *Professional status* | Housewife | 1 |
| | Retired | 2 |
| | Employed at full time | 1 |
| *Kinship with the person with dementia* | Spouse | 2 |
| | Daughter | 1 |
| | Son-in-Law | 1 |

## 4. MO: structure and description

The MO component was divided into two stages: getting to know the person with dementia (pre-contacts); meaningful occupation sessions.

### 4.1. Getting to know the person with dementia (pre-contacts)

The volunteers visited the families twice before the program began; first, to be introduced, to the person with dementia; and secondly, to evaluate the functional, psychological and social needs and potential of the person with dementia, in order to understand how best to intervene. This provided an opportunity to ask the family questions about the person with dementia and to observe family dynamics. This was also the time to explore how receptive the person with dementia was to working with the volunteer, as their acceptance was crucial to the process. These visits each took about 1 hour.

### 4.2. MO sessions

The program had 6 sessions of meaningful occupation, 120 minutes each, once per week, outside working hours. In order to ensure that the person with dementia felt safe and comfortable, the MO sessions took place in his/her own home. The sessions were organized as follows: in the 1st session, volunteers gathered information about the person with dementia (context of life, interests and preferences; observation of performance); activities which were relevant to the person's skills and preferences were then selected. Relevant activities included cognitive stimulation and self-care. Cognitive activities included:

Memory stimulation (similarities and differences exercises),

Attention and language stimulation (soup of letters, categorical evocation, and vocabulary),

Reminiscence Therapy (helping people to recall events, thoughts and feelings of earlier periods of their life), and,

Reality Orientation Therapy (e.g. during Christmas the exercises were related to the festivities).

These cognitive activities included language, calculation and recognition with the aim of stimulating the left (e.g., logical and sequential thought) and right (e.g., intuitive thinking) brain hemispheres. The cognitive stimulation sessions are summarized in Table 6.

Self-care activities included: relaxation techniques (e.g. hand massage); and functional stimulation (e.g. accompanying the person on a walk; using a ball to stimulate dexterity).

**Table 6.** Description of the cognitive stimulation sessions

| Session | Case 1 | Case 2 | Case 3 |
|---|---|---|---|
| **1** | **Knowing the elderly person with dementia (context of life)**<br>- Socio-demographic data collection (name, age, marital status, pre-retirement profession, qualifications);<br>- Explore interests and preferences.<br>**Analysis and observation of:**<br>- Performance in the areas of occupation (activities of daily living, leisure, social participation);<br>- Skills performance (motor, mental and communication/ interaction skills);<br>- Performance standards (habits, routines, roles). | | |
| **2** | Workbook: crossword puzzles, identifying colors, sequences of numbers.<br>Reality Orientation Therapy (RO). | Workbook: identifying colors, mental calculation.<br>Recognition of familiar faces from photographs. | Workbook: mazes, crosswords, identifying colors, mental calculation, soup of letters, categorical evocation, vocabulary and lexicon. |
| **3** | Workbook: crossword puzzles, identifying colors, sequences of numbers.<br>Reminiscence Therapy (RT). | Workbook: identifying colors, mental calculation.<br>Recognition of familiar faces from photographs. | Workbook: similarities and differences, inhibition.<br>Recognition of familiar faces from photographs.<br>Reality Orientation Therapy (RO). |
| **4** | Workbook: crossword puzzles, identifying colors, sequences of numbers.<br>Recognition of familiar faces from photographs. | Workbook: identifying colors, mental calculation.<br>Recognition of familiar faces from photographs.<br>*Functional stimulation* (training hands dexterity). | Workbook: similarities and differences, inhibition.<br>Reality Orientation Therapy (RO).<br>Self-care encouragement/relaxation exercises (group hands massage). |
| **5** | Talking about crops and agriculture.<br>Workbook: crossword puzzles, identifying colors, sequences of numbers.<br>Reality Orientation Therapy (RO). | Recognition of familiar faces from photographs.<br>*Functional stimulation* (training hands dexterity). | Reality Orientation Therapy (RO).<br>Teaching how to write in a portable computer (encouragement of the use of information and communication technologies). |
| **6** | Workbook: crossword puzzles, identifying colors, sequences of numbers. | Workbook: identifying colors, mental calculation. | Workbook: mazes, crosswords, identifying colors, mental calculation, soup of letters, categorical evocation, vocabulary and lexicon.<br>Self-care encouragement/relaxation exercises (group hands massage). |

## 5. Assessment of volunteers' contributions

### 5.1. Objectives and methodology

A post-intervention qualitative study was conducted aiming to explore the contributions of the volunteers (positive and negative aspects) from the perspectives of both volunteers and families. All families and volunteers agreed to take part in this evaluation.

The volunteers' experience was evaluated through a focus group interview, which took place at the University of Aveiro, one week after the last session. The focus group interview was structured around the following topics: (i) practical aspects of the program; (ii) positive elements and aspects that need to be improved; (iii) volunteers' perceptions of the relationship they developed with the person with dementia and his/her family. The focus group interview (duration of 90 minutes) was led by one facilitator (the 1st author), using the circular questioning technique (cf. Brown, 1997). The focus group was video-recorded (in order to collect visual data, which provided information on non-verbal behaviors), with the prior consent of all volunteers.

Families were interviewed as family units, in their own homes, about one month after the last session. This time period was considered sufficient for families to observe any changes in the behavior of the person with dementia and reflect on the benefits of the volunteer program. The semi-structured interviews focussed on the benefits and challenges of the volunteering component of the pro-Families intervention. The interviews lasted, on average, 15 minutes and were performed by one facilitator (1st author) and audio recorded, with the prior consent of the participants.

### 5.2. Data analysis

All interviews (focus group and individual) were transcribed verbatim and submitted to thematic analysis. All researchers read the transcripts and independently identified major themes; the themes were then compared and discussed by the team until agreement was reached; the transcripts were then coded by two of the authors; resulting themes were discussed again and areas of disagreement were identified and resolved, creating a final coding scheme for the transcriptions.

## 6. Results

### 6.1. Volunteers

*Practical aspects of the program*

Volunteers suggested that both the duration and frequency of the sessions were adequate, although they thought that more sessions would enable them to learn more about the person they were working with. They also thought that it would be beneficial to spend at least one session with the person and their carer so that they could pass on their knowledge to the carer.

*"It would be interesting to observe the carers with care recipients, to understand whether they have acquired theoretical and practical knowledge. Then we could guide carers better in their experience."* (J., 24 years)

The volunteers also valued working in pairs and felt that this improved the quality of the interactions and activities:

*"It was nice to share this experience with another volunteer…this encourages interaction and competitiveness in the games played with the person."* (L., 23 years)

*Positive elements and aspects that need to be improved*

The volunteers identified three major positive elements of taking part: (i) personal development; (ii) increased awareness of challenges faced by families; (iii) sharing/socialization.

*Personal development*

The volunteers' perceived that taking part in the program enhanced their competence and improved their communication and attitudinal skills, particularly due to the relationships they developed with the person with dementia. They also felt that they learned a lot about themselves from taking part.

*"Participating in this project helped me to reveal some aspects concerning my personality, such as my sensitivity and my discernment."* (L., 23 years)

They also realized the importance of volunteering programs for society and felt more motivated to continue, that is, they developed altruistic feelings through this experience.

*"With this experience I started thinking that everyone could spend some of his/her time to this type of cause. This has shown me how important these projects are to society."* (C., 24 years)

*"This project encouraged me to practice volunteerism and to be aware of its meaning for the others. It's so easy and rewarding to give a little of our time in favor of another."* (L., 23 years)

Volunteers also reported that they learned more about how to manage and control their emotions.

*"I have learned how to be more patient and how to better control my emotions."* (C., 24 years)

*Increased awareness of challenges faced by families*

The volunteers reported becoming aware of the difficulties and challenges faced by family members who live with a person with dementia, which they viewed as an important lesson for their professional roles. The volunteers indicated that it would be helpful to involve family members in the activities they were performing to improve the interactions between the person with dementia with their family members.

*“This experience was an essential moment of learning for my subsequent interventions with people with dementia.”* (C., 24 years)

*"I have realized the areas that need to be improved within the family: cognitive stimulation is crucial and the family must encourage the person with dementia to perform activities that give him/her pleasure and persuade him/her to practice them. In addition, I felt that communication between the family and the person with dementia needs to be improved: it is important to be more assertive and be aware of the importance of touch."* (L., 23 years)

Volunteers reported that the two initial contacts and the strategy of tailoring the intervention to the families’ needs were very important, enabling them to overcome their initial fears about not being well received by the families. They also reported feeling more professionally fulfilled.

*Sharing/socialization*

The volunteers particularly enjoyed meeting other volunteers, sharing their experiences and gaining greater knowledge.

"*I liked the fellowship, to hear other people’s experiences and other ways of doing things, exchanging ideas*." (J., 24 years)

The aspects that needed to be improved were organized into two major themes: (i) disappointment about the amount of professional growth experienced; (ii) not getting to know the person with dementia very well.

*Disappointment about the amount of professional growth experienced*

Some volunteers were disappointed that the experience was not more challenging. Some anticipated having to manage more difficult situations including aggressive behaviors and disorientation; another felt that working with a severely disabled, bedridden person didn’t provide enough opportunity to practice a range of interventions.

*"I do not know if I feel more capable of dealing with a person with dementia, because I was with someone who was already bedridden and there were many communication difficulties"* (C., 24 years)

*"I had no opportunity to deal with some behaviors that are challenging for me, such as aggression and disorientation."* (J., 24 years)

It is important to note that 4 volunteers were newly qualified, thus it is understandable that they perceived this experience has an opportunity to learn.

*Not getting to know the person with dementia very well*

Volunteers also reported that they underestimated the potential of the person with dementia. This may be due to underlying social representations of dementia, which are often negative, leading people to underestimate the potential of the person with dementia.

*"I did not know the person very well at first, and I believe that I have underestimated her, since I prepared basic exercises for the first session."* (J., 24 years)

This underlines the importance to explore the level of activity, skills, interests, routines and preferences of the person with dementia in the initial visits. Volunteers have taken advantage of the person's interests as a starting point for discussing other issues (e.g., watch his favorite program together and discuss themes that may emerge). Volunteers also mentioned that, in order to face this barrier, they tried to do the activities *with,* not *for,* the person, developing a sense of being a team.

*Volunteers' perceptions concerning the relationship with the person with dementia and his/her family*

The volunteers felt that the person with dementia and his/her family were initially insecure but that they soon adapted to their presence. Family members became more receptive to the volunteers and learned how to appreciate their work; this also happened with the person with dementia, and volunteers reported that they established a relationship of empathy, comfort, trust and collaboration.

*"At the beginning, Mr. M. was very reserved and only responded to what was requested, basically. Throughout the sessions he became more uninhibited, perhaps because he felt more secure and confident with my presence. Concerning the family, I've noticed some distrust and uncertainty regarding my presence initially, but then the family talked to me in an open and trusting way."* (J., 24 years)

This underlines the importance of maintaining the same volunteer and not abruptly breaking the link between the volunteer and the person with dementia.

### 6.2. Families

*Benefit and aspects that need to be improved*

Families valued the opportunity the volunteer program afforded them to participate in the psycho-educational sessions. They also valued the opportunity to be involved in an activity outside the caregiving context and enjoying some free time. The families felt comfortable with the volunteers and trusted them to be with their relative while they were absent.

*"The fact of having someone to provide care to my relative helped me to take some time for myself. I felt secure because I knew he was alright, with knowledgeable people."* (V., 75 years)

The main aspect that both families and volunteers wanted to see improved was the need for more interaction between the families and the volunteer.

*"We spent almost no time with the volunteer who was providing support to our relative. I think that we could have had the opportunity to be with the volunteer more times and even observed him doing things, to learn more."* (M., 39 years)

It is interesting to observe that while the families wanted time away they also wanted the chance to spend time with the volunteer and to learn how to improve the care they provided for the person with dementia. This apparent paradox is not unusual; providing care to someone often causes ambivalent emotional reactions in the family (Doka, 2004). Learning how to improve the care provided is also an active coping strategy, i.e. a way of dealing with caregiving demands and associated sources of stress.

## 7. Discussion and implications

This exploratory study reinforces the relevance of voluntary work both for receivers and givers (volunteers). Receivers had the opportunity to participate in the psycho-educational proFamilies-dementia sessions while their relative with dementia was receiving care and stimulation. The givers experienced professional and personal growth and increased empathy towards people with dementia and their families and formal carers. This study also highlighted the relevance of MO for people with dementia.

### 7.1. The MO Component: relevance

The MO component had an impact on both the volunteers and the families of the people with dementia: it showed that activities can be undertaken with people in various stages of dementia to promote their interactional skills and well-being. In fact, recent literature has suggested that sensory-based interventions can help people, even in advanced stages of dementia, to improve their communication skills and motor task performance (Chung, Chan & Lee, 2007; Fenney & Lee, 2010).

Traditional support interventions, such as nursing homes, however, tend to provide sub-optimal stimulation to people with severe dementia, resulting in behavioral and psychological symptoms and the more rapid progressive loss of motor and communication skills (Camp et al., 2002). Additionally, these behavioral, psychological and physical symptoms may also increase the risk of physical injury to the person with dementia, and stress and burnout in the caregivers (Weert, Dulmen & Bensing, 2008).

Authors have argued that cognitive stimulation can have positive impacts on patients and families, sustaining their sense of identity and preserving the dignity of people with dementia (Kitwood, 1997). This study demonstrates that utilizing MO can also have an impact on volunteers, challenging some of the most widely held prejudices, attitudes and social representations of dementia. This was true even amongst trained health professionals who aim to work with older people.

In terms of suggestions to improve the MO, both volunteers and families thought that it would be improved by: i) spending more time with the person, getting to know them before commencing MO and; ii) extending the MO sessions beyond the end of the psycho-educational sessions. We acknowledge that establishing rapport is key to commencing programs such as

MO, while the opportunity to work with relatives beyond the end of the intervention would provide them with tools to continue communicating effectively with their relatives. However, whether or not volunteers would be willing or able to commit to more sessions is unknown.

The number of volunteers recruited to this intervention was small, which is consistent with the related literature. In fact, research conducted in the public sector suggests that attracting volunteers is the most serious obstacle to implementing programs (Brudney & Kellough, 2000). This could have been due, in this program, to the: rigid time schedules; lack of time; concern about working alone with people with dementia, or anxiety about delivering the intervention. Whenever possible it would be helpful to negotiate the MO schedules with the volunteers rather than predeterming them before recruitment; however, as proFamilies-dementia was a group intervention this was not possible in this instance.

### 7.2. Volunteers: motivation, fears

Understanding volunteers' motivations and fears is vital to the planning, design and maintenance of volunteer programs (Burns et al., 2006; Wilson, 2000). It is important to consider both those factors which motivate people to start volunteering and those which retain them in the program. Our results suggest that recruitment and retaining of volunteers are promoted by experiences that provide both personal/professional enrichment and altruism, i.e., volunteers wanted to help others while also experiencing self-improvement. The results of this study corroborate the results of previous studies: the personal enrichment (associated with the development of altruism feelings), the highest sensitivity to the families' problems and the opportunity to share and socialize are results that are consistent with the results found by Shye (2009), Esmond and Dunlop (2004), and Bussel and Forbes (2002).

In addition to considering those factors which motivate volunteers, it is also necessary to consider their fears. The volunteers in this program were afraid of being unable to intervene adequately with the behavioral and psychological symptoms of dementia. It would have been easy to assume that, as these volunteers were trained health professionals, they would not have these concerns. The use of interviews prior to the program enabled us to design appropriate training. Developing both the technical and relational skills for managing behavioral issues proved vital for improving volunteers' confidence and comfort in being with person with dementia.

Interestingly, the volunteers in this study expressed a concurrent hope that the volunteering experience would be both challenging and rewarding. This has been documented previously (Chambre, 1991; Wilson, 2000). This double expectation involves some ambiguity: the volunteers reported anxiety about being unable to intervene adequately with difficult behaviors while also wanting the opportunity to manage challenging behaviors, so that they could develop new skills and improve future performance. This requires that those aiming to recruit and work with volunteers understand their fears and motivations and that they provide adequate time, support and training to enable them to successfully meet the challenges and gain the rewards they desire.

There is also a need to consider how to demystify social representations of dementia, so that people feel more motivated and comfortable dealing with this client group. In terms of the setting, it may reduce volunteers' anxiety if MO were provided in a Health Centre, instead of people homes; however, this may increase anxiety or confusion in those with dementia negating the value of the MO.

### 7.3. Limitations and future research

This was an exploratory study and the results are therefore limited by the small number of participants. Further studies involving larger samples of volunteers and families are needed to replicate the methodology and investigate the extent of the benefits. Future programs could be enhanced by encouraging interaction between families and volunteers by providing MO sessions beyond the end of the psycho-educational sessions. It is also important to develop a more extensive initial training, in order to assure the best preparation. Future research should also include both quantitative and qualitative measures; whereas quantitative methods can provide a high level of measurement precision and statistical power, qualitative methods will be invaluable in understanding the processes which contribute to the successes and weaknesses of the intervention (Matveev, 2002). Future studies should also investigate the effects of MO on the volunteers' professional performance, and on the care provided by families to their relatives with dementia.

## 8. Conclusions

Creating a group of volunteers to accompany people with dementia at the same time as their families were involved in an intervention program, proved to be an effective strategy; MO seemed to be a useful component to support people with dementia and their families. Volunteers are key to developing programs in the dementia field, mainly because many families are keen to participate but are unable to do so because they have no-one to care for their relative with dementia at the same time as they attended interventions (Brodaty et al., 2005). The volunteers enable families to participate in the psycho-educational sessions thus gathering information and emotional support, and helping them to deal with disease challenges.

Voluntary activities can also be an enriching experience for the volunteers, enabling the development of social skills and contributing to the strengthening of an active sense of citizenship. Ultimately, it also contributes to the promotion of subjective well-being because it allows people to feel good, helpful and engaged with what they do, so it is also a factor of successful aging (cf. Rowe & Kahn, 1997).

Personal/professional enrichment and altruism appear to be pervasive motivations for volunteers, i.e. volunteers want to help others while also experiencing self-improvement.

Human-service agencies and non-profit organizations should capitalize on these issues when attempting to recruit volunteers.

Volunteering constitutes a substantial part of productive work for many societies, and, by attending to the benefits that volunteering can bring to society, we have to recognize its importance. Volunteering in Portugal is gaining recognition and respect.

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## 1.4. POST- INTERVENTION REFERRAL SERVICE (PIRS): SUPPORTING FAMILIES OF PEOPLE WITH DEMENTIA AFTER A PSYCHO-EDUCATIONAL PROGRAM[7]

Sara Raquel Costa Guerra
University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago 3810-193 Aveiro, Portugal
sara.guerra@ua.pt

Sara Demain
University of Southampton, School of Health Sciences, Building 45, Highfield, Southampton, SO17 1BJ, United Kingdom

Daniela Maria Pias Figueiredo
University of Aveiro, Health School, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal
Unidade de Investigação e Formação em Adultos e Idosos, University of Porto, Portugal

Liliana Xavier Marques de Sousa
University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal
Unidade de Investigação e Formação em Adultos e Idosos, University of Porto, Portugal

### Abstract

Several programs have been developed to help families cope with the challenges of living and caring of a relative with dementia; in general outcomes are positive but tend to decrease after six months. Therefore, this study reports a Post-Intervention Referral Service (PIRS) that was performed during six months after families (living and caring for a relative with dementia) participation in a psychoeducational program (proFamilies-dementia). PIRS provides each family a social worker to help them in their needs (by direct help or referral). The sample comprises five families (six members) and five social workers. Both social workers and families were interviewed on PIRS use and perceived benefits. Thematic analysis was performed. Main findings show that three families contacted one social worker (not the one assigned to them, but the one they knew for longer time). Families perceived a few benefits, including guarantee of help whenever necessary and the dissipation of doubts and uncertainties; social workers' perceived benefits include the provision of guidance and support to the families. PIRS is a promising service that needs further development.

**KEYWORDS.** *Referral service, dementia caregiving programs, post-intervention support.*

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[7] Artigo submetido a "Activities, Adaptation & Aging" (em revisão).

## 1. Introduction

A broad range of intervention programmes have been developed to help the families to provide adequate care for people with dementia, and encouraging them to face the many challenges associated with the disease and its course (Brown, 2004; Schulz, Martire, & Klinger, 2005). The psychosocial interventions, like psychotherapy, counselling, and particularly the psycho-educational programmes, have been reported as those which have the strongest evidence of benefit (Losada, 2007; Sörensen, Duberstein, Gill, & Pinquart, 2006). However, this programmes tend to be time-limited and the achieved gains have been shown to be short-lived (around 6 to 7 months) (Pinquart & Sörensen, 2006; Sörensen, Pinquart, & Duberstein, 2002). In fact, as the disease evolves also the challenges faced by the family regain new contours. Therefore, it is essential to promote the continuity of support after the intervention programmes, not only to maintain the gains obtained by the families, but also to prevent their potential feelings of helpless and abandonment due to the challenges that will arise after the intervention. This continuity doesn't need to be intensive as most intervention programmes are. It needs to follow up the families, being attentive to new challenges and difficulties to make the appropriate support/referral in an adequate timing. Moreover, one of the major challenges faced by families, within the context of chronic diseases, relates to the difficulties of navigating formal support systems (e.g., where to go, whom to approach, what to request). A referral service, where a social worker is available to help the family, in particular to identify and contact other programmes and resources (Poulin, 2005) has potential to answer to these challenges, since it presents an opportunity to explore ways of achieving resolution, without overloading families (Larsen & Thorpe, 2006; Salfi, Ploeg, & Black, 2005).

This seems particularly relevant for families living and caring for an older relative with dementia, which is becoming a frequent event for families in later life. That is a different experience from caring for a frail person who is not cognitively impaired, who understands what caregivers are trying to do and can co-operate. Families living with a person with dementia have to deal with: twenty-four/seven vigilance, changes in personality, challenging behaviors and communication difficulties. Families perform a full-time, highly-specialized task, which requires special knowledge, skills and attitudes (Brodaty & Green, 2002; Norman, Redfern, Briggs, & Askham, 2004; Won, Fitts, Favaro, Olsen, & Phelan, 2008). It also involves a continuous process with family members going through several cycles of adjustment-crisis-adaption (Dupuis, Epp, & Smale, 2004).

### 2. Interventions in Dementia Field: The Relevance of Following Participants

In recent years, there have been significant advances in the development of interventions for families of people with dementia. The psychosocial interventions, like psychotherapy or psycho-educational programmes, have the strongest evidence of benefit (Losada, 2007). Recent meta-analysis studies (cf. Sörensen *et al.*, 2006; Sörensen *et al.*, 2002) suggested that these types of interventions have the most consistent short-term effects on a wide range of outcomes measures, such as burden, depression, and coping abilities. Psycho-educational interventions are considered particularly effective at improving family members' knowledge, reducing burden and depression symptoms, increasing subjective wellbeing and satisfaction, and improving family functioning (Guerra, Mendes, Figueiredo, & Sousa, 2011; Sörensen *et al.*, 2006; Sousa, Mendes, & Relvas, 2007). Previous research also suggests that psycho-educational interventions have moderate effects in terms of delaying the institutionalization of those receiving care by improving the psychological well-being of the caregiver (Kennet, Burgio, & Schulz, 2000). Recent interventional studies found a significant reduction in health-risk behavior and improvements in self-care and self-efficacy in family caregivers following a psychoeducational intervention (Andrén & Elmstal, 2008; Boise, Congleton, & Shannon, 2005; Kennet *et al.*, 2000; Won *et al.*, 2008).

However, these benefits have shown to be short-lived, persisting after an average of a maximum of seven months post-intervention (Pinquart & Sörensen, 2006; Sörensen *et al.*, 2002). This can be explained by the brief duration of these interventions, which are generally time-limited (e.g., 6 to 12 sessions) in order to prevent overloading families; and concomitantly, because dementia is a progressive disease, always presenting new challenges and difficulties to the families. Preserving the benefits across time and responding new challenges is important, in particular to recognise when a more intensive intervention is needed. In fact, these families have little free time, since they are centred in providing care to their relatives, which means that they can't be overloaded with these interventions.

Larsen and Thorpe (2006) argue for post-intervention support for families. They suggest that this would benefit families, providing support as they adjust to the changing demands of the disease and preventing sudden ruptures in the caregiving support. They also argue that post-intervention support may be cost-effective, since it is less expensive to monitor and prevent complications rather than deal with those complications later. Without this post-intervention support, the cost of formal health care can rise substantially, particularly related to increased institutionalization and potential secondary disability in the primary caregiver (Havens, 1998; Levine, 1999; Roberts *et al.*, 1999). In fact, every intervention programme needs a follow-up process, because users need to feel supported and it is not reasonable to suppose that a time-limited intervention solves all the present and future caregiving problems. The Mittelman studies (Mittelman *et al.*, 1995; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman, Roth, Coon, & Haley, 2004) are a case in point. After completing the core treatment programme (about six sessions of individual and family counseling), participants were referred to ongoing support groups. Counselors could also engage in additional follow-up sessions by telephone or in person, according to the caregiver's needs. Given the long-term course of dementia care, it is not surprising that an intervention that provides ongoing support was found to have good immediate and long-term outcomes (cf. Mittelman *et al.*, 2004).

This study describes a Post-Intervention Referral Service (PIRS) provided by social workers (who mediated and facilitated the access of families to other resources in the community), following the participation of families living and caring of relatives with dementia in a psycho-educational programme – proFamilies-dementia (Guerra *et al.*, 2011). It also explores the social workers perspectives on PIRS' benefits and risks, and the families' point of view on PIRS' usefulness. This will contribute to improve PIRS and to develop guidelines for other interventions that want to offer a post-intervention referral service.

## 3. ProFamilies-Dementia

ProFamilies-dementia is a psychoeducational intervention programme based on a participatory approach (Guerra *et al.*, 2011). The name 'proFamilies' was adopted to reflect three aspects – pro is an abbreviation of programme; pro is also used as a term meaning in 'favour of', reflecting the aim of supporting families caring for people with dementia; finally pro can also be used to reflect the positive aspects or strength of something (i.e. pros and cons), hence the term aims to acknowledge and utilize family strengths in supporting people with dementia.

ProFamilies-dementia adopts the following principles: (a) family centred, since it considers family potential as a fundamental social support resource for elderly people with dementia; (b) integrated, that is, it involves social, health, educational and psychological support, combining support for the patient and for the non-patient family members and offering short- and medium-term support; and (c) uses an empowering approach, which shifts the emphasis of the intervention from what went wrong, to what can be done to enhance functionality, and builds on family strengths and resources (Saleebey, 2001). ProFamilies-dementia was developed to support families that care for an older person with dementia in their homes. It aims to promote family and community care, and to facilitate the connection between family and formal support systems (social and health). The programme consisted of six sessions of 90 minutes, one per week. A multi-family discussion group format was adopted and followed a highly structured protocol, consisting of two components: educational and supportive. A psychologist and a gerontologist, who combine experience and training in psychoeducational and family interventions for families caring for older people with dementia, facilitated the sessions. The programme used a multidisciplinary approach with additional input from a family general practitioner, nurse and social worker. Table 7 briefly describes the components of the sessions.

**Table 7.** Components of the sessions

| Session | Components |
|---|---|
| 1 | Presentations<br>Information about the disease<br>Impact of the disease in family life |
| 2 | Self-care<br>Introduction of relaxation techniques |
| 3 | Caring for the older person with dementia<br>Stress management |
| 4 | Communicating feelings<br>Communication and dementia<br>Social networks |

| Session | Components |
|---|---|
| 5 | Community resources<br>Emotion-management |
| 6 | Mastering caregiving decisions<br>Legal and financial issues<br>Ritualise and finalisation of the group |

## 4. Post-Intervention Referral Service (PIRS): A Service of ProFamilies-Dementia

The Post-Intervention Referral Service (PIRS) was developed to be used by families in the six months following their participation in proFamilies-dementia. To our knowledge, psychoeducational programmes have not provided a referral service to families after their participation. This project was approved by the Ethics Committee of the Health Administration of the Centre Region, in Portugal, and authorized by the Health Care Centre where it took place.

### 4.1. Objectives and Assumptions

PIRS provides a social worker to each family that participated in profamilies-dementia in order to help them in any issue, in particular to mediate the relationship between families and the social and health community services available (i.e. to identify, contact and access available programmes and resources). PIRS can be used only if and when families feel the need.

The research team invited social workers working in the community where profamilies-dementia was carried out to perform this support service. In Portugal, these professionals combine the role of bringing together health and social services and of promoting family adjustment to their social environment by helping them to solve their problems (e.g., financial, relational). Actually, social workers are a privileged source of information concerning community resources. In the context of dementia caregiving, the social worker fulfils tasks which are usually highly valued by families (Dupuis *et al.*, 2004): (a) Providing timely access to precise and current information about community resources and services; and, (b) facilitating the integration and co-ordination of health services and social support. Good social work systems promote positive attitudes towards receiving help, encouraging families to use formal services without feelings of guilt by emphasizing that formal services complement rather than substitute informal care (Chappell & Blanford, 1991; Litwak, 1985; Sousa & Costa, 2010).

### 4.2. Procedures

Social workers were recruited during the development of proFamilies-Dementia (Guerra *et al.*, 2011), through a *snow ball* approach that started with the social worker from the Health Care Centre where the proFamilies-dementia was implemented. Five social workers from the close community were identified and accepted to integrate PIRS into their practice. In a first individual meeting, they were asked to commit to applying PIRS to support the families, during a six month period. This timeframe was considered reasonable for evaluating and redesigning this service. Then, the first author scheduled a second individual meeting with each social worker at their workplace, to gather socio-demographic information and to clarify eventual doubts. Social workers were invited to participate in the last psycho-educational session of proFamilies-dementia in order to be randomly assigned to each one of the five families and have the first encounter. In that last session of profamilies-dementia, families were introduced to the social workers, presented to PIRS and encouraged to contact the social worker whenever they felt the need in the following six months; that is, whenever they had doubts, particularly about the level of community resources and other available support.

### 4.3. Participants

Participants comprise five social workers and five families. Regarding social workers' characteristics, all of them are female (one for each family), aged from 31 to 54 years old; one works at the Health Care Centre where profamilies-dementia was carried out; three work at nursing homes; and one works for the City Council. Regarding families' characteristics (profamilies-dementia participants, in a total of six members), five of them are female, aged from 39 to 75 years old. As regards the kinship to the person with dementia, there were two spouses, two children, one niece and one son-in-law. For information on families' recruitment, see Guerra *et al.* (2011).

## 5. PIRS' assessment

Individual semi-structured interviews were conducted with both social workers and families two weeks after PIRS have completed six months of duration; the interviews were performed individually. PIRS' was assessed to collect data on: its use (frequency) and motivations; perceived benefits by social workers and families.

The interviews with the social workers were arranged by telephone and performed at their workplace by the first author (average duration of 15 minutes). The interviews were structured around seven topics: a) How many contacts did the family make? b) What were the reasons/motivations for their contact? c) How long did it take before the family contacted you? d) How did the family arrange the meeting? e) What are the main benefits and risks of PIRS'? f) How do you assess this experience? g) Do you think PIRS could be implemented in community services? The interviews with the families were also arranged by telephone and conducted in their homes by the first author (average duration of 20 minutes). These interviews focused the following topics: (a) Did you contact the social worker? (b) How many times and why? c) How long did it take before you contacted the social workers? (d) How it felt having someone available to answer your doubts and concerns? (e) How useful is PIRS? (f) Did the social worker meet your expectations?

All interviews were audio-recorded (codes were assigned to each interview, to preserve the anonymity of participants), transcribed and submitted to thematic analysis. Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data; it organizes and describes data set in (rich) detail (Braun & Clarke, 2006). The analytical procedures recommended by Foster-Fishman, Nowell, Deacon, Nievar, and Mccann (2005) were adopted: 1. all researchers read the transcripts and independently identified major themes; 2. the themes were compared and discussed until agreement was reached; 3. the transcripts were coded by two of the authors; 4. resulting themes were discussed again and areas of disagreement were identified and resolved, creating a final coding scheme for the transcriptions.

## 6. Assessment results

### (a) PIRS use by families: frequency and motivations

Only three families reported the use of PIRS; and just one social worker reported being contacted by those 3 families. The two families that did not contact the social worker reported that: (a) they did not feel the need during the period of 6 months, but emphasized that the contact details for the social worker were kept carefully in case of future need; (b) they wished to try to find solutions for themselves. All the 3 family that used PIRS decided to contact the same professional: the social worker from the Health Care Centre (and not the one assigned to them), who had provided advice and information about community resources during the psycho-educational sessions of proFamilies-dementia. The families reported feeling more comfortable asking for support from this social worker because they had already established a relationship with her during the psycho-educational sessions. All the families were interviewed, even those who did not report the use of the PIRS. And all five families mentioned feeling a sense of security knowing that they had a service available to help, even if they chose not to use it.

In terms of number of contacts: 1 family made 3 contacts (1, 4, and 6 months after the end of profamilies-dementia); 1 family made 2 (3 and 4 months later); and 1 family made 1 contact (1 week later). All families contacted the social worker by telephone, in order to schedule a meeting convenient for both parties. All meetings were held at the Social Office of the Health Center. According to the only professional contacted by the three families, the main reasons families contacted her were related to: screening; self-care; community financial resources; emotional support.

One family reported that they requested PIRS in order to understand their current situation on social workers' perspective (*screening*). They needed assurance about the way they were doing things. That is, they felt the need to review the current diagnosis of the family situation.

*"Family A needed me to analyze their situation as a whole and they needed help to realize that they had been doing things well, and, furthermore, they wanted to know if they were enjoying all the support that they had the right to enjoy. They wanted to be sure that they were on track."* (SW 3)

One family also requested PIRS in order to gather information about the availability of respite services, in turn to have some time to *self-care.*

*“Family A wanted to know if her husband* (care recipient) *could join the National Network of Integrated Care for 2 weeks period during which she would be absent. She has osteoporosis and likes to go to the thermal baths at this time.”* (SW 3)

Three families requested support about *community financial resources*.

*“Family B remembered that we had spoken about the financial support available for people with dementia. She wondered if she had the right to receive some financial support, namely the* Long Term Care Supplement, *and I told her “*Yes*”! So, she started receiving the supplement.”* (SW 3)

*“Family A had to call an ambulance for their care receiver go to the hospital with some frequency, which represented an increased cost to the family. So, the family came to me to know what they could do, in order to decrease the expenses.”* (SW 3)

One family asked support from the social worker because they need to talk, to be listened and to share emotions (*emotional support*).

“*Family C needed to talk and to gain relief. Mrs. P. told me how stressful and tiring it is to care for a person with dementia*.” (SW 3)

(b) Social workers’ perceptions on PIRS’ benefits

All five professionals were interviewed, even though only one had actually been contacted by the families. Given the circumstances, the research team decided to explore social workers’ perspectives on the potential PIRS benefits. Social workers perceived the following benefits: (a) to provide guidance and support to families; (b) to integrate and facilitate information on community resource support; (c) to provide an opportunity for them (the social worker) to be altruistic.

Three social workers considered PIRS an opportunity to provide guidance and support to families who might feel lost and helpless. They stated that the service could allow families to share their emotions, feelings and thoughts. They viewed PIRS as providing not only information, but also emotional comfort. Professionals also believed this could encourage a closer relationship with families, building a feeling of trust between them and promoting an atmosphere of comfort.

