

Burden of Family Caregivers of Patients with Dementia: Profile of Men Caregivers

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Abstract

The purpose of this study was to measure the burden on family carers of older people with dementia in the community and also capture the characteristics of male caregivers. The envisaged population consisted of 102 Greek family caregivers of patients with dementia in a city in Peloponnese, Greece. Data collection was performed by measuring burden scale "The Zarit Burden Interview", which was supplemented by demographics. The results showed that men constituted the minority of caregivers at a rate of 22.5%. The mean age of all caregivers were 60.6 years and they had provided care for an average of 5.4 years. The results showed that 57.8% of all carers had high burden and 33.3%, had moderate to severe, with men suffer less. The gender was the most significant factor predicting the degree of burden. As indicated by this study, caregivers people suffering dementia, experiencing high burden in a large proportion for a small provincial town. Men caregivers, for various reasons still "hold stocks" and affected much less from the burden of care.

Keywords: Dementia, caregiver burden, Alzheimer's disease.

1 Introduction

In the vast majority the demented patients are cared for at home by family members, spouses, children, etc. The burden resulting from the management of BPSD (cognitive,

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behavioral, psychological symptoms of dementia) [1], is higher compared with the burden of carers of people with other chronic diseases [2,3,4].

Social, demographic, economic factors as well as behavioral disorders, hours of care, the existence of social support networks, limited access and use of health services, etc. could affect the health of caregivers [5,6,7,8]. Furthermore, the severity and type of dementia, deterioration in functional ability and the level of daily activities of the patient [9,10,11,12,13], the depression of caregiver [14], but also poor communication with the family, causing high burden [12].

In several studies, high rates of burden for carers of dementia patients [15,16,17,18] have been found. In Greek population, in Greece and Cyprus, it is found that moderate to severe burden experienced the 41.61% [16] and severe the 68.02% [15] of the population. Arguably therefore the emotional, psychological, but also practical burden of caregivers is large, so burdened the mental but also physical health [19]. Outcome of those, the development of emotional disorders such as major depression and anxiety disorder [2,14,20,21,22]. