

## **Effects of supporting patients with dementia: A study with dyads**

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## **Effects of supporting patients with dementia: A study with dyads**

### **Abstract**

**Purpose:** This study aimed to examine the factors associated with the development of higher burden in informal care-givers of patients with dementia, using dyadic data.

**Design and Methods:** Seventy-two dyads of patients with dementia and their informal care-givers were assessed, the former in terms of behavioral-psychological symptoms and autonomy, the latter in terms of burden and individual needs.

**Findings:** Care-givers at risk for developing higher burden are those who are female, whose care recipient present psychiatric symptoms and lower autonomy, and those who recognize the need for more information/support.

**Practice Implications:** Interventions should offer care-givers the tools to provide care, maintaining their psychological well-being. Interventions should target not only common aspects of care-giver burden but also the specificities of caring for a person with dementia.

**Keywords:** Informal care-givers; burden; dementia; behavioral symptoms; autonomy

## Introduction

Dementia has become an important public health problem, as it is one of the most common condition in older age, capable of causing great incapacity and dependence on others. The *World Alzheimer Report* (2016) estimates that, in 2050, there will be 131.5 million people diagnosed with dementia worldwide, highlighting the need to provide care not only to the people with dementia but also to their families, who are typically their main care-givers (WHO, 2017). In Portugal, a demographically aged country, it is estimated that 5.91% of those over the age of 60 have a diagnosis of dementia (Santana et al., 2015).

The care of people with dementia depends largely on the informal care of someone close to them, typically a family member and it is, therefore, a condition that affects not only the patient with dementia, but also those around them. Given its incapacitating condition, both physically and psychologically, dementia may come with burden for the care-givers. This burden can be subjective, when it refers to the feelings derived from the task of caregiving (Zarit et al., 1986), or objective, attained through the time spent on this task (Wasilewski, 2012).

Informal care-givers can suffer a major negative impact both on their well-being and on their own physical health (Pego & Nunes, 2018) because: they assume many different responsibilities in providing care for the patient with dementia on a daily basis; they are not remunerated (Braithwaite, 2000; Donelan, et al., 2002; Hollander et al., 2009); they often have to sacrifice their professional life (Brodaty & Donkin, 2009), and do not have formal training to provide this care (Matthews, 2018).

Specifically, studies have shown that care-givers tend to experience higher levels of burden with consequences on the personal, social, professional, physical, and emotional levels (Marques et al., 2012). According to existing data, about 50% of

informal care-givers are at risk for developing psychiatric issues such as depression (Harding et al., 2015), which is a widely diagnosed disorder in this group (Cooper et al., 2007; Cooper et al., 2008; Dang et al., 2008; García-Alberca et al., 2012; García-Alberca et al., 2011). Anxiety and burnout symptoms have also been identified (Truzzi et al., 2012; Yilmaz et al., 2009).

In the specific case of care-givers of patients with dementia, the burden is associated with the physical nature of the care tasks but also with the behavioral changes (Brodaty et al., 2014; Fulton & Epstein-Lubow, 2011; Abreu, Rodrigues, Sequeira, Pires, & Sanhudo, 2017) and cognitive decline (Beeber & Zimmerman, 2012) that characterize this condition, which constitute an additional challenge to the care-giver. On the other hand, the characteristics of this condition itself lead to a progressive loss of autonomy and consequent increase in the dependence of the patient with dementia, which can contribute equally to increase the care-givers' burden (Chiao et al., 2015; Reichman, 2000; Pérez-Fuentes et al., 2017). In a previous study, care-givers of elderly people with dementia showed higher levels of burden, lower satisfaction with the care-giver role, and more challenges in dealing with care-givers' tasks, when compared to care-givers of elderly people without dementia (Sequeira, 2013). This evidence seems to demonstrate the impact that the characteristics of this condition itself can have on the worsening of care-giver burden.