*“The families have a reference person available to listen to their concerns and inform them about their rights.”* (SW 2)

Three social workers reported that, currently, it is difficult to share information among professionals from different areas; therefore PIRS could bring together and facilitate information on community resources. They stressed that referral services can facilitate the connection between services.

*“The referral service provides a bridge with the available local services."* (SW 1)

The one social worker contacted by the families felt this experience was an opportunity to be altruistic. She felt the need to contribute, as a citizen, by volunteering and wished to have positive feelings by helping those in need. She stressed that participating in the programme could help professionals to create a positive perception of themselves.

"*Being a social worker is useful and rewarding. I liked participating in PIRS because it is part of my area of focus, so I feel comfortable with it.*" (SW 3)

Four social workers also mentioned some potential risks: (a) loss of family autonomy; (b) time limitations.

Three social workers, who weren't contacted by the families, stressed that PIRS may result in a loss of family autonomy and encourage their dependence on formal services. Specifically, they thought that families could be at risk of not being able to make their own decisions. Professionals feared that some families might always call on their social worker in case of doubt or uncertainty, rather than exploring solutions within the family.

"*There aren't negative aspects, but families risk remaining focused on social workers and losing their autonomy. However, I've always tried to promote their independence."* (SW 3)

*"The existence of this service may create a dependency and the social worker may be prompted several times for what is not fundamentally necessary, given the potential loneliness of these families."* (SW 2)

Social workers were recruited to PIRS on a volunteering basis. Their job requirements and demands were their first duty, therefore, time limitations were perceived, by one social worker (who wasn't contacted by the family), to be a potential threat to the success of PIRS.

*"As we have our professional work, we end up having little time to orient accurately the requests of 'our' family."* (SW 4)

(c) Families' perceptions on PIRS' benefits

The 3 families who requested PIRS reported that its main usefulness was: (a) the dissipation of doubts and uncertainties; and (b) having available help whenever necessary.

All families (n=3) reported that the social worker was relevant for dis*sipation of doubts and uncertainties*; she was able to answer the questions and concerns and helped them to solve their problems.

"*The social worker was able to answer my questions. She explored my concerns and encouraged me to find solutions with her help*." (Family A)

Two families stated that the social worker was an *available help whenever necessary*, therefore a fundamental support they could count on whenever they needed. As stated by one of the families, chronic diseases "offer" challenges over time and new difficulties will always emerge, underlying the importance of PIRS support.

*"It's great to know that there is one person who can help us to answer our questions. The social worker helps us, gives us a light... guides us!"* (Family C)

## 7. DISCUSSION

Referral service offers a centralized service, preventing fragmentation and, therefore, facilitating a better access to the existing responses by the families. This paper is, to our knowledge, the first globally to report on the use of a referral support aiming at facilitating and mediating the access of families caring for relatives with dementia to community resources, after their participation in a psycho-educational intervention. It therefore makes a novel and important contribution to the literature, addressing the calls of researchers (e.g., Dupuis *et al.*, 2004) and professionals to provide longer term support beyond the short-term provision of psycho-educational interventions.

The findings revealed that post-intervention supports such as PIRS could be important for these families, since they can work as a *back stop service* for them. The fact of families knowing that there is a professional with expertise available to guide them in case of need gave them a sense of safety, confidence and control in their caregiving role. Families did not even need to use the service in order to benefit from it; just knowing that it existed made them feel safer. That is, PIRS offers support to these families, preserving their autonomy and empowering them; it doesn't promote, therefore, their dependency on the service. Actually, the main challenge of PIRS was related to professionals' concerns about families: they considered that PIRS could encourage family dependency on practitioners or services, a common concern in these areas of social intervention (e.g. Colapinto, 1995). However, results suggest that families only resorted to PIRS in very specific and limited situations: three families requested the service, and only a few times in six months (maximum of three times). It seems that families required little help from the services, showing a resilience and capacity that went against professionals' expectations. It is possible that these social workers are used to deal with families who are socially more vulnerable, which implies a greater amount of involvement and monitoring for these professionals.

The three families who requested PIRS support resorted to the same social worker. The main reason seemed to relate to the rapport already established. Future interventions should create and encourage opportunities between families and social workers, in order to foster bonds of trust and comfort; otherwise, families may worry about bothering the social worker and therefore feel inhibited about contacting them. It could also be useful: to invite all the social workers to the psycho-educational session where the community resources are explored, giving all a better opportunity to meet each other; and to encourage the social workers to contact the families with some frequency (e.g., every week, by telephone), so that the families could feel more comfortable to ask for support if they need.

Results suggested that this kind of referral support is useful for answering questions and dissipating uncertainties regarding available financial support, services in the community, screening and, ultimately, to provide emotional support. Some families experienced an atmosphere of trust that allowed them to express their concerns, share their anxieties and to feel relief. That is, besides the inherent role of providing information on community resources, PIRS might also extend the supportive component addressed within the psycho-educational sessions. PIRS has also the potential to encourage these families to engage in self-care, an issue which is often neglected. In fact, one of the caregivers requested support to obtain information about community respite services so that she could enjoy some time and take care of her own needs. Social workers can play an important role in encouraging such decisions, by reinforcing the importance of self-care, and avoiding caregivers' feelings of guilt. PIRS is, therefore, a service that goes beyond health or social service: it provides a integration of both areas.

Also, the existence of PIRS can facilitate access to community services and resources: For instance, one family started receiving long-term care insurance and another family showed willingness to use respite care services. That is, PIRS is a way to trigger other types of support, particularly in the cases where families don't know the available community resources and in the cases where they know its existence but they are reluctant to use them. This is relevant, since these families often only look for formal support at a crisis situation, when they are too overloaded and experience feelings of great burden. Additionally, it is important to note that institutional respite is one of the least common forms of services used by caregivers (cf. Sussman & Regehr, 2009). The help provided by the social worker encouraged a better integration of formal and family support for the person with dementia, and, consequently, it is expected, will prevent families reaching a critical point of exhaustion that threatens their health status.

### 7.1. Limitations and Future Directions

The results of this pilot study are promising. However, the findings are limited by three main reasons: (a) the nature of the study, which is an uncontrolled pilot study; future interventions should consider a randomized controlled design, comparing the impact of PIRS after families participation in psycho-educational sessions with psycho-educational sessions without any kind of post-intervention support; (b) small number of participants; further studies with larger samples are needed, to analyse if these results are replicated and identify any other issues which may be relevant to different settings; (c) biases in the results, as only one of the five social workers and three out of five family caregivers provided valid information. Indeed, four other social workers also contributed information which probably brings pre-perception or biased opinions held before this study. This post-intervention support could be available to all the families who have relatives with dementia and not only for those who have the opportunity to participate in such communitarian programmes. Furthermore, the value of PIRS needs to be re-evaluated; the cost benefit analysis would be important if PIRS becomes a large scale community programme.

## 8. Final remarks

PIRS is a promising intervention in the support for the families who care for a relative with dementia. Further research into the development and evaluation of PIRS are needed. In fact, it is a good example of how to promote continuity of the interventions that are developed for these families, without overloading them or the providers. The families reported that they felt more confident just by knowing this type of support is available. Even if they don't use it, they reported that it can help dissipate their doubts and promote a sense of comfort. However, it would be relevant to promote the use of these types of services near to families.

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# CAPÍTULO 2

## CONSTRUÇÃO DA INTEGRIDADE FAMILIAR: A INFLUÊNCIA DA PRESTAÇÃO DE CUIDADOS EM CONTEXTO DE DEMÊNCIA NO CUIDADOR PRINCIPAL

## 2.1. CONSTRUCTING FAMILY INTEGRITY IN LATER LIFE: THE CASE OF OLDER DEMENTIA CAREGIVERS [8]

Sara Guerra, Marta Patrão, Daniela Figueiredo, Liliana Sousa

**Sara Guerra** (corresponding author)
Academic degree: Degree in Gerontology; PhD Student in Gerontology and Geriatrics.
Mailing address: University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal.
E-mail address: sara.guerra@ua.pt Tel.: +351 91 840 2043; fax: +351 23 440 1597

**Marta Patrão**
Academic degree: Degree in Psychology; PhD in Health Sciences.
Mailing address: University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal.
E-mail address: martapatrao@gmail.com

**Daniela Figueiredo**
Academic degree: Degree in Educational Sciences; PhD in Health Sciences.
Mailing address: University of Aveiro, Health School, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal.
E-mail address: daniela.figueiredo@ua.pt

**Liliana Sousa**
Academic degree: Degree in Psychology; Master in Clinical Psychology; PhD in Educational Sciences; Aggregation in Health Sciences.
Mailing address: University of Aveiro, Department of Health Sciences, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal.
E-mail address: lilianax@ua.pt

### Abstract

Family integrity is a normal developmental challenge for older people influenced by factors within the family system, and constitutes a developmental approach to older people that also involves their families. Family integrity is the positive outcome, revealing overall satisfaction with life; family disconnection (dissatisfaction with some family relations) and alienation (sense of family estrangement) constitute the negative routes.

This study aims to contribute to a better understanding of how the experience of caring for a relative with dementia can influence the development of a sense of family integrity in older

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caregivers. An exploratory cross-sectional qualitative study was performed on 26 participants, 16 of whom were women, $M_{\text{age}}$ = 74.11 (SD: 7.4). A semi-structured interview was carried out and subjected to content analysis.

The main findings suggest that old caregivers of a relative with dementia at home mainly face “difficulty in achieving projects” and “decrease of their reciprocity”. The hierarchisation of the two most frequently mentioned categories according to the pathway shows: (a) family integrity: 1 – “difficulty in achieving life projects”; 2 – “decrease in the frequency of family contacts”; (b) family disconnection: 1 – “increase in the frequency of family contacts”; 2 – “difficulty in achieving life projects”; (c) family alienation: 1 – “decrease in caregiver's reciprocity”; 2 – “difficulty in achieving life projects and “difficulty in solving family conflicts”. More attention needs to be paid to research and practice regarding old age and older caregivers’ developmental issues.

**Keywords.** *Families in later life; family integrity; family disconnection/alienation; dementia caregiving.*

# 1. INTRODUCTION

Family integrity, as defined by King and Wynne (2004), is a normal developmental challenge for older persons influenced by factors within the family system. The authors associated the construction of ego identity (Erikson, 1950) with a much wider process of relational development, in which the old person aims at establishing bonds within the multi-generational family that contribute to his/her self-valorisation of life. Family integrity (versus family disconnection and alienation) indicates that the older adult's striving towards ego integrity is inextricably bound up with the wider process of constructing meaning and relational development at the level of the family system.

Family integrity represents the positive outcome, characterised by the older person's sense of peace and satisfaction with family relations. Family disconnection (prevailing sense of isolation and disengagement between the older persons and their family) and family alienation (lack of family identity) constitute the negative outcomes. This family integrity approach offers an important framework for the study of old people and their families from a normative and developmental perspective (Sousa, Silva, Marques, & Santos, 2009). Actually, in contrast with the rich and abundant literature on the early stages of the individual and family lifecycle, there are relatively few theoretical accounts of individual and family developmental processes in later life.

Caregiving has been a major topic in gerontological research since the 1980s. The volume of literature produced paints a rich picture (Barbosa, Figueiredo, Sousa, & Demain, 2011): (a) caregiver profiles (including gender, age, kinship with the cared-for person, types and amount of care provided); (b) the negative impacts of the caregiving role on caregivers' mental and physical health and other life spheres (e.g. work, finances and social life), which has usually been described in terms of burden or stress, caregivers' needs resources, coping strategies and service use. The influence of caregiving on caregivers' self-development and their family process is rarely addressed, however (Sousa et al., 2009). Therefore it seems appropriate to look for a deeper understanding of how the experience of caring for a relative with dementia can influence the development of a sense of family integrity in older caregivers.

## 1.1. Building Family Integrity

Erikson (1950), in his theory of psychosocial development, argued that identity development takes place from the cradle to the grave, which, at that time, was a daring conceptual idea as it associated two apparent contradictory concepts: old age and development. For Erikson, old age is a period in which individuals reflect on their lives and relive their triumphs and setbacks, incorporating self in memories and meaningful experiences about themselves and the world. The eighth stage (after 65 years) engenders the dichotomy of integrity versus despair. Sense of integrity begins to be questioned in adulthood and gains ascendance in later life, when older people look for meaning in their past life and try to build a sense of integrity of the self (as opposed to despair), accepting losses and preparing for death.

Erikson has highlighted the influence of the family, and social and cultural contexts, and King and Wynne (2004), in an effort to understand the relationship between the individual and family development in later life (or aged families), associated the construction of the identity of the ego with a wider process of constructing meaning and significance (for life): family integrity. The process of building family integrity starts in the previous stages of individual and family lifecycles but can only be concluded in later life (epigenetic process), as this is the period of grand generativity (Erikson, Erikson, & Kivnick, 1986) in which older people assume the role of "keeper of meaning" (embodying the traditions of the past and thus providing vital family and social links between the past, present and future) (Vailland, 2002). Family integrity constitutes the ultimate, positive, outcome of the older adult's developmental striving toward meaning, connection, and continuity within his or her multigenerational family. It is a normative developmental challenge, fundamental to the well-being of older people. This process may follow a negative pathway, putting the older person at risk of family disconnection or alienation. Some families are characterised by infrequent contact and lack of meaningful communication between family members, resulting in a predominant sense of isolation or disconnection within or between generations. When the disconnection is such as results in a lack of common values, beliefs, and family identity, the isolation may reach the point of estrangement or alienation between individuals and/or generations (King & Wynne, 2004).

An older person's ability to achieve family integrity depends on three vital functions or competencies of the family system (King & Wynne, 2004; Patrão & Sousa, 2009): (a) the transformation of relationships across time in a manner that is dynamic and responsive to the changing lifecycle needs of family members; it includes the maintenance of long-term commitment to family relationships and realignment of family relationships in order to deal with later life transitions; in the oldest generation the couple faces the re-invention of close bonds, and parents and children have to renegotiate power hierarchies and participation in family activities, involving the establishment of mutually beneficial transactions; (b) the resolution or acceptance of past losses, disappointments, or conflicts, with the dead as well as the living; in the face of personal and parental mortality it becomes imperative to deal with old grievances, cut-offs or unmourned losses from the past and handle present family problems or crisis situations (illness, financial difficulties), which requires an open communication style, and the willingness and strength to confront emotionally charged issues (on the part of older parents as well as children and grandchildren); (c) the creation of meaning and legacy facilitates the coherent integration of personal life stories and family themes (creation of sustainable individual and family legacies), through family storytelling, passing on of shared interests, life themes, values and material possessions, and participation in family activities and rituals; this process benefits both the older members of the family, by maintaining their sense of purpose and respect in the family, and the younger generations, who inherit a family legacy (a model for their own ageing process); and it requires family cohesion and emotional closeness (greater interaction and sharing).

Sousa et al. (2009) find that the construction of family integrity seems to be anchored to three closely related processes developed by the older person which require the family's support: forgiveness, self-acceptance and self-worth (meaning). Although no consensus exists on what constitutes forgiveness, it is commonly held that interpersonal forgiveness involves a reduction in negative responses (e.g. retaliation, estrangement) and an increase in positive responses (e.g. reconciliation) towards the transgressor and that both types of response are evoked and expressed in terms of behaviour, affectivity, and cognition (Tse & Cheng, 2006). Family integrity emerges in older individuals capable of self-forgiveness and forgiveness of others; those who receive forgiveness from others but are still incapable of self-forgiveness find obstacles in achieving family integrity; the blame attitude (the opposite of forgiveness) emerges when the individual is unable to accept him/herself and/or others, and triggers a process that facilitates family disconnection or alienation. Self-acceptance can be defined as a positive attitude toward oneself (e.g. Gough & Bradley, 1996; Ryff, 1989). In general, a high level of self-acceptance indicates that an individual has a good opinion of him/herself, acknowledges and accepts the various aspects of his/her character, including good and bad qualities, and feels positive about the past. Conversely, low levels of self-acceptance indicate self-doubt, dissatisfaction with self and disappointment with what has occurred in the past. Self-acceptance allows the older person to live with whatever he/she has done for good or bad in life and therefore facilitates his/her journey towards family integrity. Accepting others emerges as a concomitant process, since individual well-being leads to the understanding of others. Those who experience difficulty in accepting their lives show a tendency to control other people, leading to disconnection or alienation. Self-worth (the sense of living a meaningful life) is associated with the experience of having a meaningful and respected place in the family and the community and serves almost as authority to value others and map out family integrity. The feeling that one has an insignificant and/or less important status within the family seems to lead to trivialising (devaluing) others and to family disconnection and alienation.

### 1.2. Older Caregivers of Relatives with Dementia

Family members have been recognised as a fundamental resource for individuals with chronic illness and disability. As chronic diseases tend to increase and occur in later life, caring for an older frail relative has been progressively considered a normative life event (Cavanaugh, 1998), provided mainly by middle-aged women. As life expectancy continues to grow, however, there is a significant increase in the proportion of primary caregivers who are themselves quite old (Spillman & Pezzin, 2000).

Caring for an older person with dementia is a completely different task from caring for a frail older person whose cognition is not compromised and who can thus co-operate. Family caregivers of an older person with dementia living at home have to deal with 24-hour vigilance, changes in personality, perplexing behaviours and difficulties in communication. They perform a full-time, highly-specialised task, which requires special knowledge, skills and the right attitude.

Most caregivers of persons with dementia face three to fifteen years of exposure to physical and psychosocial demands (Vitaliano, Zhang, & Scanlan, 2003). They take over household chores and are exposed to symptoms of depression, anger, agitation, and paranoia in their care recipients (Teri, Truax, & Logston, 1992). Exposure to chronic stressors can lead to psychosocial distress and risky health behaviours (Vitaliano et al., 2003).

It can therefore be assumed that the demands and challenges associated with the task of caring for a relative with dementia in later life interfere with the process of constructing family integrity. This exploratory study aimed at understanding the factors that influence the construction of a sense of family integrity (versus disconnection and alienation) in older people who are primary caregivers of relatives with dementia. The results are relevant in that they better explain the influence of caring for a relative with dementia in older caregivers' personal development and well-being and define some guidelines for intervening in families in later life who are experiencing dementia.

## 2. METHODS

### 2.1. Procedures

An exploratory cross-sectional qualitative study was performed. The managers of ten community services attending older persons with dementia were contacted and informed about the purpose of the study. All agreed to collaborate and each one was asked to select a practitioner to mediate the contact between the first author and potential participants; the ten practitioners (social workers, all female) were identified and contacted to explain their collaboration, study objectives and participants' inclusion criteria. Participants had to meet the following criteria: more than 65 years old, the primary caregiver for a relative with dementia for at least two years, living and caring in the community, and able to express opinions.

The practitioners pre-selected eligible participants, made a first contact to explain the objectives and collaboration expected, and asked permission to put the researcher in contact with them. For those who agreed, the researcher made a first contact by phone, reiterating details of the collaboration that was requested and why they were chosen. All the individuals who were contacted agreed to collaborate and the interview was scheduled during this first contact. The interview took place at the caregiver's home, at their own request; signed and informed consent agreements were obtained. The interviews lasted between 12 and 50 minutes and were performed by the first author. Data collection ended at 26 participants since saturation was reached (Miles & Huberman, 1984).

### 2.2. Instrument

A semi-structured interview consisting of open questions based on King and Wynne (2004) and Sousa et al. (2009) (Table 8) was used. For the purpose of this study, one question was added at the end of each domain, focusing on the influence of the caregiving role. Characterisation data were also obtained for gender, age, marital status, household composition, academic level, kinship with the person with dementia, and time as a caregiver.

**Table 8.** Family integrity semi-structured interview

**1. Family integrity (general)**

1.1. Do you feel satisfied or at peace with your family relationships?
1.2. What aspects of your family life are most satisfying? Least satisfying?
1.3. How do you deal with those aspects (negatives and positives), taking into account the way you face your life?
1.4. What are your goals for the future in terms of your family and personal life?
1.5. Although you may or may not see family members as much as you would like, do you feel close or connected to members of your family?
1.6. If possible, tell me about one or two of your closer relationships.
1.7. Are there family members to whom you would like to feel closer or more connected?
1.8. Is there anything that has influenced the aspects mentioned above?
1.9. Is there any event associated with caregiving that you think has influenced (positively or negatively) any of these aspects? If so, how?

**2. Resolution of conflicts/losses**

2.1. Do you have regrets about any of your family relationships?
2.2. Do you have a sense of “unfinished business” with any of your family members?
2.3. If so, have you tried to address this issue? How (if at all)?
2.4. Are there any issues or problems that you wish you could discuss with someone in the family?
2.5. If so, what do you think could help you to accept or solve those issues?
2.6. Is there anything that has influenced the aspects mentioned above?
2.7. Is there any event associated with caregiving that you think has influenced (positively or negatively) any of these aspects? If so, how?

**3. Creation of meaning and legacy**

3.1. What aspects of family tradition, history, or values have you passed on to younger family members?
3.2. What material inheritances have you passed on to younger family members?
3.3. What would you still like to share or pass on to others (material and/or symbolic)?
3.4. Do you feel that you have a meaningful and respected place in your family?
3.5. How will you be remembered by family members after you are gone?
3.6. How would you like to be remembered?
3.7. Are there still things you would like to do or say to influence your family’s future memories of you?
3.8. Is there anything that has influenced the aspects mentioned above?
3.9. Is there any event associated with caregiving that you think has influenced (positively or negatively) any of these aspects? If so, how?

**4. Transformation of relationships**

4.1. How have your relationships with family members changed as you’ve got older?
4.2. Do you think that your relationship with family members will change in the future? If so, how? And how will you deal with it?
4.3. Are there family members whom you can count on for help or support if you need it?
4.4. Is it hard for you to ask family members for help or support?
4.5. Are there family members who count on you for help or support?
4.6. Is it hard for others to ask you for help or support?
4.7. Is there anything that has influenced the aspects mentioned above?
4.8. Is there any event associated with caregiving that you think has influenced (positively or negatively) any of these aspects? If so, how?

### 2.3. Sample

The sample consisted of 26 primary caregivers of relatives with dementia (16 women, $M_{age}$ = 74.11, SD: 7.4) (Table 9). As regards academic qualifications, 16 caregivers had four years of schooling and seven were illiterate. Regarding kinship with the person with dementia, there were 20 spouses, four children, one sibling and one mother-in-law. Fifty per cent of caregivers had provided care to relatives with dementia for more than five years, and all of them were retired. All caregivers cohabited with care recipients.

**Table 9.** Caregivers of people with dementia: characterisation

| ***Caregivers of people with dementia (n=26)*** | | |
|---|---|---|
| ***Gender*** | Female | 16 |
| | Male | 10 |
| ***Mean age in years*** | | 74.11±7.4 |
| ***Marital status*** | Married | 24 |
| | Divorced | 1 |
| | Widowed | 1 |
| | Illiterate | 7 |
| ***Academic qualifications*** | 4 years of schooling | 16 |
| | 6 years of schooling | 2 |
| | Higher education | 1 |
| ***Kinship with the person with dementia*** | Spouse | 20 |
| | Children | 4 |
| | Siblings | 1 |
| | Mother-in-law | 1 |
| ***Time as a caregiver*** | 1 to 2 years | 5 |
| | 3 to 5 years | 8 |
| | More than 5 years | 13 |

### 2.4. Data Analysis

The interviews were audio-recorded, transcribed, and subjected to content analysis, family integrity being used as the conceptual framework (King & Wynne, 2004; Sousa et al., 2009). The analysis began with the identification of the factors that influenced older primary caregivers' construction of family integrity while caring for a relative with dementia in the community. The procedure was developed in two phases. The first phase was dedicated to the definition of categories and sub-categories: the process of creating and testing the categorisation system was gradually refined by two independent judges (first and second authors); each judge read the interviews and drew up a list of categories and subcategories; then, they met to compare and discuss their proposals until agreement was reached; finally they produced a list of categories and sub-categories, which included definitions and examples (Table 10).

Then, the two independent judges classified each participant in three different pathways according to King and Wynne (2004) and Sousa et al. (2009): family integrity, disconnection or alienation. This method was based on participants' self-reported feelings as follows (as recommended by King & Wynne, 2004): integrity – overall satisfaction with life and family; disconnection – dissatisfaction with life and with some family relationships; alienation – overall detachment from individual life meaning and a sense of family estrangement. It is essential to emphasise that a person classified as being on one of these routes does not present all the characteristics of that route, since this is a continuous process from integrity to alienation and disconnection (cf. Sousa et al., 2009). The process was as follows: (1) each judge independently read the interviews and attributed one route to each participant; (2) the judges met to compare and discuss their proposals until agreement was reached. Consequently, 17 participants were classified in family integrity, five in disconnection, and four in alienation; (3) afterwards, the analysis was centred on the classification of the participants' responses into the categories and sub-categories that had previously been defined (Table 10); (4) the first author classified the interviews, which were then reviewed by the second author, and both judges had to be in full agreement. We also analysed commonalities (using crosstabs), i.e. categories that were mentioned together by the same respondent.

**Table 10.** Factors influencing the (de)construction of family integrity in older caregivers of relatives with dementia: sub-categories

| **(sub)Categories** | **Definition and examples** |
|---|---|
| **Integrity (general)** | |
| **1. Frequency of family contacts** | Influence of caregiving on the frequency of contacts or gatherings between caregivers and their extended family. |
| 1.1. Increase | Caregivers report increase in the frequency of contacts with members of the extended family mainly because of their need for help in delivering instrumental support to the care receiver (e.g. hygiene; transportation to medical appointments) which is provided mostly by adult children, but also siblings.<br>"*My children come here and help me with the hygiene of my husband, or bring me things I need to my home. They have to come more often, because I can't leave my husband alone*" (Sonia, 79, wife). |
| 1.2. Decrease | Participants report a decrease in the frequency of contacts and/or meetings with the extended family (mostly children), which they attribute to: caregiver´s difficulty in leaving the care receiver alone, so he/she does not visit his/her family members, especially those living abroad; the extended family does not visit them because they find it difficult to deal with the dementia situation.<br>"*They say that they can't see my husband in this situation ... They no longer visit me and they even tell me 'oh, I don't know how to deal with this and how to look after him!'* (Maria, 75, wife). |
| **2. Difficulty in achieving life projects** | Caregivers feel unable to achieve personal goals and life plans owing to caregiving demands which constitute a full-time occupation, depriving them of time for personal projects/desires. The plans usually compromised are: spending more time with grandchildren; visiting family members more often; visiting their country of origin or their birthplace; more time for leisure.<br>"*My goal was to be able to be with my grandchildren and follow them ... but I can't! I have to be with my husband, I can't leave him here ... and my grandchildren are in France!*" (Clara, 65, wife). |
| **Transformation of family relationships** | |

| | |
|---|---|
| **3. Decrease in caregiver's reciprocity** | Caregivers state that caregiving has a double consequence: they ask for/need more help from family members (particularly children); however, they receive fewer requests for help from the family, which realises that caregivers have a lack of availability. In consequence, caregivers feel they are not (or cannot be) reciprocal.<br>"*The family is now asking for less support because they know that I am less available*" (Carina, 65, daughter). |
| **4. Emotional proximity** | Caregivers feel that providing care influences their emotional proximity with family members. |
| 4.1. Increase | Caregiver's emotional proximity with the family increases, because the caregiving task improves the family bond (belonging, sharing, protection, understanding and mutual help).<br>"*I'm providing care while I can ... and my daughters feel proud of it, because they have less work and can take care of their lives!*" (António, 81, husband). |
| 4.2. Decrease | Caregivers describe a decrease in their emotional proximity with the family (less sense of belonging), mainly because they feel their family is not there for them.<br>"*If I'm feeling down, I won't let them notice*" (Sofia, 73, wife). |
| **5. Confrontation with loss and death** | Providing care confronts the caregivers with the loss (it is no longer the *same person*) and death of the care receiver (usually, a significant and close person). As a consequence the caregiver is confronted with his/her own death.<br>"*When we love the person and then we have to face this situation... it is very difficult. And one day there will be a fatality... with a lot of grief and sadness*" (Rodrigo, 82, husband). |
| **Resolution of past losses and conflicts** | |
| **6. Solving family conflicts** | Influence of caregiving on conflict or resentment resolution within the extended family. |
| 6.1. Facilitate | Caregivers feel that the challenges, demands and meanings of the illness/care facilitate family conflict resolution and generate feelings of cohesion and support, diminishing eventual resentments.<br>"*I have tried for 30 years,to fight a very tough battle because of my wife. She did not get along with my mother. Nowadays, my wife helps my mother in everything!*" (Pedro, 65, son). |
| 6.2. Difficult | Caregivers consider that the illness and associated care needs make it more difficult to resolve conflicts within the family: the caregiver has less chance to visit the relatives with whom he/she has some conflict. Conflicts may even be exacerbated and resentments arise, particularly when the caregiver feels misunderstood: he/she is spending money on care and the family does not understand (often associated with inheritance); the family does not understand the caregiver's lack of time and exclusive dedication to the care receiver.<br>"*I was even willing to go and talk to my sister ... But I can't, I can't go anywhere... and leave my husband here!*" (Clara, 65, wife). |
| **Creation of meaning and legacy** | |
| **7. Family appreciation of caregiver's role** | The caregivers feel that the family appreciates his/her role and commitment to the relative with dementia. The caregiver feels proud and respected by the family.<br>"*I think that, from what I hear, I am doing very well in this role! People now see me differently, they value what I do*" (Alexandra, 66, wife). |
| **8. Dissatisfaction with grandparents' role** | The caregiver experiences feelings of dissatisfaction, frustration, and self-devaluation because he/she has no time to be with their grandchildren and pass on some symbolic legacy (often related to geographical distance).<br>"*The less good news is related to the geographical distance between me and my children and grandchildren... we are not often together! We love to go and visit them in their country*" (Hugo, 86, husband). |

## 3. RESULTS

### 3.1. Factors Influencing the Construction of Family Integrity

The emerging themes show that some factors are experienced in similar ways by the caregivers (“difficulty in achieving life projects”, “decrease of caregiver's reciprocity”, “confrontation with loss and death”, “family appreciation of caregiver’s role” and “dissatisfaction with grandparents' role”); others, however, experienced the opposite (“increase/decrease in the frequency of family contacts”, “increase/decrease in family emotional proximity” and “easier/more difficult to resolve family conflicts”). Therefore, there are factors which are common to older people's experience whereas others display difference.

Results show that the greatest commonalities (all occurring three times) involve the category “difficulty in achieving projects” and each of the following: “increase in the frequency of family contacts” (domain general integrity); “decrease in caregiver's reciprocity” (domain transformation of family relationships”; “family appreciation of caregiver’s role” and “dissatisfaction with the grandparents' role” (domain creation of meaning and legacy). That is, difficulty in achieving life projects might be associated with the ability to relate to family members, increase support and generate a legacy.

### 3.2. Pathways and Factors

The sample comprises a higher number of participants in the pathway of family integrity; however, the interviews of those in the routes of disconnection (5) and alienation (4) also showed saturation. The participants’ discourses in each pathway show some particularities: those in family integrity tend to be more concise and direct when answering the questions, and therefore interviews have a shorter duration (mean of 21.6 minutes; ranging from 12 to 40 minutes); those in family disconnection have a slightly longer interview duration (mean of 24.2 minutes; ranging from 14 to 40 minutes) and the discourses tend to be focused on a specific event in their lives (usually a family conflict) that is accompanied with feelings of anger, often punctuated by crying and repetition; those in the pathway of family alienation have the longest interviews (mean of 33.25; ranging from 22 to 50 minutes), and in their discourse typically tend to avoid issues related to the family and dislocate their focus to other issues not related to the interview (such as neighbours' behaviour). The participants’ interviews were classified into the sub-categories, considering the pathways: family integrity, disconnection and alienation (Table 11). No significant statistical differences were found when the three distributions were compared ($\chi 2$; $p>0.05$).

**Table 11.** Sub-categories versus pathways: family integrity, disconnection and alienation

| **Sub-categories** | **Family Integrity (n=17; 65.4%)** | **Family Disconnection (n=5; 19.2%)** | **Family Alienation (n=4; 15.4%)** |
|---|---|---|---|
| | n | n | n |
| **Integrity (general)** | | | |
| 1 Frequency of family contacts | 9 | 3 | 2 |
| 1.1 Increase | 2 | 3 | 1 |
| 1.2 Decrease | 7 | 0 | 1 |
| 2 Difficulty in achieving life projects | 10 | 2 | 2 |
| **Transformation of family relationships** | | | |
| 3 Decrease of caregiver's reciprocity | 4 | 2 | 4 |
| 4 Emotional proximity | 2 | 1 | 0 |
| 4.1 Increase | 2 | 0 | 0 |
| 4.2 Decrease | 0 | 1 | 0 |
| 5 Confrontation with loss and death | 0 | 1 | 0 |
| **Resolution of past losses and conflicts** | | | |
| 6 Solving family conflicts | 3 | 2 | 2 |
| 6.1 Facilitate | 1 | | 0 |
| 6.2 Difficult | 2 | 2 | 2 |
| **Creation of meaning and legacy** | | | |
| 7 Family appreciation of caregiver's role | 1 | 2 | 0 |
| 8 Dissatisfaction with grandparents' role | 3 | 1 | 0 |

Globally, the factors most mentioned were: “difficulty in achieving projects” (domain general integrity; 14 citations) and “decrease in caregiver's reciprocity” (domain transformation of family relationships; 10 citations). The hierarchisation of the three categories cited most often according the pathway shows: (a) family integrity: 1 – “difficulty in achieving life projects”; 2 – “decrease in the frequency of family contacts”; 3 – “decrease in caregiver's reciprocity”; (b) family disconnection: 1 – “increase in the frequency of family contacts”; 2 – “difficulty in achieving life projects”, “decrease in caregiver's reciprocity” and “difficulty in solving family conflicts”; (c) family alienation: 1 – “decrease in caregiver's reciprocity”; 2 – “difficulty in achieving life projects” and “difficulty in solving family conflicts”. These categories mostly occupy the following domains of family integrity construction: integrity (general) and transformation of family relationships; also resolution of past conflicts, but not in the domain creation of meaning and legacy. The sub-categories mentioned most often are described below, showing the different experiences of those in each pathway.

### 3.2.1. Difficulty in achieving life projects (FI, FD, FA)

Caregivers in family integrity state that caring for the relative with dementia compromises the achievement of their plans and projects; however, they assume that "*it has to be*" and understand and accept that it implies less time for them. These caregivers reveal they transformed their plans and purposes in life in order to adapt to the caregiving situation.

> "*I would like to spend more time with my children... but I understand that they have their life and I have more chores currently. I use the telephone to communicate with them... we are very close, that's what matters. Furthermore, my life project at this moment is to take care of my wife*" (António,[9] 81, husband).
>
> "*This increases our stress level, but I can deal with it! (…) Because even with the work it takes, I have got used to it! Sometimes I thought, "What am I going to do now?*" (Carina, 65, daughter).

Caregivers in family disconnection describe the difficulty of achieving life projects with: (a) upheaval (feelings of grief, despair and injustice); (b) resignation (they deal "*as they can*" and they do not know where they find the strength to cope with such challenging illness); (c) giving up (they no longer have life projects, a loss which they also attribute to their old age); (d) or have projects focused on the past (e.g. resolving family conflicts).

> "*I don't have goals ... any longer!*" (Benilde, 65, mother-in-law).
>
> "*I don't know ... I deal as I can ... whatever! What can I do?*" (Manuel, 78, husband).
>
> "*I am too old to have life projects*" (Sofia, 73, wife).

