

# Features of family caregivers of people with dementia attended at a neurology consultation

## Summary

Providing care to someone with dementia is a complex task, that requires a set of specific skills and knowledge that family caregivers often lack. Training family caregivers of people with dementia is paramount, and the first step towards such purpose should be the identification of their features and the evaluation of their needs. The main aim of this study is to identify the major characteristics of family caregivers of people with dementia in early or moderate stage living at home, who attend the dementia consultation at a hospital in the north of Portugal, through a quantitative, descriptive and cross-sectional study. This study is a section from a previous randomized controlled trial, performed to assess the short-term efficacy of a training programme for family caregivers of people with dementia (the programme “Living together with Dementia”). Regarding the findings, we realized that the average age of family caregivers is 52, and these are mostly women, married, with basic education levels and employed. They display intense overload and difficulties levels, but also high degrees of satisfaction. They mostly resort to mixed coping/problem resolution strategies and their main needs are expressed as follows: managing emotions and feelings associated with the caring process; developing strategies to preserve physical and mental health; developing knowledge about dementia and its stages and finally, seeking support from formal institutions.

**KEYWORDS:** DEMENTIA; FAMILY CAREGIVERS; NEEDS ASSESSMENTS.

## Introduction

Dementia is a progressive syndrome that affects memory, thought, behaviour and performance of daily life activities<sup>1</sup>. Dementia has a greater impact on elderly population but, nonetheless, there have been a progressively greater number of reported cases in people under 65 years of age<sup>1</sup> and its incidence and prevalence tend to increase, which makes of this syndrome a public health problem<sup>2</sup>.

It becomes hereafter necessary to rethink the impact of this health issue in the community and in the families. It is fundamental to educate and support the caregivers and improve life quality of people with dementia in their own

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home environment<sup>1</sup>. The training programmes creation, implementation and effectiveness evaluation for family caregivers of people with dementia living at home should be a target for health professionals. The first step towards this objective is to identify the features and the needs of family caregivers.

Due to psychological and behavioural changes in early and moderate stage of dementia, caregivers deal with great stress and overload levels. Intervention on behalf of these caregivers should therefore be a priority for health professionals with the identification of their features and main needs as a first action to be taken.

## Methods

A quantitative, descriptive and cross-sectional study, which is a section of a randomized controlled trial that aims at evaluating the short-term efficacy of a psychoeducation programme for family caregivers of people with dementia in early or moderate stage living at home (“Living together with dementia” programme). This is a short part of a larger study developed for a nursing PhD thesis<sup>3-5</sup>.

Between October 2015 and March 2016, 48 family caregivers were identified (by neurologists) in the dementia consultation at a hospital in

FAMILY CAREGIVERS FEATURES

1

Family caregivers (n = 27)

Age (SD)	52 (11.7)
Gender	Male – 7 (26%) Female – 20 (74%)
Schooling	0-4 years – 6 (22%) 5-12 years – 17 (63%) > 12 years – 4 (15%)
Marital status	Married – 18 (67%) Not married – 9 (33%)
Occupation	Active – 20 (74%) Not active – 7 (26%)
Duration of family member's illness (SD)	3.0 years (2.2)
Type of dementia of the relative	Alzheimer – 15 (56%) Others – 12 (44%)
Kinship with the person with dementia	Partner – 7 (26%) Son/daughter – 16 (59%) Other – 4 (15%)
Previous relationship with the person with dementia	Good relationship – 26 (96%) Bad relationship – 1 (4%)
Years as a caregiver (SD)	3.3 (2.2)
Hours of day care (SD)	7.5 (7.4)
Help in caring	Yes – 19 (70%) No – 8 (30%)
Previous training as a caregiver	Yes – 1 (4%) No – 26 (96%)
Type of coping/problem-solving strategies	Focused on problem – 9 (33%) Focused on emotion – 1 (4%) Mixed – 16 (59%) None – 1 (4%)
Mean SCB score (SD)	57.1 (13.2) – Intense overload (> 56 score)
Mean CADI score (SD)	62.3 (20.7) – High level of difficulties (90 top score)
Mean CASI score (SD)	89,4 (18,6) – High satisfaction (120 top score)
Legend: SD – Stand Derivation; SCB – Scale of Caregiver Burden; CADI – Caregiver Assessment Difficulties Index; CASI – Caregiver Assessment Satisfaction Index	

the north of Portugal, who met the following inclusion criteria: being the main caregiver of the person with dementia in early or moderate stages; being literate; being motivated to participate in the programme; and residing in Porto. The family caregivers were excluded in the following cases: care recipients did not have dementia in early or moderate stage and the people with dementia suffered from other severe mental pathology. 27 family caregivers agreed to participate in study.