However, studies show that not everyone who provides care to people with dementia is likely to suffer from burden (Ramos, 2004; Savage & Bailey, 2004). This evidence emphasizes the need to investigate whether this intraindividual variability is related to the care-giver's own personal resources, or if the variables of the patient with dementia (including those related to the characteristics of this condition) also contribute to explain such variability.

A study about the prevailing aspects of the health of informal care-givers has shown that the factors which negatively impact the quality of life of the patient with dementia also directly affect the care-givers (Matthews, 2018). The presence of more co-morbidities, greater incapacity/disability, less perceived health and poor psychological well-being of the patients with dementia are all associated with higher levels of care-giver burden (Metzelthin et al., 2017). These data confirm the relevance of analyzing the possible influence of variables pertaining to the patient with dementia on the care-giver's burden.

Research has focused, mainly, on assessing the level of burden and the mental health status of the informal care-givers (Mosquera et al., 2016), leaving unexplored the factors that may influence care-giver burden. In a recent literature review, Grant and Graven (2018) identified four key problems for the care-giver: performing multifaceted activities; maintaining their own well-being; not seeking support for themselves; providing care with uncertainty and lack of appropriate knowledge. Bednarek et al. (2016) recognize the difficulty to determine accurately which factors are most relevant in explaining care-giver burden.

Thus, the aim of the present study was to examine the association between the variables of the patients with dementia - level of autonomy and behavioral and psychological symptoms – and care-giver burden. Because some studies have highlighted the important role of number of hours providing care for care-giver burden (Chiao et al., 2015) and because number of hours providing care is an objective measure of burden (Wasilewski, 2012), we also investigated the relationship between years of care and levels of burden.

Moreover, we analyzed whether the needs for support of the care-giver are associated with their levels of burden. Although some studies have identified a lack of

information and psychological support among care-givers (Pereira, 2015; Pesantes et al., 2017), none have investigated their role as factors associated with increased burden. Finally, because there is a higher percentage of female among care-givers (Bednarek et al., 2016; Pinquart & Sörensen, 2006), we investigated whether gender is a factor associated with burden. By adopting a dyadic approach that simultaneously takes into account variables of the care-giver and of the patient with dementia, this study fills a gap in the literature by contributing to increase the knowledge about the variables involved in the “process” of care-giver burden.

Thus, the following hypotheses were tested: the presence of more neuropsychiatric alterations (behavioral and psychological symptoms) and a decrease in the levels of autonomy of the patient with dementia (H1), as well as a greater amount of time providing care and higher levels of perceived needs by the care-giver (H2) were associated with more care-giver burden. Moreover, women were more likely to suffer from higher levels of care-giver burden than men (H3).

## **Methods**

### *Participants*

For this cross-sectional study, patients with dementia and their care-givers were recruited during one year at two public hospitals and one health care center in || removed for blind review || in the Dementia Appointment. Inclusion criteria for dyads were: (1) to be a patient with a formal diagnosis of dementia (DSM-V) with a score  $\geq 3$  on the Global Deterioration Scale and  $\leq 24$  on the Mini-mental State Examination; (2) to be the primary care-giver of the patient with dementia, without past/actual formal or structured support from professionals or public or private services; (3) both residing in the community.

Eighty-five dyads were screened for the inclusion in the study. From these, 13 were excluded because patients with dementia scored  $< 3$  on GDS and  $> 24$  on MMSE. Thus, 72 dyads were included. Patients with dementia, 44 females (61%), had a mean age of 78.39 ( $SD = 8.25$ ; range 60-94 years), and care-givers, 47 females (65%), had a mean age of 64.68 ( $SD = 13.99$ , range 19-94). In terms of educational levels, 77% of care-givers had less than 9 years of education, 17% had 12 years of education, and 6% held a university degree. The majority of care-givers were retired (54%), 25% were employed and 21% were unemployed.