Caregivers in family alienation justify why they cannot achieve their life projects for reasons associated with their poor health status, which are amplified by the caregiving demands. They demonstrate some difficulty in dealing with this situation, assuming a pessimistic perspective regarding their well-being and the future.

> "(…) *I have been sick for 20 years or so, I can't do anything… my life went down. I see myself dying to live; I don't have anybody to help me. My legs are always shaking and my wife is very nervous!*" (Filipe, 83, husband).

### 3.2.2. Frequency of family contacts (FI, FD)

Participants in family integrity describe a "decrease in the frequency of family contacts", mainly because of geographical distance, which does not hinder emotional proximity. Caregivers would like to be in the presence of their relatives more often, but they understand that *children do not visit them as they wish because they reside abroad and work there.* Emotional proximity is maintained by telephone contact and frequent use of the family photo

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[9] All names used are fictitious to protect participants' anonymity.

albums. Despite the geographical distance, these caregivers describe support and companionship between them and their children.

> "*We don't see our family every day! However, I can see them every day in photos! We must accept this type of situation and try to focus on the good moments*!" (Hugo, 86, husband).
>
> "*I have a daughter abroad who is very loving. Her support is very important and helps me deal with the situation*" (Luísa, 79, wife).

These caregivers feel that they have someone in their family (children, grandchildren and/or siblings) with whom they can share what they think and feel about caregiving.

> "*Whenever there is a problem we talk (with the siblings) and take decisions. What comes up is promptly resolved*" (Carina, 65, daughter).

Despite this reduction in the frequency of contacts, caregivers state that they receive the support they need from the family, easily identifying the relatives that provide help to them.

> "*Yes! I have my daughters, my niece ... if I need help they help* me!" (Lúcia, 84, wife).

Caregivers in family disconnection describe an increase in contacts, which occurs essentially because of their increased need for instrumental support, which is assumed by one or two relatives (who often visit them and help). They show dissatisfaction, however, with family relationships, describing feelings of isolation and loneliness (they need more closeness to their family); yet they sometimes denote ambiguity (whereas they acknowledge that having someone who helps suggests emotional proximity, support and discomfort, they highlight that help comes only from one or two family members). In their view, all family members (especially siblings and children) have obligations and responsibilities regarding caregiving. Some caregivers try to cope with the situation without the support of family, hiding what they feel and the hardship they go through.

> "*My family is a disgrace ... The daughter who comes here is a pearl and my son-in-law too ... my son is also good, but he is far away from here... but brothers and so on,...*" (João, 78, husband).

Additionally, caregivers demonstrated discontent and resentment regarding the geographical distance between them and some relatives: "*I don't understand why my children are so far away from me. They could live here with me, they don't need anything else. My son is a really good person... but I am upset that he went abroad*" (João, 78 years, husband).

There are situations of break-up or contact avoidance (mainly related to financial issues) with part of the family (usually siblings and/or in-laws).

> "*I stopped to talk to some relatives, especially my sister-in-law, who is a liar. She injured me a lot; she robbed me and seized some land of mine. I feel very sad and angry... I have done everything for her and look what she did to me*!" (Filipe, 83, husband).

### 3.2.3. Decrease in caregiver's reciprocity (FI, FD, FA)

In family integrity, caregivers understand that they cannot provide support to other relatives besides the person with dementia, and they recognise that their relatives have to deal with other demands (professional and personal). Yet they wish to receive support without asking for it.

> "*It is said that we know whom we have, but we don't know what may come. I am OK with my children. But I can't say the same regarding my husband since I need help to support him. I would like it if my family could provide some support without being asked for it, that is, they should be more proactive*" (Alexandra, 66, wife).

Caregivers in the family disconnection state they feel compelled to ask for support, although they understand that they cannot reciprocate. Therefore, they do not ask for support, despite the need; the main reasons are related to family conflicts, especially with in-laws, so they feel inhibited and tend to retract.

> "*I have no support from anyone, I'm alone. My family also doesn't ask for support… they just want to steal from me*" (Filipe, 83, husband).
>
> "*I feel that now I have to ask for help because sometimes it's hard to cope. However, I can't help them as before*" (Manuel, 78, husband).

Caregivers in family alienation described insufficient support from the family, namely at the instrumental (e.g. the hygiene of the person with dementia and transportation to the physician) and financial (e.g. expenses related to treatments and medication) level. They feel unhappy and showed feelings of injustice and revolt; they are also very pessimistic and usually complain, blaming the relatives who should but do not provide support.

> "*My life is full of sadness. My husband is sick and so am I ... I have no support from my family. I have no family, nothing ...*" (Marta, 75, wife).
>
> "*Whom do I have? I have no support from anyone. I can only count on myself. I need money for medicines and that ... but my children don't care, they just want the money for themselves*" (Filipe, 83, husband).

They feel that the family requests less support from them because they know that the caregiver cannot provide support. They state their difficulty in asking their family for help since they feel shame; that is, they used to be independent and usually help others and now they feel embarrassed at showing their family they have difficulties and need help.

> "*I feel ashamed. I don't like to disturb anyone. This is a difficult situation for me; I don't like to ask for help, only if I am really in need*" (Marta, 75, wife).

### 3.2.4. Solving family conflicts (FD, FA)

Caregivers in the disconnection route often describe unresolved family conflicts and resentments (especially with siblings and in-laws) related to inheritance or family business (highlighting financial aspects). Conflicts are described as long-lasting (persistent), the blame being put on the other side and caregivers feel they have no time to resolve the difficulties that arise. Caregiving exacerbates this aspect, since the caregiver is focused on the person with dementia, which makes him/her feel powerless regarding family problems.

> "*I sometimes feel sad and wonder why the family stopped talking to me. This started when I had a problem with my brothers. But nobody takes any interest! Neither family nor outside! I feel sad because someone should tell them things can't go on like this*!" (Rodrigo, 82, husband).

The existence of conflicts is associated with feelings of loss of self-value.

> *"I don't put much value on life. I've always been a very lively and cheerful person ... I loved to have friends when I was younger* (...) *since the problems arose in my family, everything changed. I have no objectives*" (Rodrigo, 82, husband).

Caregivers in family alienation feel the need to discuss problems with the family, especially because they feel misunderstood (e.g. when they have to spend a lot of money on the person with dementia; lack of time for other relatives). Therefore they feel that caregiving promotes family conflicts, which are usually motivated by financial issues and personal matters (for instance, Sandra feels that she has to compensate for the support that her brother, the care receiver, once gave to her, and she wants to repay him by providing him with quality care). Caregivers tend to drag out these conflicts because they cannot find an effective and simple solution; they are concerned with and focused on caregiving issues.

> "*Now I have more conflicts with my husband… he's jealous because I spend a lot of time with my brother* (person with dementia)*. He can't stand that! My children are a little jealous, too. However, my brother has always helped me through life…*" (Sandra, 66, sister).

Commonalities for each pathway were then calculated; although numbers were low, they offered some clues of how participants associate categories within their narrative. In the route of family integrity the main commonalities involve "difficulty in achieving life projects" (domain integrity general) and: "increase/decrease in the frequency of family contacts" (2+2) (domain integrity general), "decrease in caregiver's reciprocity" (3) (domain transformation of family relationships), "dissatisfaction with grandparents' role" (2) (domain creation of meaning and legacy); also "decrease in caregiver's reciprocity" and "decrease in family contacts" (2). In family disconnection a commonality emerges: "difficulty in achieving life projects" (domain integrity general) and "family appreciation of caregiver's role" (domain creation of meaning and legacy). Commonalities do not emerge in the path of family alienation.

## 4. DISCUSSION

The main factors emerging in this study as influencing caregivers' construction of family integrity (versus disconnection and alienation) are as follows: difficulty in achieving life projects and an increase/decrease in the frequency of family contacts (domain - general integrity); decrease of caregiver's reciprocity (domain - transformation of family relationships); and difficulty in solving family conflicts (domain - resolution of conflicts). The domain "creation of meaning and legacy" was not amongst the most cited, but nevertheless two factors emerged within that domain: (1) family appreciation of caregiver's role, that seems to imply that caregiving may be viewed as a legacy itself; (2) dissatisfaction with grandparents' role, revealing that the lack of contact with the younger generations is felt to restrict the possibilities of leaving a symbolic legacy which constitutes the guarantee of symbolic continuity after death (Hunter & Roles, 2005; Schaie & Willis, 2002). Both these factors were associated with the difficulty of achieving life projects when overall commonalities were calculated; therefore it seems that creation of meaning and legacy is a life project which is affected by the caregiving role.

The domain general integrity is related to overall satisfaction with individual and family life. Caring for a relative with dementia at home is a full-time task, which completely absorbs the caregiver; in addition it is usually a long-term task (13 of the participants have been caring for more than five years), thereby affecting caregivers' personal goals for old age. Goals in old age are related to the process of life review, which involves contacts with the wider family and other significant persons, visiting significant places and having time to reflect on own life significance (Marcoux, 2001; Marx, Solomon, & Miller, 2004). Caregiving blocks or, at least, strongly limits these opportunities, because it affects, or at least alters, the family contacts. The caregiver is limited in terms of leaving home and visiting someone, because he/she cannot leave the care receiver alone. The emotional, family and social life of the caregiver becomes restricted in a life stage (old age) that, in relation to personal development, demands the review of life. Therefore, caring for a relative with dementia transforms family relationships, which become centred largely on the care receiver's needs and on the accomplishment of all instrumental tasks involved. Caregivers report a feeling of lack of reciprocity towards those that are helping them: on the one hand, they are receiving more help from relatives; on the other, they are being asked for less support. This seems to be embedded in a complex emotional process: it seems that caregivers are too demanding of themselves, because the task of caregiving is a huge contribution for the family; but as caregivers are mainly spouses and children, they probably assume it is an individual obligation. In fact, the caregiving role is a huge contribution for the family, both in symbolic (value of caring for those in need in the family) and practical (performing a highly demanding task) terms. In addition, caregivers also feel that caregiving makes it more difficult to resolve family conflicts: those from the past, because the caregiver has fewer possibilities to focus on the conflicts and develop ways to resolve them, and those in the present, since caregiving can exacerbate latent conflicts because it is a very tense, long-term situation, that stresses all those involved. Yet caregivers may need to receive more concrete feedback and valorisation regarding their contribution to the family as caregivers (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullan, Semple, & Skaff, 1990).

These factors are experienced, in general, by all caregivers, but some are in a pathway of family integrity whereas others are in routes of family disconnection and alienation. Our findings, and those in other studies (e.g. King & Wynne, 2004; Sousa et al., 2009), highlight that what seems to discriminate the pathways' evolution is not so much the factors involved but how people perceive and experience the events. Literature on caregiving, in particular the stress transactional models (Lazarus & Folkman, 1984; Pearlin et al., 1990), has also highlighted the same findings: stress is more determined by people's assessment of their circumstances (their coping strategies) than by their concrete and objective circumstances.

Some processes have been identified in the literature as suitable to describe why older people tend to interpret these kinds of common events differently (cf. Sousa et al., 2009): forgiving (self and others) versus blaming others; accepting (self and others) versus controlling others; meaning (self and others) versus trivialising others. These processes are relevant to the understanding of caregivers' developmental processes within their multigenerational family (Table 12); they can also be interpreted as internal coping factors that are crucial mechanisms explaining individual differences (Kim & Knight, 2008; Noonan, Tennstedt, & Rebelsky, 1996).

Older caregivers of relatives with dementia who are tracking the route of family integrity (Table 12) show an optimistic and flexible attitude towards life that gives them the opportunity to adjust to life changes and unexpected demands, maintaining a sense of self-worth. They are able to: embrace caregiving as new life project and readjust or give up previous plans; understand family members’ life circumstances that prevent them from making more visits and helping; recognise the need to change patterns of support, admitting that they cannot be as reciprocal as before. Caregivers in the route of family integrity: (a) forgive, i.e. they reduce negative (such as resentment) responses and increase positive responses (viewing the good that is occurring) themselves (embracing the new life demand) and others (understanding their life circumstances); (b) accept both themselves (maintaining a positive attitude, for instance when having to give up old projects, experience fewer family contacts or be less reciprocal) and others (understanding they have their own life challenges); (c) assign meaning, i.e. they continue feeling that they are living a meaningful life, because they have new projects (albeit focused solely on caring for the relative with dementia) and they also acknowledge others' contributions according to their availability.

**Table 12.** Older caregivers of relatives with dementia: family integrity, disconnection and alienation routes

| | **Family Integrity** | **Family Disconnection** | **Family Alienation** |
|---|---|---|---|
| **Integrity general** | | | |
| Difficulty in achieving life projects | Understand and accept that caregiving compromises the achievement of previous | Struggle to maintain life projects or give up. | Give up life projects (owing to age and health problems). They try to adapt to caregiving, but |

| | | | |
|---|---|---|---|
| | plans. Assume caregiving as the present life project; redefine or embrace new projects. | | experience sadness. |
| Family contacts | Accept the decrease in family contacts, assuming the maintenance of family proximity. | Assume the increase of family contacts, but feel decrease in emotional proximity. Struggle to accept relatives' lack of time to visit and support them. | |
| **Transformation of family relationships** | | | |
| Decreases in caregiver's reciprocity | Accept change in the patterns of support. | Do not accept changes in patterns of support: they want more support, but do not ask for it (it would make them feel inferior). | Do not accept changes in patterns of support: complain and blame relatives who should help and do not do. |
| Family conflicts | | Unresolved long-lasting family conflicts and resentments, which are described as being the fault of others. | Need to discuss existing conflicts with family members; feeling misunderstood. |
| | Optimistic and flexible attitude towards life.<br>Maintain self-worth.<br>Self and others acceptance.<br>Forgiveness.<br>Caregiver constructs a meaning to own life. | Pessimistic and inflexible attitude towards life.<br>Loss of self-worth.<br>Self and others non-acceptance.<br>Blaming and trivialisation of others.<br>Caregivers build a victim attitude towards life. | Defeated and passive perspective on life.<br>Caregivers develop a lack of meaning in life. |

Older caregivers experiencing the pathway of family disconnection denote a pessimistic and inflexible attitude towards life that inhibits their chance of feeling self-worth and having a significant life. They become unable: to rebuild family projects, struggling to maintain old projects (which cannot be achieved when caregiving is a full-time task); to recognise the large contributions made by family members (related to the increase of family contacts) despite their own life demands; to ask for the support they need, because they associate it with self-devaluation; to go beyond conflicts and resentments, which are blamed on others. Therefore, caregivers in the route of family disconnection: (a) blame others, increasing the negative responses towards them (guilt, censure, accusation) while feeling powerless, which seems to constitute (albeit paradoxically) their source of power is being powerless; (b) attempt to control others, trying to compel more visits and support, but without asking, and waiting for others to accept the blame for conflicts; this involves a process of self non-acceptance because own contributions to problems (inevitably present) are not assumed; (c) trivialise others, since their contributions or attempts to contribute (for instance, with instrumental support) are not recognised.

Caregivers in family alienation emerge as living embedded in a sense of passivity and resignation, revealing a lack of meaning and involvement with life and showing a defeated and/or passive perspective on life. Therefore it seems that: (a) they do not forgive (self and others) but they also do not blame others, as they just feel sad and helpless (for instance, concerning life projects); (b) they make some attempt to control others, by blaming them for not helping more, while trying to accept changes in their own life, but feeling compelled to complain about others; (c) they do not seem to trivialise (devalue) others completely or to devalue themselves completely, merely revealing a sense of estrangement or vagueness, almost a “non-existence”.

## 5. Implications

The family integrity framework challenges academics and practitioners to view caregiving (and old age in general) from a developmental perspective while abandoning the traditional perspective that mainly focuses on health problems and caregiving impacts on caregivers' health and emotional feelings (Sousa et al., 2009). Research on family caregiving in later life needs to go beyond the impacts and demands of caregiving to include developmental issues, as later life represents a developmental stage. In addition, the study models of caring in later life should include the developmental issues and challenges, because being an older caregiver providing care to a relative of advanced age is different from caring at an earlier age for a child with disabilities.

Our results raise two main challenges regarding intervention: (a) that provided before old age, because developmental processes are epigenetic and therefore evolve in previous stages of life; (b) that available in old age, which has to take into consideration the epigenetic process.

Family integrity is a condition that needs to be facilitated and cultivated by everyone during life. Practitioners and academics need to pay attention to how to promote these processes during life from the perspective that successful ageing is prepared for during life. Research has shown that everyone needs to learn to focus on the moment and appreciate experiences, transforming even negative situations into life lessons that need to be used to construct a life philosophy (Erikson, 1950). This life philosophy constitutes an identity which functions as a guide to the past, present and future interpretation of events.

Interventions to support older people that have not evolved towards family integrity also need more attention. Current practitioners have a tendency to look for and assess the caregiver and care receiver situation in terms of health status and practical issues (such as hygiene and feeding). Practitioners also need to be attentive to development issues. Findings suggest that they should be attentive to caregivers' discourse: older caregivers in family integrity display short and concrete discourses, revealing feelings of well-being; those in disconnection tend to have longer discourses, centred on past events and showing anger and despair; and those in alienation also have long discourses but these are punctuated by sadness and resignation.

## 6. Limitations of the Study and Recommendations for Future Research

The findings are limited by the small sample size. Despite the data showing saturation it would be appropriate to have a larger sample, particularly of those in the route of alienation, to facilitate better comparison between the three pathways. Sample enlargement would also allow the analysis of the influence of variables such as gender, academic status, kinship with the care receiver, and years of caregiving. For better understanding of the feelings of these older people instruments that measure subjective well-being (such as the Satisfaction with Life Scale, by Diener, Emmons, Larsen, & Griffin, 1985) could be used. We believe that a quantitative measure could be adopted to promote data triangulation and improve understanding. Life stories should be collected to reveal how the routes towards each of the three pathways started to evolve, which could help to develop intervention guidelines. Further studies could benefit from focusing on the influence of the care receiver's institutionalisation and death in the caregiver route towards family integrity.