Assessment of the family caregivers who integrated the study was performed by an instrument, containing features of the family caregiver: three open questions regarding the number and type of strategies used as a daily resource; these are: the Scale of Caregiver Burden (SCB) (validated for the Portuguese population)<sup>6</sup>; the Caregiver Assessment of Difficul-

ties Index (CADI) (validated for the Portuguese population)<sup>6-7</sup>; the Caregiver Assessment of Satisfaction Index (CASI) (validated for the Portuguese population)<sup>6-7</sup> as well as pinpoint the 5 major daily needs from a supplied list (the 16-needs list was collected by means of an integrative review of the literature). For data analysis, SPSS software 21 (SPSS® Inc., Chicago, IL, USA) application was used, as well as descriptive statistics. The study was approved by The Health Ethical Commission of the Hospital Centre and all those participating in the study signed a free, prior and informed consent.

Results and discussion

The average age of family caregivers included in the study is 52, they are mostly women, married, and are daughters or wives of the person with dementia. Most of the caregivers' level of education goes from 5 to 12 schooling years, they are employed and have no training or experience as a caregiver. The socio-demographic characteristics found in this study are in accordance with other studies in the area, such as Boise, Congleton and Shannon (2005)<sup>8</sup>, Chien & Lee (2010)<sup>9</sup>, Ducharme et al. (2011)<sup>10</sup>, Hepburn, Lewis, Tornatore, Sherman and Bremer (2007)<sup>11</sup>, Judge, Yarry and Orsulic-Jeras (2009)<sup>12</sup> and Samia, Hepburn and Nichols (2012)<sup>13</sup>.

The previous relationship with the person with dementia was a positive one and most caregivers have a support net for the caring of their loved ones. They have been undertaking this task for about 3 years and devote about 7.5 hours a day to their family member with dementia. Alzheimer's dementia is the most common one among people who are under the care of these family caregivers, whose features can be analysed in table 1.

As can be observed in table 1, the family caregivers who participated in the study resort mostly to mixed coping/problem resolution strategies; in other words, they focus on solving

## FAMILY CAREGIVERS NEEDS

## 2

## Family caregivers (n = 27)

To manage emotions and feelings associated with the caring process	15 (56%)
To manage expectations and requirements associated with the caring process	3 (11%)
To develop effective coping strategies	7 (26%)
To develop problem-solving techniques.	7 (26%)
To develop strategies to maintain physical and mental health	20 (74%)
To develop knowledge about dementia and its stages	12 (44%)
To develop knowledge about psychological and behavioral changes in people with dementia	10 (37%)
To develop knowledge about communication strategies and behavior management	6 (22%)
To develop knowledge about adaptive strategies for daily life activities	7 (26%)
To develop knowledge about adaptive strategies for instrumental life activities	0 (0%)
To develop knowledge about strategies of general stimulation of cognition	2 (7%)
To develop practical skills for the execution of care	10 (37%)
To adapt the environment to the needs of the person	7 (26%)
To manage family, social and work relationships	8 (30%)
To know resources in the community	8 (30%)
To seek support from formal institutions	13 (48%)

the problem, but also on managing the emotion associated with the problem. An instance is asking for the help of other relatives to solve the problem and going for walks with friends to cope with stress.

Family caregivers present high overload and difficulties levels, which is compliant with some studies that state that as a result of the behaviour and psychological changes associated to the early and moderate stages of dementia, family caregivers that undertake this responsibility are more exposed to stress than other caregivers<sup>14</sup>.

However, these caregivers present high levels of satisfaction, which may be related to the positive meanings associated with caring, as some authors claim<sup>6,15</sup> and also due to a prior positive relationship with the person with dementia, which is a predictor of greater satisfaction in caring<sup>16</sup>.

As can be seen in table 2, the main needs expressed by family caregivers were: managing emotions and feelings associated with the caring process; developing strategies to preserve physical and mental health; developing knowledge about dementia and its stages; developing knowledge about psychological and behavioural changes in people with dementia; developing practical skills for the performance of care and seeking support from formal institutions. Developing strategies to preserve physical and mental health – possibly due to the intense overload presented by these caregivers – accounted for 74% of the answers.

## Conclusion

This study made it possible to understand the features of family caregivers

of people with dementia in early or moderate stage, who attend the dementia consultation at a hospital in the north of Portugal and to identify their levels of overload, difficulties and satisfaction. It was also possible to understand their main needs and the type of coping/problem resolution strategies they use.

These results are fundamental for the construction of adapted training programmes. The construction, validation and implementation of training programmes for family caregivers of people with dementia presents itself as a priority in health in the national context. The programme “Living together with Dementia” arises as a response to this need, as well as a guideline for the professionals’ intervention.



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