The relationships of care-givers to patients with dementia were spouses ( $n = 38$ ), adult children ( $n = 28$ ), sisters ( $n = 2$ ), grandchildren ( $n = 1$ ) and neighbor ( $n = 1$ ). Essentially, women care for their male spouses (79%) while adult children care for the female patients with dementia (58%). Care-givers have been providing support, on average, for 4.38 years ( $SD = 2.67$ ; range 1-13 years). Most of them provided care seven days a week (75%), with a mean age of 18.72 hours per day ( $SD = 6.89$ ). Half of the sample provided care 22-24 hours per day. Only 25% provided care less than 16 per day.

### *Measures*

**Sociodemographic data.** Sociodemographic data for patients with dementia (i.e., gender and age) and care-givers (i.e., gender, age, education, profession and occupation, type of relationship with the patient with dementia, years of caregiving and hours per day) were gathered using a structured questionnaire.

**Zarit Burden Interview.** The Zarit Burden Interview (ZBI) (Zarit et al., 1980; Pereira & Sobral, 2008) is a self-report scale to measure subjective burden of care-givers. It is

composed of 22 items (e.g., ‘*Are you afraid what the future holds for your relative*’), rated on a 4-point rating scale ranging from 0 (*never*) to 4 (*nearly always*), with higher scores indicating greater burden (range 0-88). For this study, good internal consistency was found (Cronbach's alpha for this study = .88).

**Behavioral and psychological symptoms of dementia.** Behavioral symptoms of dementia were measured with the Neuropsychiatric Inventory (NPI), (Cummings et al., 1994; Leitão & Nina, 2008). It comprises 12 subscales assessing the frequency, severity and care-giver distress of 12 neuropsychiatric symptoms (delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor activity, behavioral disturbances and appetite and eating abnormalities). Frequency of the symptoms is rated on a 4-point scale and severity of the symptoms is rated on a 3-point scale. Scores (frequency X severity) ranged between 0 to 144 with higher scores indicating a greater frequency and severity of behavioral symptoms (Cronbach's alpha for this study = .61).

**Autonomy.** Autonomy was measured with two indexes. The Barthel Index (BI) (Mahoney & Barthel, 1965; Araújo et al., 2007). It allows establishing the degree of independence of the patients with dementia with regards to daily activities (i.e., feeding, bathing, grooming, dressing, bowels, bladder and toilet use, transfers bed to chair and back, mobility, stairs). Each item is scored on difference point scales, with higher scores reflecting greater functional independence (Cronbach's alpha for this study = .93).

The Lawton–Brody Scale (LBS) (Lawton & Brody, 1969; Madureira & Verdelho, 2008) measured the independent living of the patients with dementia through eight domains of function: ability to use the telephone, shopping, food preparation,

housekeeping, laundry, mode of transportation, responsibility for own medication, ability to handle finances. These skills are more complex than those assessed by the Barthel Index. Patients with dementia are scored according to their level of functioning, with values ranging between 8 and 31. Higher values indicated higher dependence (Cronbach's alpha for this study = .91).

A total score of autonomy was computed for the purpose of this study using both scales. The following formula was used: Total autonomy = Barthel Index +  $[100 - 100(\text{Lawton Index} - 8) / 23] / 2$ . Lawton's scale was transformed into a 0-100-point scale with higher values indicating higher levels of autonomy. Then, the arithmetic mean of both scales was obtained. The total score of autonomy varied between 0 and 100 with higher scores indicating higher autonomy.

**Perceived individual needs.** Perceived individual needs were measured with the Perceived Needs Questionnaires (PNQ) developed for the purpose of this study by the authors. It is composed of 14 items (e.g., "*Having more knowledge about this disease*"), rated on a four-point Likert scale, ranging from 1 (*nothing*) to 5 (*very much*). A higher score indicates more perceived needs. In this study, this scale presented good internal consistency (Cronbach's alpha = .81).