## 7. CONCLUSION

The prevailing biomedical view pathologises later life owing to its focus on disease and treatment (Sousa et al., 2009). As the process of an extended later life is still recent and unknown (or still not experienced by a large number of people), and providing care is becoming a normative event in later life, older caregivers have no models for ageing; practitioners also lack developmental approaches to support older people, including caregivers. Caregiving for a relative with dementia at home constitutes a demanding task in physical, emotional, relational, and developmental terms. The findings in this study show that these older caregivers mainly feel challenged by the difficulty of achieving projects and the decrease in reciprocity regarding the family. Those crossing the pathway of family integrity are able to review their life projects and assume caregiving as their present goal; those in the route of disconnection struggle to hold on to previous life projects, assuming a victim's posture towards life; and those in the pathway of family alienation tend to give up on life projects and suffer a lack of meaning in life. Attention to these developmental issues needs to be deepened in terms of support in old age and during life.

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# CONCLUSÕES GERAIS

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A abordagem adotada nesta tese reflete a hierarquização contextual que impele à incorporação de unidades de análise cada vez mais alargadas e complexas nos processos de significação (Bateson, 1972). Neste estudo desenhou-se um processo de intervenção que inclui a pessoa com demência e a sua família no contexto onde vivem os seus desafios. Assim, respeita-se que a demência, enquanto condição crónica, afeta todos os elementos da família e a família como unidade (não apenas a pessoa com doença), sendo experienciada num contexto que influencia a vivência da condição demencial (i.e., relações familiares, sistemas de saúde e acção social, comunidade) (cf. Rolland, 1990; Góngora, 1996).

Os estudos nesta tese incluem o desenho, implementação e avaliação de um programa integrado de apoio para pessoas com demência e seus familiares (proFamílias-demência), num contexto de cuidados de saúde primários; simultaneamente, analisa-se a influência da prestação de cuidados a uma pessoa com demência na construção do sentido de integridade familiar, no cuidador principal idoso. A configuração desta tese engloba capítulos compostos por artigos publicados em revistas científicas, ou em vias de publicação, que apresentam conclusões específicas relativamente aos resultados obtidos, reflexões críticas face à metodologia utilizada e perspetivas de pesquisa. As conclusões gerais procuram lançar uma visão reenquadradora dos principais resultados e conclusões dos diversos estudos, culminando com recomendações para a intervenção no âmbito da demência. Providencia-se, também, uma reflexão crítica do desenho metodológico, bem como dos principais contributos, limitações e perspetivas de pesquisa. Dispõe-se ainda a análise da replicação da implementação da intervenção no local onde foi inicialmente desenvolvida (Centro de Saúde) e a sua evolução, com base nas sugestões das famílias e dos profissionais que participaram e se envolveram nas edições seguintes; a relevância da participação do investigador noutros projetos é também analisada, pois permitiu nortear e amadurecer linhas de orientação importantes para a prossecução dos objetivos traçados.

## Tema Principal

A prestação de cuidados a uma pessoa com demência emergiu nesta investigação como ponto focal na história e na dinâmica das famílias envelhecidas, central para a reorganização das relações familiares e para o desenvolvimento individual na velhice.

O principal objetivo do programa de intervenção desenvolvido nesta tese (proFamílias-demência) centra-se na necessidade de disponibilizar ferramentas e recursos às famílias que cuidam de pessoas com demência, no sentido de promover uma adaptação salutogénica à doença. A avaliação do programa forneceu bons indícios sobre a sua qualidade na resposta às necessidades das famílias, em particular por permitir a troca de experiências, normalização de sentimentos e de pensamentos e aumento do sentido de controlo (cf. *proFamilies-dementia: A programme for elderly people with dementia and their families,* capítulo 1). As famílias que participaram no programa também identificaram impactos a médio prazo que incluem: melhoria da gestão emocional; maior união familiar; consciencialização da importância do autocuidado; melhor compreensão da doença; normalização de sentimentos; capacidade para reconhecer aspetos positivos na situação; maior capacidade para procurar, pedir e receber ajuda (cf *Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance*, cap 1).

A generalidade dos resultados sugere que as abordagens psicoeducativas respondem às necessidades informativas e de suporte dos cuidadores, permitindo um reforço dos laços sociais e afetivos entre quem cuida e o aumento do sentido de eficácia para a prestação de cuidados, favorecendo uma adaptação salutogénica à evolução da doença. A partilha e normalização de emoções e sentimentos contraditórios associados às exigências de cuidados permitiu: (a) atenuar o sentimento de isolamento social e emocional nas famílias; e (b) desenraizar a crença de que os nossos problemas são únicos e imutáveis – princípio da universalidade (Yalom, 1995). A componente de suporte estimula ainda o desenvolvimento de estratégias de *coping* mais positivas (e.g., estabelecer relações de suporte; crença/fé em Deus; utilizar o humor em situações menos agradáveis). As famílias reconheceram a importância do autocuidado após a sua participação no programa e o impacto no bem-estar das pessoas com demência: isto é, ao cuidar de si, terão maior capacidade para cuidar melhor dos seus familiares. As famílias sentiram-se ainda mais competentes na resolução de problemas e mais capazes de enfrentar as exigências do quotidiano até noutras esferas da vida para além do cuidado. Portanto, este tipo de intervenção, ao facilitar o desenvolvimento de mecanismos de *coping* funcionais, potencia a prevenção do *stresse* e sobrecarga associados ao cuidado de pessoas com demência (cf. Figueiredo, Guerra, Marques, & Sousa, 2012). Este modelo de intervenção é estabelecido no âmbito das intervenções familiares em contexto grupal e tem vindo a ser destacado e reconhecido na literatura pela sua abordagem colaborativa, enfoque na promoção da resiliência familiar, partilha de experiências e normalização de sentimentos e pensamentos (cf. Gonzalez & Steinglass, 2002; Mendes, Chiquelho, Santos, & Sousa, 2011).

Um dos aspetos mais significativos deste programa foi a replicação da intervenção no local onde foi inicialmente desenvolvido, o que constitui um bom indicador do seu sucesso junto das famílias e profissionais. A primeira edição do proFamílias-demência constitui o foco desta tese; entretanto, decorreram mais três edições, coordenadas pela autora desta tese, que tem acompanhado os resultados juntos das famílias e profissionais.

## 1. CONTRIBUTOS, LIMITAÇÕES E PERSPETIVAS DE PESQUISA

A expressão das conclusões gerais de um trabalho de investigação com um período de quatro anos impõe uma tendência recapituladora. Neste exercício, emerge um enfoque teórico-conceptual e especificidades dos vários momentos do estudo. Esta análise foi enformada pelas experiências entretanto apreendidas, particularmente relacionadas com as novas edições do proFamílias-demência, que apelam a um equilíbrio entre o desenho de investigação *ideal* e o destaque dos seus principais fatores de sucesso, contributos e limitações.

### 1.1. Contributos do proFamílias-demência

O principal contributo que pretendemos com esta investigação consiste em: (a) facultar dados para o desenho, implementação e avaliação de uma intervenção integrada de apoio a pessoas com demência e seus familiares mais próximos (cf. capítulo I - *ProFamilies-dementia: A programme for elderly people with dementia and their families; Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance; Being a volunteer: motivations, fears and benefits of volunteering in an intervention program for people with dementia and their families; Post- intervention referral service (PIRS): Supporting families of people with dementia after a psycho-educational program*); e (b) explorar a influência que a prestação de cuidados a um familiar com demência exerce na configuração do sentido de integridade do cuidador principal idoso (cf. capítulo II - *Constructing family integrity in later life: The case of older caregivers of relatives with dementia*).

Em Portugal, à semelhança de outros países (cf. Dupuis, Epp, & Smale, 2004), escasseiam intervenções de cariz psicoeducativo centradas na família como unidade no âmbito da demência, em unidades de cuidados de saúde primários. Esta circunstância reflete uma prática de serviços ou respostas enraizada nos pressupostos de uma perspetiva tendencialmente biomédica e individualizada. Este programa pretende ajudar a responder a essas lacunas, concorrendo: (a) para o desenvolvimento de um enfoque psicossocial face à demência, já que a sua manifestação clínica não se explica apenas por défices neurológicos, mas engloba também fatores psicossociais; (b) para o desenvolvimento de uma intervenção integrada, que se foca na pessoa com doença, no cuidador e na família como unidade, desenvolvida num contexto de cuidados de saúde primários, destinada a promover o bem-estar de pessoas com demência e seus familiares; (c) para promover a continuidade do apoio disponibilizado; (d) para uma dimensão comunitária, ao envolver e valorizar o papel do voluntariado no apoio a estas famílias. Os resultados são relevantes em termos da provisão de apoio familiar no contexto da demência a nível europeu, onde há esforços para que os governos nacionais declarem a demência como uma prioridade de saúde e se desenvolvam estratégias de apoio a pessoas com demência e suas famílias (ADI, 2010).

O desenho, implementação e avaliação da intervenção baseou-se na revisão da literatura, nos objetivos das intervenções em contexto de demência e das necessidades e expectativas das famílias que participaram no proFamílias-demência. As famílias participaram nesta intervenção para: melhorar o seu bem-estar emocional e desempenho na prestação de cuidados à pessoa com demência; obter informação acerca da doença; e partilhar as suas experiências. Estes relatos vão ao encontro dos resultados obtidos num estudo recente de Rosa *et al.* (2010), onde são identificadas as principais necessidades médicas, educacionais e psicológicas de 112 cuidadores de pessoas com demência (moderada a severa): adquirir informação sobre a doença (78%) e conhecer o diagnóstico exato (65%); adquirir competências comunicacionais (83%); saber lidar com os desvios cognitivos (77%) e comportamentais (81%); gerir o stresse (37%) e sentimentos de ansiedade, revolta e culpa (49%). Os resultados reiteram a necessidade em proporcionar mais e melhor informação sobre a doença, gestão dos desvios cognitivos e comportamentais e prover apoio psicológico a estas famílias, aspetos considerados na estruturação do proFamílias-demência. As famílias revelaram ainda a sua experiência de prestação de cuidados, mostrando viver um complexo emocional descrito por sentimentos como: impaciência, não-aceitação, *stresse*, sofrimento, ansiedade, medo e cansaço.

Os estudos do capítulo 1 contribuem para um entendimento mais alargado da demência como doença crónica, ao incluir a vertente psicossocial e ao disponibilizarem os procedimentos de um programa de intervenção centrado na família no âmbito da demência. O objetivo orientador do programa centrou-se na verificação da adequação estrutural e funcional do seu formato face às necessidades das famílias. O programa evidenciou uma estrutura e conteúdos geralmente adequados; apesar dos pressupostos realçados anteriormente, a inclusão de medidas quantitativas, num formato pré e pós-intervenção, pode apresentar-se como uma perspetiva de pesquisa futura valiosa.

As famílias consideraram que os temas trabalhados nas sessões foram adequados. Saliente-se a importância da sessão dedicada ao autocuidado, referida pelos participantes como uma das mais importantes para o seu bem-estar. As exigências associadas à prestação de cuidados a um familiar com demência implicam consequências pessoais que se relacionam com a ausência de períodos de alívio/descanso e com a impossibilidade de tirar tempo para si (cf. Thomas *et al.*, 2002). É fundamental que os cuidadores reconheçam as suas necessidades e limites e, nesse sentido, é necessário reconhecer e valorizar o papel destas famílias, estimulando-as para o autocuidado e reforçando a sua importância na vida diária. O momento de relaxamento em todas as sessões revelou-se indispensável; em contexto grupal, é mais fácil as famílias envolverem-se neste tipo de comportamentos: primeiro, porque o relaxamento é considerado uma tarefa da intervenção; e segundo porque as famílias observam outras famílias que se encontram na mesma situação (i.e., prestam cuidados a um familiar com demência) envolvidas na atividade (deixam de existir sentimentos de culpa associados à prática de uma atividade prazerosa e relaxante). Losada, Márquez-González e Romero-Moreno (2010) desenvolveram uma intervenção psicológica de 12 sessões grupais, sobre técnicas cognitivo-comportamentais, junto de 170 cuidadores de pessoas com demência. Os autores concluíram que os aspetos positivos da intervenção (e.g., diminuição do nível de depressão e de pensamentos disfuncionais dos cuidadores) se centraram no incentivo aos cuidadores pensarem de forma diferente, promovendo o seu envolvimento em atividades prazerosas. Estes resultados corroboram a importância do módulo dedicado ao autocuidado, que exige a atenção aos facilitadores do autocuidado. As famílias que participaram no proFamílias-demência identificaram alguns: possuir uma boa rede de suporte familiar (que forneça apoio emocional e instrumental); apoio e visita domiciliar dos profissionais; e partilha de experiências com pessoas que vivem a mesma situação. Poderá ser útil promover as visitas dos profissionais envolvidos na intervenção ao domicílio destas famílias regularmente: para facultar assistência instrumental ou apenas passar algum tempo (companhia), permitindo que se descentralizem, ainda que por momentos, da tarefa de cuidar.

A análise do processo de desenvolvimento e implementação da intervenção permite ainda identificar alguns fatores que potenciaram o sucesso, devendo ser considerados em futuras intervenções.

Em primeiro lugar, a *análise das expectativas/necessidades das famílias e sua incorporação nos objetivos do programa.* Raivio *et al.* (2007) desenvolveram um estudo junto de uma amostra aleatória de 1943 cuidadores de pessoas com a doença de Alzheimer, na Finlândia, com o objetivo de verificar a adequação dos serviços às necessidades dos cuidadores. Apenas 39% dos cuidadores demonstraram satisfação com os serviços que lhes eram providos e 69% não identificaram qualquer tipo de impacto. Os serviços oferecidos a estes cuidadores parecem não satisfazer as suas necessidades. A análise inicial das necessidades e das expectativas dos participantes em relação à intervenção ou aos serviços que lhes são oferecidos revela-se fundamental. No proFamílias-demência, essa análise favoreceu um desenho sustentado e adequado às necessidades das famílias, potenciando a sua eficácia. Este procedimento enquadra-se numa abordagem que visa envolver as famílias e capacitá-las; os objetivos das famílias são mais relevantes do que os objetivos traçados pelo investigador. Esta é uma forma de *ouvir a voz das famílias* e intensificar a valorização e a integração das suas necessidades. O programa em grupos multifamílias constitui um processo de reflexão sobre a prestação de cuidados, operando como uma (re)aquisição de competências e um espaço de desenvolvimento da autonomia e poder. Uma apreciação insuficiente das perspetivas dos participantes em relação aos objetivos da intervenção contribui para algumas das discrepâncias nos resultados (cf. Kazdin, 1999). Pode acontecer que os participantes abandonem as intervenções precocemente porque, apesar de os objetivos não terem ainda sido cumpridos, os objetivos desses participantes face à sua participação já o poderão ter sido (cf. Kazdin, 1999).

Em segundo lugar, a *forma como as sessões foram conduzidas/dinamizadas*. As sessões foram dinamizadas por profissionais que ativaram o conhecimento a partir da experiência vivida pelos participantes, potenciando uma aprendizagem mais significativa e duradoura das competências necessárias para o cuidado. Os profissionais não ensinaram: partilharam e facilitaram. Tratou-se de uma abordagem colaborativa, onde os profissionais ajudaram as famílias a identificar problemas e discutir estratégias em conjunto (cf. Nomura *et al.*, 2009). Por outras palavras, os profissionais não ofereceram respostas aos problemas das famílias, ativaram-nas para as capacitar a encontrar as suas soluções, pois acredita-se que a família/pessoa é naturalmente criativa e dispõe de recursos (cf. Nomura *et al.*, 2009). As famílias partilharam a sua experiência e os profissionais os seus conhecimentos. Constrói-se, assim, uma postura de equidade, empatia e reciprocidade entre famílias e profissionais, deixando os participantes mais à vontade para expor temas mais pessoais. Nesse sentido, consideramos que os facilitadores devem adotar uma atitude empática, reconhecendo e valorizando os conhecimentos e competências que as famílias foram adquirindo ao longo da sua trajetória de cuidados (postura de curiosidade que honra o saber das famílias). Assim, as famílias são ajudadas a desenvolver sentimentos de autovalorização e maior motivação para o cuidado. Esta atitude empática ajuda as famílias a melhorar a sua autoestima e, neste contexto, o grupo cria um ambiente protetor, em que os membros encontram compreensão, confiança e contactos sociais, que posteriormente promovem o desenvolvimento pessoal e interpessoal. A não utilização de novas tecnologias (mais especificamente apresentações em diapositivos com recurso ao programa *Microsoft PowerPoint*) no decorrer das sessões psicoeducativas constituiu uma vantagem: as tecnologias podem inibir as famílias, particularmente aquelas com menos habilitações literárias; mas como Bateson (1972: 459) afirma, "*informação é diferença que faz diferença*", ou seja, sendo o uso de tecnologias bastante disseminado, fazer algo diferente acaba por ter maior impacto.

Em terceiro lugar, as *características associadas à intervenção (contexto e filosofia)*: a intervenção foi desenvolvida num contexto de cuidados de saúde primários, o que permitiu criar uma atmosfera de proximidade e confiança, facilitando o comprometimento e envolvimento dos participantes no grupo e nas sessões; e envolveu uma componente de voluntariado, com profissionais de saúde e de acção social e estudantes e recém-licenciados na área da saúde. Consideramos que podemos falar em *empowerment comunitário*, pois as redes formais e informais, congregando profissionais e voluntários, entreajudaram-se. Estes aspetos reforçam a importância de motivar e envolver voluntários, para que sintam enaltecido o seu trabalho e continuem a esforçar-se e a evidenciar motivação e empenho. As expectativas e os receios dos voluntários foram considerados e houve uma disponibilidade contínua, por parte da equipa de investigação, para acolher as suas dúvidas. A componente de voluntariado faz com que esta intervenção possa ser desenvolvida envolvendo custos reduzidos, sendo fácil de replicar e disseminar; paralelamente, permite promover uma cultura de solidariedade na comunidade, aumentando o nível de participação cívica. Na participação cívica, através de uma cidadania ativa e responsável, os voluntários encontram um espaço propício à realização da relação solidária com o seu próximo, de forma livre e desinteressada e, simultaneamente, organizada em torno da solução dos problemas que afectam a sociedade (Chambel, 2011). Os voluntários que acompanharam as pessoas com demência eram, na maioria, jovens recém-licenciados à procura de uma oportunidade em afirmar o seu altruísmo e aprofundar o seu conhecimento e experiência. A autora desta tese co-coordenou um projecto intergeracional (P=LHNS, Parque=Lugar com Histórias e Natureza para Socializar), financiado pela Fundação Calouste Gulbenkian no âmbito do concurso EntreGerações 2011, que lhe permitiu consolidar e reforçar a relevância em envolver pessoas de diferentes gerações num projeto comunitário. As relações intergeracionais constituem uma ferramenta mobilizadora das pessoas e comunidades, baseada num processo humano básico, que combina diferentes gerações para alcançar um bem comum (Kuehne, 2003). Estas relações caracterizam-se pela combinação de duas (ou mais) pessoas em diferentes estádios de desenvolvimento, que interagem em várias situações e contextos com a expectativa de uma ligação (Bostrum, 2000; Vanderven, 2001). Os voluntários (geração mais nova) acompanharam a pessoa com demência e a sua família (geração mais velha), disponibilizando o seu tempo, saber e experiência e transmitindo conhecimentos. Por seu turno, estas famílias permitiram aos voluntários, ao confiarem neles e no seu trabalho, uma oportunidade de desenvolvimento pessoal e profissional. Ou seja, a intervenção (proFamílias-demência) pode constituir um veículo priveligiado para a troca progressiva e propositada de recursos, saberes e oportunidades entre gerações mais novas e mais velhas com benefícios individuais e sociais (cf. Bostrum, 2000).

Em quarto lugar, saliente-se que o proFamílias-demência se trata de uma *intervenção integrada*. Um dos maiores problemas que tem sido apontado à intervenção usual é a fragmentação dos serviços (principalmente, sociais e de saúde) (cf. Jansen, 2008). Tal advém da especialização biomédica, associada aos sistemas tradicionais de cuidados agudos, resultando na prioritarização das necessidades dos prestam os serviços em relação às daqueles que os recebem (cf. Jansen, 2008). As famílias, já sobrecarregadas pelas exigências do cuidado, têm de procurar os diversos apoios que necessitam junto de diferentes serviços e profissionais; um dos caminhos a percorrer no sentido de ultrapassar estas limitações reside na adoção de abordagens integradas. Estas abordagens assistem os profissionais a responder às necessidades mais complexas das famílias e, nesse sentido, têm-se vindo a desenvolver modelos de cuidados 'baseados em equipa' ("*team-based*") (Jansen, 2008). Estes modelos caracterizam-se pela existência de equipas interdisciplinares, que colaboram para alcançar decisões que vão ao encontro das necessidades, objetivos e valores das famílias (cf. Jansen, 2008). Essas equipas podem fornecer diferentes serviços, constituindo o alicerce dos modelos integrados de prestação de serviços. O proFamilias-demência demonstrou potencial para prover apoio integrado, ao conjugar respostas sociais e de saúde, a curto e médio prazo.

Em quinto lugar, a utilização de uma *metodologia de avaliação da intervenção* inovadora: *photovoice*. Esta metodologia qualitativa permitiu que os participantes refletissem sobre a prestação de cuidados e suas implicações na vida familiar, facilitando a partilha de testemunhos e encorajando-os a adoptar um papel mais ativo e positivo em relação a si e aos que os rodeiam (cf. capítulo 1, *Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance*). O photovoice permitiu capturar a significância clínica da intervenção, tornando-se uma extensão da própria intervenção, pois encorajou as famílias a recordar e a refletir o significado do proFamílias-demência (olhar retrospetivo). Adicionalmente, a discussão de fotografias em grupo permitiu que os profissionais entendessem de forma mais aprofundada a experiência subjetiva da participação de cada família no programa (cf. Thompson *et al.*, 2008), reforçando a filosofia de intervenção centrada na pessoa. Ainda que seja mais simples pedir às famílias para excluirem fotografias com pessoas, por aspetos associados à obtenção de consentimento informado, é importante incentivar as famílias a fazê-lo. Este aspeto foi relevante nesta intervenção, pois permitiu que os investigadores se apercebessem a forma como as pessoas mais importantes na vida destas famílias interagem com elas (cf. Thompson *et al.*, 2008).

Em sexto lugar, a *continuidade de apoio*, através do serviço de referência pós-intervenção (PIRS, Post-Intervention Referral Service). As famílias nem sempre utilizaram o serviço, mas sabiam que existia e que podiam recorrer quando necessário, revelando-se garantia de segurança e conforto. Este tipo de serviço de suporte revelou-se útil na dissipação das incertezas destas famílias sobre apoio financeiro, serviços comunitários, 'diagnóstico' da sua situação atual ("*screening*") e, em última instância, revelou-se útil na prestação de apoio emocional. Algumas das famílias que participaram na intervenção revelaram ter experienciado uma atmosfera de confiança que lhes permitiu expressar as suas preocupações, partilhar as suas ansiedades e sentirem-se aliviados. Ou seja, além da função de providenciar informação sobre os recursos comunitários, o PIRS revelou potencial para ampliar os benefícios da componente de suporte/emocional das sessões psicoeducativas.

## 1.2. Contributos do estudo sobre a Integridade Familiar

A prestação de cuidados está a tornar-se um evento normativo para as famílias; contudo, não existem atualmente modelos para compreender os desafios da experiência de cuidar em termos desenvolvimentais. A literatura tem privilegiado o estudo da sobrecarga e dos impactos da prestação de cuidados, negligenciando o seu impacto no desenvolvimento individual e familiar. Os resultados do estudo *Constructing family integrity in later life: The case of older caregivers of relatives with dementia* (cf. capítulo 2) demonstram que os cuidadores familiares idosos de pessoas com demência sentem dificuldade em concretizar os projetos de vida idealizados e que a reciprocidade familiar diminui. Este aspeto é consistente com os impactos processuais da doença crónica (Góngora, 1996), que indicam que perante um familiar com doença crónica severa, a tendência é envolver-se na gestão da doença negligenciando as restantes tarefas. Os cuidadores no caminho da integridade familiar têm capacidade para rever os seus projetos de vida e assumir a prestação de cuidados como o seu objetivo atual; contudo, aqueles no percurso da desconexão debatem-se com os projetos já traçados, assumindo uma postura vitimizante face à vida; os cuidadores no caminho da alienação tendem a desistir dos seus projetos de vida e a sofrer com a falta de significado da sua existência. O quadro concetual da integridade familiar desafia os investigadores e profissionais a *olhar* a prestação de cuidados (e as pessoas idosas, em geral) sob uma perspetiva desenvolvimental, abandonando a abordagem tradicional focada nos problemas de saúde e nos impactos na saúde e nos sentimentos do cuidador (Sousa, Silva, Marques, & Santos, 2009). Todas as pessoas necessitam de aprender a focar-se no momento e a apreciar as experiências, transformando, inclusivamente, situações negativas em lições de vida (cf. Sousa *et al.*, 2009), essenciais na construção de uma filosofia de vida (cf. Erikson, 1950). O contexto das significações exerce um papel fundamental na construção da integridade familiar. Este estudo reforça que é primordial atentar a estes desafios e integrá-los nas intervenções dirigidas aos familiares de pessoas com demência, providenciando recursos que os apoiem a lidar com a situação de forma salutogénica, incentivando-os a serem proactivos e a lidarem com as vicissitudes da vida.

### 1.3. Limitações

As limitações deste estudo centram-se, fundamentalmente, no desenho metodológico. A natureza exploratória do programa de intervenção fez-nos optar por metodologias qualitativas. Consideramos estas metodologias como veículos privilegiados para captar a complexidade dos impactos vividos pelas famílias após a sua participação num programa de intervenção. Esta escolha pautou-se pela crescente consciencialização da importância em considerar a significância clínica na avaliação das intervenções (cf. Kazdin, 1999). A significância clínica refere-se ao valor prático ou aplicado ou à importância do efeito de uma intervenção; ou seja, se a intervenção produz uma diferença real (e.g., genuína) na vida quotidiana dos participantes ou daqueles com quem interagem (Kazdin, 1999). É crível que uma pequena mudança possa gerar uma significativa diferença na vida do participante (ou seja, possa ser clinicamente significativa) e ter influência no funcionamento quotidiano (Kazdin, 1999). Tradicionalmente a avaliação dos programas define-se *à priori*, ou seja, existem variáveis em que se pretende que os participantes atinjam maiores níveis de funcionalidade; o impacto do programa centra essas variáveis, ignorando outros impactos (positivos e negativos) que possam eventualmente ocorrer. Contudo, o impacto sentido pelos participantes na sequência da intervenção pode não se encontrar relacionado com as alterações nas variáveis previamente definidas pelos investigadores/interventores (Lunnen & Ogles, 1998). Neste contexto, torna-se relevante atentar nos conceitos de mudança real e mudança percebida (cf. Kazdin, 1999). Um exemplo de mudança real é a melhoria dos sintomas dos participantes na sequência da intervenção (normalmente refletida em testes/escalas objetivos e estandardizados). A mudança percebida associa-se às perspetivas dos participantes em relação às mudanças ocorridas. A diferença entre mudança real e percebida é reconhecida como importante no contexto da vida diária sendo refletida, por exemplo: em *estar* mais competente (real) e *sentir-se* (percebida) mais competente (cf. Kazdin, 1999). A auto-percepção das pessoas em relação a si e ao mundo que as rodeia são críticas, porque detêm o poder de influenciar alguns sintomas (por exemplo, associados à depressão) e se relacionam com a preocupação que tende a estar na origem da participação destas pessoas nas intervenções.

A metodologia selecionada para avaliar o impacto da intervenção junto das famílias, o *photovoice*, permitiu considerar a sua visão em relação aos benefícios e impacto. A familiarização da autora com esta metodologia deve-se à sua participação no projeto “Caminhar Juntos para Gostar de Aprender e Aprender com a Escola”, financiado pela Câmara Municipal de Cantanhede e pela Junta de Freguesia da Tocha, em parceria com a Universidade de Aveiro, sob orientação científica da Doutora Liliana Xavier de Sousa e do

Professor Doutor Júlio Pedrosa. O projeto, na área da intervenção psicológica em contextos educativos, visa fomentar o envolvimento de pais, professores e alunos na promoção e valorização da educação, e o desenvolvimento de competências cognitivas e sociocognitivas em alunos do 4º, 5º e 6º ano de escolaridade (com baixo aproveitamento e em risco de abandono escolar). Neste projeto dinamizaram-se grupos baseados nesta metodologia, tendo a autora colaborado.

A avaliação da intervenção proFamílias-demência com esta metodologia revelou apenas impactos positivos para as famílias; esses impactos parecem descrever a significância clínica da intervenção ao nível de um processo que vai além da doença, negatividade e solidão destas famílias (cf. *Evaluating proFamilies-dementia: Adopting photovoice to capture clinical significance*, capítulo 1). Os impactos percebidos pelas famílias participantes indicam que conseguiram de alguma forma descentrar da doença, permitindo-lhes adotar uma postura mais positiva e lidar melhor com a situação. A metodologia de avaliação demonstrou o caminho das famílias no sentido de *colocar a doença no seu lugar* ("*putting illness in its place*") (Gonzalez, Steinglass, & Reiss, 1989).

O desenho metodológico não inclui um grupo de controlo, justificado pela natureza exploratória do estudo. De qualquer modo, neste caso o foco estava em se o funcionamento destes participantes melhorou, ou se foram detetados efeitos com a intervenção (cf. Kazdin, 1999). O recurso exclusivo a metodologias qualitativas junto dos participantes suscita algumas reflexões. O uso combinado de métodos de recolha de dados quantitativos e qualitativos poderia, potencialmente, providenciar uma avaliação com maior acuidade no impacto da intervenção. Por exemplo, é reconhecido que os familiares responsáveis pela prestação de cuidados a uma pessoa com demência podem experienciar sobrecarga (associada aos comportamentos desafiantes e *distress* do cuidador) com repercussões psicofisiológicas, colocando-os em risco de doenças físicas e psicológicas. Poderá ter interesse avaliar o impacto psicossocial e também o físico associado ao desempenho dessas tarefas. Assim, a inclusão de marcadores biológicos de *stresse*, tal como o cortisol, poderá ser vantajoso e fornecer uma avaliação mais criteriosa.

Outra limitação relaciona-se com a participação da família como unidade central de investigação. Apesar de a intervenção incidir na família como unidade, os participantes consistiram, fundamentalmente, nos cuidadores principais da pessoa com demência. Apenas uma das famílias contou com a presença de dois elementos. Uma das estratégias para reforçar a família como unidade de intervenção foi centrar e desenvolver os módulos considerando o contexto familiar (e.g., "*Como é que a família acolheu a chegada da doença*?"). Além disso, os participantes foram incentivados a partilhar os conhecimentos e as experiências das sessões com os familiares que não tiveram oportunidade de participar no programa. Alguns participantes revelaram que faziam um resumo das sessões junto dos familiares mais próximos, o que contribui para maior união familiar. Não obstante, teria sido relevante incentivar o cuidador principal a encorajar a participação de outros membros. É importante que alguns membros da família alargada participem, para que se apercebam das verdadeiras dificuldades do cuidador principal, que (con)vive com a doença a todo o momento.

Outra limitação relaciona-se com as dificuldades no recrutamento das famílias, limitação sobejamente referida na literatura (Gonzalez & Steinglass, 2002). Recrutar familiares de pessoas com demência para participação em programas de intervenções constitui uma tarefa exigente (Murphy *et al.*, 2007). Algumas famílias mostram-se desinteressadas nos primeiros contactos, alegando falta de tempo e de identificação em relação à doença; principalmente, não perspetivam a demência como uma condição crónica, não vislumbrando potenciais benefícios da sua participação numa fase inicial da doença do familiar (cf. Areán & Gallagher-Thompson, 1996). Ou seja, os cuidadores continuam a expressar baixos níveis de consciencialização em relação à doença (cf. Rosa *et al.*, 2010). Nota-se, igualmente, alguma desconfiança, pois estas famílias não acreditam que o apoio não tenha custos. Algumas das estratégias para ultrapassar esta limitação poderão passar por: envolver participantes de edições anteriores nos primeiros contactos, no sentido de incentivar e demonstrar, através do testemunho e experiência, a relevância da participação; o primeiro contacto com a família poderia ser realizado pelo médico de família ou outro profissional que trabalhe no local onde a intervenção é desenvolvida, que conheça bem as famílias, para que se sintam mais seguras e confiantes. É fundamental reforçar as motivações altruístas das famílias e fazê-las entender a importância do estudo e das intervenções (Murphy *et al.*, 2007);

A nossa experiência indica-nos a importância em selecionar um número superior de famílias em relação ao necessário, para não se correr o risco de ter um grupo muito pequeno (desistências); nesta intervenção, uma das famílias desistiu após a primeira sessão, por não se identificar com os relatos dos outros participantes (i.e., não perspetivava a demência como uma condição crónica, cujos sintomas e sinais vão evoluindo). É importante que a equipa responsável pela intervenção perceba o que as famílias sabem em relação à doença e o que pretendem saber, providenciando a informação necessária para que sintam que a intervenção lhes poderá trazer benefícios e ajudá-las a ultrapassar os desafios que se avizinham.

### 1.4. Perspetivas de Pesquisa

Estudos futuros envolvendo um número mais alargado de famílias e de voluntários são necessários, no sentido de replicar a metodologia utilizada e investigar a extensão dos benefícios. Neste estudo foi avaliado apenas o impacto a curto e a médio prazo, pelo que se torna pertinente averiguar se esses impactos se mantêm a longo-prazo (6 e 12 meses depois). A avaliação em estudos futuros deveria incluir medidas quantitativas e qualitativas; os métodos quantitativos fornecem um elevado nível de precisão e poder estatístico da medição; e os métodos qualitativos são valiosos para o entendimento dos processos que contribuem para o sucesso e/ou fracasso da intervenção (Matveev, 2002).

Poderia ser importante avaliar a perceção dos profissionais que trabalham com estas famílias (e.g., médico de família) em relação ao impacto da intervenção, na tentativa de perceber se foi detetada alguma mudança. Esta avaliação também poderia ser desenvolvida junto dos familiares da pessoa com demência que não participaram na intervenção (e.g., elemento da família alargada) ou junto da rede informal (e.g., um vizinho da família).

As famílias poderão beneficiar da utilização do método do *photovoice* durante a intervenção, para além do momento onde esta metodologia foi aplicada (avaliação da intervenção).

Em relação à componente de voluntariado (MO, *Meaningful Occupation*), seria interessante que estudos futuros analisassem os seus efeitos no desempenho profissional dos voluntários e nos cuidados prestados pela família à pessoa com demência. O valor do serviço de referência pós-intervenção deve ser reavaliado; uma análise dos benefícios em termos de custo seria importante se este serviço se tornasse um programa comunitário de maior escala.