### *Procedure*

The study protocol was approved by the Ethical Committee of the || removed for blind review || and by the hospitals' Clinical Research Ethics Committees. Participants were approached by their physicians during their routine visits at Dementia Consultation. A detailed description of the research objectives was given to participants and a written informed consent was obtained. Assessment was completed during their routine

appointment with the doctor. The time required for each assessment was, on average, 30 minutes. Participants were volunteers and received no incentives or monetary compensation for their participation in the study.

### *Data analysis*

Data analysis was conducted using SPSS (version 24; IBM, SPSS Inc., Chicago, IL). Missing data were imputed using expectation maximization (EM) which is an adequate method for missing data at random for items with less than 5 per cent of missing values, which was the case (Tabachnick & Fidell, 2007).

The Shapiro-Wilk test, used to determine whether data is normal, shows that all variables present a normal distribution, except for NPI and years of caregiving (see Table 1).

Independent *t*-tests were used to analyze differences between groups, concerning burden and individual needs. Pearson's and Spearman's correlation were used to investigate relationships among study variables. To better understand variables associated with care-giver burden, a multiple linear regression model was tested. Two blocks of independent variables were used: one with the variables of the patients with dementia (NPI and Total Autonomy) and one with care-givers' variables (gender, years of caregiving and PNQ). All statistical tests were two-tailed and P values < .05 were considered statistically significant.

## **Results**

### *Descriptive statistics*

(Insert Table 1 around here)

Almost 80% of the care-givers presented some level of burden: moderate (38%), moderate/severe (35.2%) or severe (5.6%) (see Table 2). Women, in comparison to men, presented higher levels of burden ( $t(69) = -3.52, p < .01$ ). No differences were found between women and men on perceived individual needs ( $t(70) = -0.69, p = .495$ ).

(Insert Table 2 around here)

In terms of functioning of the patient with dementia, they scored, on average, 16.39 ( $SD = 5.52$ ) in the Mini-Mental State Examination, 5 ( $SD = 1.12$ ) on the Global Deterioration Scale, 28.74 ( $SD = 17.74$ ) on the Neuropsychiatric Inventory, 73.88 ( $SD = 28.73$ ) on the Barthel Index, and 23.63 ( $SD = 6.33$ ) on the Lawton Index.

#### *Correlates of burden*

We found a negative correlation between ZBI and Total Autonomy, and between NPI and Total Autonomy. Positive correlations between ZBI, years of caregiving and PNQ were also found (see Table 1)

A significant regression equation was found ( $F(5, 62) = 10.762, p < .001$ ), with an adjusted  $R^2$  of .42, being NPI, total autonomy, care-giver gender, and PNQ significant predictors of burden. Years of caregiving was not a significant predictor (Table 3).

(Insert Table 3 around here)

## **Discussion**

The aim of this study was to contribute to a widened understanding of the factors associated with burden in care-givers of people with dementia, using a sample of dyads of patients with dementia and their care-givers. Variables pertaining to the patients with dementia (e.g., behavioral and psychological symptoms, and autonomy) and variables pertaining to the care-givers (e.g. gender, duration of care provided, and perceived individual needs) were included in the model. Overall, our findings provided evidence for the multidimensionality of the care-giver burden, with variables of the patient with dementia and of the care-givers being interrelated and having a relevant positive association with burden associated with care-giving.

Most of the participants showed moderate to severe levels of burden, in accordance to previous studies of care-givers of patients with dementia (e.g., Papastavrou et al., 2007, Sussman & Regehr, 2009). In fact, the task of providing care for someone with dementia can be demanding with repercussions on many levels. This emphasizes the need to understand which are the factors associated with the care-giver burden.

As hypothesized, one of the factors associated with levels of care-giver burden was the presence of behavioral and psychological symptoms in the patient with dementia. This result was in line with previous studies that have found an association between neuropsychiatric and behavioral alterations in the patient with dementia and levels of burden in the care-givers (Brodaty et al., 2014; Dauphinot et al., 2015; Fulton & Epstein-Lubow, 2011, Lima-Silva et al., 2015; Martinez-Martyin et al., 2015; Reichman, 2000; Sutcliffe et al., 2016), as they contribute to increase the level of dependence of the patient with dementia. Pocinho et al. (2016) have also found evidence for the effect of patient with dementia demands resulting from psychological alterations (perceived manipulation, feelings of offense, and reduced privacy) on care-giver burden. As mentioned in a previous study (Rinaldi et al., 2005), these behavioral alterations may demand a greater

monitoring of the patient with dementia and their treatment (pharmacological or otherwise), and may also interfere with the caregiving itself, thus contributing to higher levels of burden in care-givers.

Additionally, the level of autonomy of the patient with dementia emerged as another related factor, with lower levels of autonomy associated with higher levels of burden, as found in previous studies (Pérez-Fuentes et al., 2017; Reichman, 2000). The functional decline associated with the loss of autonomy leads, inevitably, to an increase in the dependence of patients with dementia and, consequently, to a greater involvement of care-givers in the daily tasks of the patients with dementia, which seems to be a factor associated with their burden (Bednarek et al., 2016; Brodaty et al., 2014; Sutcliffe et al., 2017).

Surprisingly, and contrary to what was expected, years of caregiving were not associated with care-giver burden. However, some studies have found similar results, which may help us to understand this finding. According to Herrera et al. (2008), care-givers who have been providing care for a long time seem to present some characteristics (i.e., relativization of the family, information about the available support services, sharing of responsibilities) that, in certain way, seem to protect them against burden. From a different perspective, the study by Pocinho et al. (2016) found a positive relationship between years of caregiving and satisfaction with the role of care-giver with the relationship with the patient with dementia, providing evidence for the emergence of positive emotions resulting from the relationship between the patient with dementia and the care-giver. These findings seem to suggest that, as the time goes by, care-givers go through a process of adaptation to their role that includes the development of positive emotions within their relationship with the patient with dementia. This seems to contribute to reduce levels of burden and to improve their psychological well-being.

Indeed, some studies have found that some care-givers report benefits from caregiving. These include the possibility to give back, personal growth, discover inner strengths, a sense of competence, or even an opportunity for a close relationship (e.g., Peacock et al., 2010).

As hypothesized, higher levels of perceived needs by the care-giver were associated with higher levels of burden. The perception of these needs seems to constitute a factor that aggravates the inherent stress of caregiving, as they are associated with the lack of formal training for performing caregiving tasks. A study by Cruz et al. (2010) about the motivations to be a care-giver reveals that people become care-givers for reasons such as financial dependence, family tradition, avoidance of institutionalization, or lack of available formal care. In this sense, the care they provide is, in most situations, characterized by a lack of preparation or training, which may lead to feelings of inability, translated into a set of perceived needs.

Finally, we confirmed the hypothesis that women were more vulnerable to burden. The fact that women (mainly wives and daughters) suffer from higher levels of burden is a consensual finding in the dementia caregiving literature (Chiao et al., 2015; Kim et al., 2012; Sutcliffe et al., 2017). A review by Li and Loke (2013) about female care-givers of patients with cancer may help to explain these differences. The authors demonstrated the influence of cultural assumptions about females (being more likely to perform more personal care and to assume the household tasks; presenting more emotion-focused strategies and supportive coping strategies).

### *Limitations*

Some limitations must be recognized and, therefore, these findings should be interpreted with caution. Firstly, this is a cross-sectional study, which does not allow

inferring causality among the study variables. The process of caregiving is dynamic, so it is necessary to understand how it develops over time. For this reason, future studies should adopt a longitudinal approach. Moreover, other variables should be explored (e.g., emotion regulation strategies). Secondly, the size of the sample is small. Finally, the care-givers that participated in this study were those that accompanied the patients with dementia to their routine dementia appointments, so it is possible that these care-givers present higher levels of burden for assuming all tasks related to the patient with dementia.