Em relação ao estudo da integridade familiar, os resultados são limitados pelo tamanho da amostra; apesar de os dados terem demonstrado saturação, seria apropriado aplicar a entrevista junto de uma amostra maior, particularmente para os cuidadores no caminho da alienação familiar (cf. capítulo 2). Isto permitiria a comparação entre os três caminhos (integridade *vs* alienação *vs* desconexão). Outras perspetivas incluem: análise da influência de variáveis como o género, habilitações literárias, relação com o recetor de cuidados, duração da prestação de cuidados. Além disso, seria interessante adoptar metodologias quantitativas que avaliam o bem-estar subjetivo da pessoa e que promovam uma triangulação dos dados e sua melhor compreensão (e.g., *Satisfaction with Life Scale*, by Diener, Emmons, Larsen, & Griffin, 1985); ou então, recolher histórias de vida (*life stories*), para perceber a forma de evolução para cada um dos três caminhos, o que poderia ajudar a desenvolver diretrizes de intervenção. Estudos futuros poderão focar a influência da institucionalização ou da morte do recetor de cuidados na construção do sentido de integridade familiar.

## 2. PROFAMÍLIAS-DEMÊNCIA: EDIÇÕES POSTERIORES

Um forte indicador do sucesso da intervenção passa pela sua replicação no Centro de Saúde onde foi implementado pela primeira vez. O proFamílias-demência conta já com 4 edições. A intervenção expandiu-se às extensões do Centro de Saúde, tendo ganho projeção junto dos profissionais envolvidos. A ideia de base é disseminar a intervenção ao nível dos cuidados de saúde primários, formando profissionais para, autonomamente, implementar e coordenar a intervenção.

A segunda edição do proFamílias-demência envolveu um grupo de cinco famílias, num total de dez participantes. Os recursos da unidade de saúde foram envolvidos, nomeadamente: uma sala, com os materiais necessários para acolher as famílias; e os profissionais necessários ao desenvolvimento da intervenção (fisioterapeuta, psicólogo, médico e enfermeiro). A autora desta tese manteve-se como coordenadora da intervenção e facilitou todas as sessões. Este aspeto foi crucial, pois permitiu que a equipa integrasse de forma mais aprofundada a filosofia e os pressupostos do programa. Na segunda edição, os participantes revelaram que os principais impactos do programa foram a consciencialização da importância do autocuidado, mais união familiar, normalização de sentimentos e pensamentos (associada à partilha de experiências) e aquisição de informação sobre a doença (e.g., aprender a comunicar com a pessoa com demência e a lidar com os comportamentos desafiantes). Estes impactos são consistentes com os obtidos junto das famílias na primeira edição. Contudo, estas famílias identificaram novos impactos: aumento do bem-estar pessoal e criação de laços fortes e significativos entre os elementos do grupo. As famílias que participaram nesta edição continuam a reforçar os laços que as unem e identificaram a experiência como o "*melhor que já me aconteceu na vida*".

A terceira edição contou com oito famílias, num total de nove participantes. Os impactos foram avaliados duas semanas após a intervenção (impacto a curto-prazo) e três meses depois (avaliação a médio-prazo). Os resultados preliminares indicam que os principais benefícios da participação destas famílias na intervenção a curto-prazo são: aquisição de informação sobre a doença (o módulo sobre os cuidados a prestar à pessoa com demência foi muito apreciado, particularmente pela metodologia que incluiu um vídeo demonstrativo dos cuidados ao nível do banho, higiene, comer, vestir/despir, complementado com os comentários da enfermeira); consciencialização da importância do autocuidado, em que os participantes instituíram um plano de autocuidado semanal (e.g., uma cuidadora dedica todos os dias alguns minutos à costura; outra faz caminhadas; outra afirma que vai mais vezes ao cabeleireiro; outra faz quase todos os dias um exercício de relaxamento aprendido nas sessões); e partilha de experiências. Ou seja, a consciencialização da importância do autocuidado, a aquisição de informação sobre a doença e a normalização de sentimentos e pensamentos (associado à partilha de experiências) assumiram-se como impactos da intervenção positivos transversais às edições desenvolvidas. Relativamente aos impactos a médio-prazo, analisados a partir da metodologia *photovoice* (à semelhança das edições anteriores), os resultados indicam que estas famílias: aprenderam a lidar com o comportamento desafiante do familiar com demência (e.g., mudanças súbitas de humor; alucinações); aprenderam a comunicar de modo mais eficaz com a pessoa com demência (as terapias exploradas, nomeadamente, a terapia da validação e a terapia das reminiscências foram valorizadas); adquiriram competências a nível instrumental (e.g., como fazer transferências com o familiar). Foi interessante observar que estas famílias, na sessão de avaliação com o *photovoice*, começaram por partilhar novidades em relação à sua vida pessoal e familiar fora do contexto de prestação de cuidados.

Nenhuma família destes grupos requisitou o serviço de voluntariado, ainda que tenha sido disponibilizado; estas famílias mobilizaram outros elementos da sua família para assegurar a prestação de cuidados ao familiar com demência, durante a sua ausência. Neste momento, encontra-se em desenvolvimento a quarta edição. O grupo iniciou com seis famílias, num total de sete participantes.

De referir ainda que a autora desta tese foi contactada: (a) pela Alzheimer Portugal (delegação da Madeira), que demonstrou interesse em adotar o proFamílias-demência junto da população que assiste; a associação já teve acesso aos manuais e à descrição detalhada da intervenção (cedidos pela autora), e prepara-se para arrancar com a primeira edição; e (b) pela equipa técnica do Centro de Saúde da Figueira da Foz, que demonstrou interesse em replicar a intervenção e em receber formação para o desenvolvimento do programa.

## 3. RECOMENDAÇÕES PARA INTERVENÇÕES PSICOSSOCIAIS NO ÂMBITO DA DEMÊNCIA

Conforme realçado ao longo da tese, as implicações das condições demenciais extravasam o domínio individual. São doenças interpessoais, relacionais, cujo impacto e gestão da saúde assume um enfoque familiar. Esta investigação reafirma a pertinência de uma abordagem centrada na família no âmbito das intervenções em contexto de demência, partindo do modelo ecológico (baseado em Góngora, 1996) constituído por um triângulo cujos vértices são ocupados pela pessoa doente/doença, pelo sistema de saúde e pela sua família/rede social. Salienta também uma centralização nas competências e recursos das famílias (fatores salutogénicos) e a pertinência em adotar uma abordagem colaborativa no apoio assente numa filosofia de *empowerment*. Paralelamente, focaliza a importância da intervenção integrada, a partir da articulação entre serviços sociais e de saúde, bem como a relevância em contemplar as fases temporais das doenças crónicas, ou seja, o contínuo biopsicossocial que inclui indivíduo, família, rede social e comunidade (Engel, 1977).

Apresentamos, em seguida, algumas recomendações para a provisão de uma intervenção psicoeducativa no âmbito da demência, com base nos resultados desta investigação, nos resultados obtidos com a replicação da intervenção (junto das famílias e dos profissionais envolvidos) e na pesquisa da literatura. Pretende-se que possam contribuir para a discussão de temas associados ao planeamento, implementação e avaliação de serviços neste contexto.

- Dos princípios orientadores que norteiam as nossas recomendações, o enfoque assenta na intervenção centrada na pessoa com demência e sua família, para assegurar o bem-estar de todos. Nesse sentido, é fundamental reconhecer a história pessoal da família, a sua cultura, valores e interesses, expectativas e receios em relação à intervenção, integrando-os no plano de intervenção (cf. Nomura *et al.*, 2009). A família deve ser reconhecida como parceira na avaliação, planeamento, provisão e apreciação da intervenção.
- A provisão de serviços no âmbito da demência deve considerar: (a) a pessoa com demência e a sua família (cf. Nomura *et al.*, 2009); (b) os cuidados de saúde primários; (c) os profissionais de saúde e de ação social; (d) os voluntários; e (e) a comunidade.

Assim, requer coordenação interprofissional, pressupondo um cariz multidisciplinar e colaborativo.

- É indispensável orientar os profissionais que conduzem as sessões psicoeducativas (facilitadores), familiarizando-os com a tipologia psicossocial da doença (Rolland, 1990, 1993) e com a abordagem subjacente à intervenção (postura facilitadora na condução das sessões). Alguns encontros, ou pequenos *workshops*, entre a equipa que coordena a intervenção e os profissionais que se irão envolver poderão ser úteis numa fase pré-intervenção. As intervenções devem promover uma relação horizontal entre profissionais, pessoa doente e sua família. Este tipo de relação indica que o profissional deixa de ser o único *expert*, passando a existir uma interação entre dois especialistas: a família é especialista na sua vida e vivências; o profissional é competente numa forma específica de apoio. Este cuidado deve centrar-se na pessoa e no seu contexto, procurando: informar e envolvê-la na tomada de decisões; promover a autogestão da saúde; e compreender e aplicar os princípios da promoção da saúde às diferentes populações/comunidades. Quando as famílias são consideradas especialistas das suas vidas sentem-se mobilizados e encorajados a utilizarem os seus recursos em direção aos seus objetivos (Smith, 2006).
- O programa permitiu-nos perceber que as famílias participam mais pela partilha de experiências do que pela necessidade em receber informação sobre a doença; os conteúdos são importantes, mas o que fica é a troca de perspetivas, sentimentos e de experiências. As famílias demonstram necessidade extrema de partilhar os seus problemas, necessidades e aspetos positivos que decorrem da situação que vivem. É essencial que os profissionais considerem estes aspetos e *não caiam na tentação* de “asfixiar” a família com informação. Este aspeto permite-nos discutir algumas questões relacionadas com a eficácia das intervenções individualizadas; alguns estudos de meta-análise sobre intervenções psicológicas de apoio a cuidadores de pessoas com demência (cf. Sörensen *et al*., 2002) sugerem que as intervenções são menos eficazes quando são desenvolvidas em contexto grupal. Contudo, ainda que as intervenções individualizadas possam ser mais direcionadas, carecem da partilha e troca de experiências entre pessoas que vivem a mesma situação. No proFamílias-demência, essa troca revelou-se fundamental, tendo-se assumido, em praticamente todas as edições desenvolvidas, como um dos principais impactos positivos, pois permitiu a normalização de sentimentos e pensamentos destas famílias. Ter a oportunidade de ouvir testemunhos de famílias que vivem a mesma situação é fundamental para que sintam que não estão “sozinhas”. Contudo, algumas famílias poderão reagir melhor às intervenções em grupo e outras famílias poderão reagir melhor às intervenções individuais.
- A intervenção permitiu-nos reconhecer a importância de melhorar a transmissão do diagnóstico por parte dos profissionais de saúde, designadamente, pelos médicos, a estas famílias. São poucas as famílias que reconhecem a doença do familiar e que a

entendem. Ou seja, as pessoas sabem que o familiar tem uma doença, mas carecem de informação sobre a sua etiologia, evolução e tratamento (cf. Fleming, Mahoney, Carlson, & Engebretson, 2009). É fundamental que estes profissionais providenciem informação mais específica e cuidada na transmissão do diagnóstico de demência às famílias, começando a prepará-las para os desafios que se avizinham. Esta falta de conhecimento em relação à doença foi, inclusivamente, motivo de desistência de uma família, face ao não reconhecimento do caráter crónico da doença.

- Em relação aos aspetos funcionais e estruturais da intervenção: com as novas edições, apercebemo-nos da necessidade de proceder a algumas alterações (tabela 1). Assim, o módulo sobre o autocuidado, pela relevância, passou para a primeira sessão. Adicionalmente, o módulo sobre os cuidados à pessoa idosa com demência passou a ocupar uma sessão, pois é necessário tempo para que a enfermeira possa demonstrar, em termos práticos, como cuidar e lidar com as AVD's de forma eficaz. Este módulo suscita muitas dúvidas e, paralelamente, muita partilha de experiências. Foi introduzido um novo módulo sobre "estimulação funcional da pessoa com demência e prevenção de quedas" (Quadro 5), com base nas sugestões das famílias que participaram na segunda edição. É essencial estimular as pessoas com demência, a nível cognitivo e funcional (Christofoletti *et al.*, 2008; Fowler, 2007). Desta forma, foi acrescentada uma sessão, com o objetivo de fornecer informações úteis e práticas às famílias em relação à forma como poderiam estimular o seu familiar a nível funcional/motor. Como é importante *ouvir a voz destas famílias* e, simultaneamente, provê-las de informação para que possam responder aos desafios associados à doença, tornou-se fundamental acrescentar uma sessão. Desta forma, os módulos não são prejudicados e as famílias têm oportunidade de partilhar experiências, sentimentos e pensamentos.
- Poderá ser interessante introduzir o método *photovoice* como um exercício no início da intervenção, para ajudar as famílias a adaptarem-se ao método e desenvolver capacidade para utilizar a fotografia como forma de expressão ao longo da intervenção. As famílias devem ser, igualmente, encorajadas a tirar fotografias em todos os contextos da sua vida, no sentido de capturar a espontaneidade do seu pensamento e aperceberem-se do impacto mais abrangente da intervenção.

**Quadro 5.** Módulos das Sessões Psicoeducativas da Intervenção proFamílias-demência

| Sessão | Vertente | Módulos |
|---|---|---|
| 1 | Suporte | Apresentações<br>«Cuidar de si».<br>Impacto da doença no cuidador, na pessoa com demência e na família. |
| 2 | Educacional<br>Suporte | Informação sobre a doença.<br>Introdução às técnicas de relaxamento. |
| 3 | Educacional | Cuidados à pessoa idosa com demência. |
| 4 | Suporte<br>Educacional | Comunicação de sentimentos, necessidades e preocupações.<br>Comunicação na demência. |

| Sessão | Vertente | Módulos |
|---|---|---|
| 5 | Suporte<br>Educacional | Gestão de *stresse* e coping.<br>Importância das redes sociais. |
| 6 | Educativa<br>Suporte | Estimulação funcional da pessoa com demência e prevenção de quedas<br>Gestão das emoções. |
| 7 | Educacional | Serviços de Apoio.<br>Aspetos legais e financeiros.<br>Ritualização e finalização. |

- Em relação à componente de Ocupação Significativa (*Meaningful Occupation)*, e para que haja uma intervenção centrada na pessoa, é essencial considerar alguns fatores na avaliação inicial da pessoa com demência, para que a intervenção vá ao encontro das suas necessidades, designadamente (cf. Hoe & Thompson, 2010): (a) tipo de demência e nível de comprometimento da função cognitiva; (b) saúde física; (c) história de vida e/ou biografia (i.e., obter informação sobre amigos, família, interesses, gostos); (d) personalidade (i.e., obter informação sobre a personalidade da pessoa antes do diagnóstico, incluindo formas de *coping*, necessidades psicológicas e preferências ao nível dos cuidados); (e) psicologia social e ambiente envolvente (i.e., avaliar e considerar o impacto da interação com os outros, na perspetiva da pessoa, bem como os efeitos do ambiente que a rodeia - ruídos, sinalizações, cores). A consideração do modelo "*VIPS*" (Brooker, 2007) poderá ser útil na provisão de cuidados individualizados e centrados na pessoa: "V" – *valor* base que reconhece o valor de todos os seres humanos, independentemente da sua idade ou funcionamento cognitivo; "I" – abordagem *individualizada* que reconhece a unicidade de cada pessoa; "P" – entender o mundo na *perspetiva* da pessoa que utiliza o serviço; "S" – proporcionar um ambiente *social* que responda às necessidades psicológicas da pessoa. As memórias de vida da pessoa, suas conquistas e características valorizam-na a si e à sua família e podem ajudar a mapear perceções sobre quem é a pessoa (Jenkins & Price, 1996).
- Ainda em relação à componente de Ocupação Significativa é essencial encorajar a interação entre as famílias e voluntários, estendendo o número de sessões além das sessões psicoeducativas onde participam os familiares da pessoa com demência; esta opção poderá constituir uma forma de os familiares observarem a interação entre a pessoa com demência e o voluntário e, assim, adquirir ferramentas e conhecimentos para lidar mais com pessoa com demência. Além disso, criam-se condições para que não haja uma quebra abrupta na relação entre voluntário e pessoa que acompanha. É importante alargar o período de formação inicial ministrado pela terapeuta ocupacional, para que os voluntários (que poderão não se sentir confortáveis ou estarem receosos na prestação de cuidados a uma pessoa com demência e/ao contexto de apoio) possam estar melhor preparados; esta formação deverá atentar na desmistificação de mitos e estereótipos associados à demência. Poderá ser vantajoso atribuir dois

voluntários por família, para que se sintam mais confortáveis e pela partilha de responsabilidade; isto depende da aceitação da família e da pessoa com demência.

- Oferecer um serviço de referência pós-intervenção, que promova a continuidade da intervenção; neste estudo foram recrutadas, a título voluntário, técnicas de serviço social para assegurar a provisão do serviço. Este serviço é importante para que estas famílias se sintam acompanhadas, em vez de abandonadas. Como foi possível constatar (cf. *Post- intervention referral service (PIRS): Supporting families of people with dementia after a psycho-educational program,* capítulo 1) mesmo que as famílias não solicitem o serviço, apenas saber que existe já lhes traz conforto e segurança. Esta continuidade é importante para a construção de uma relação sólida entre os profissionais e as famílias, fomentando laços de confiança e proximidade. Contudo, é crucial encorajar a interação prévia entre as técnicas de serviço social e as famílias, promovendo mais encontros antes do início deste serviço.
- Dar continuidade do grupo psicoeducativo. As famílias reforçaram a importância de continuar com as sessões em grupo, ainda que com menor frequência (e.g., uma vez por mês). Torna-se primordial assegurar alguns encontros com as famílias no final das intervenções; a periodicidade poderá ser mensal, tal como sugerido. Este aspeto reforça a necessidade da continuidade de apoio: o serviço de referência pós-intervenção é valorizado, mas a partilha com os outros elementos do grupo é mais relevante. Esta partilha deve manter-se, dado que os participantes sentem que ganharam uma nova família e se sentem confortáveis quando estão juntos a expor os acontecimentos mais recentes e a trocar perspetivas. Inicialmente, poderá estar presente algum elemento da equipa que coordena a intervenção e, posteriormente, as famílias podem combinar e preparar esses encontros. Ou seja, os grupos psicoeducativos podem originar grupos de suporte que permitam assegurar a continuidade da intervenção, provavelmente ajudando na manutenção dos ganhos alcançados pelas famílias.

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