### *Clinical implications*

The *World Health Organization* (2017) report alerts to the need of providing care not only to the patients with dementia but also to their families, who are typically their main care-givers (WHO, 2017). Beside the psychological consequences, Fonareva and Oken (2014) state that there is now evidence about the biological alterations in the care-givers of patients with dementia resulting from their care-giver role. A greater number of hospitalizations among care-givers as well as higher mortality rates (Vitaliano et al., 2003) have been found. These alterations derive from the direct effects of caregiving, such as exhaustion, lack of sleep, or negligence for self-care, so it is of high importance to develop interventions capable of minimizing care-giver burden (physical and psychological).

It is widely accepted that mental health professionals should provide care-givers with necessary tools to provide care to others but, at the same time, maintain their psychological well-being (Hardin et al., 2015; Kurz et al., 2010). Zarit (1996) states that care-givers should develop coping strategies that allow them to manage the potential threat that is to “become” a care-giver. Providing them with emotional and informational support may contribute to attenuate the challenges associated with the caregiving task,

contributing to improve the quality of their care, and maintain patients with dementia in the community for a longer period (Mayo, et al., 2000; Stephens et al., 1991).

In the specific case of care-givers of people with dementia, interventions should target not only common aspects of care-giver burden but also the specificities of this condition (i.e., inability and dependence of the patients with dementia as well as poor prognosis) that can amplify the burden within this context (Jackson et al., 2009).

Given females higher vulnerability to care-giver burden, more studies are needed to deeply explore the specific risk and protective factors for this group of care-givers in order to prevent burden in this specific vulnerable group.

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Table 1.

Descriptive statistics, Shapiro-Wilk normality tests and bivariate correlations among study variables.

	1.	2. <sup>1</sup>	3.	4. <sup>1</sup>	5.	Shapiro-Wilk
1. ZBI	-					W (71) =.98
2. NPI <sup>1</sup>	.413**	-				W (71) =.92**
3. Total Autonomy	-.516**	-.342**	-			W (71) =.97
4. Years of caregiving <sup>1</sup>	.245*	.215	-.223	-		W (68) =.91**
5. PNQ	.271*	-.013	-.091	.000	-	W (71) =.98
Mean	36.25	28.74	52.97	4.38	33.07	
SD	15.72	17.74	25.66	2.67	9.95	

Note. \*  $p < .05$ ; \*\*  $p < .01$ . <sup>1</sup> For NPI and Years of Caregiving Spearman correlation was used.

AUTHOR'S VERSION

Table 2

*Descriptive statistics for burden (total sample, men and women)*

<b>Level of Burden</b>	<b>Total sample (n=71)</b>	<b>Men (n=25)</b>	<b>Women (n=46)</b>
Absence	15 (20.8%)	9 (36%)	6 (13%)
Moderate	27 (37.5%)	11 (44%)	16 (34.8%)
Moderate/ severe	25 (34.7%)	3 (12%)	22 (47.8%)
Severe	4 (5.6%)	2 (8%)	2 (4.3%)
	<b>M (SD)</b>	<b>M (SD)</b>	<b>M (SD)</b>
	36.25 (15.72)	28.84 (25.28)	40.28 (13.49)

Table 3

Summary of Hierarchical Regression Analysis for Variables Predicting Burden ( $N = 72$ )

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
NPI	.257	.094	.291**	.220	.087	.250*
Total autonomy	-.249	.065	.409**	-.215	.060	-.353**
PNQ	-	-	-	.344	.148	.216*
Género	-	-	-	8.325	3.047	.256**
Years caregiving	-	-	-	.982	.560	.168
$R^2$		.300			.421	
<i>F</i> for change in $R^2$		15.38**			10.762**	

Note: \* $p < .05$ . \*\* $p < .01$ .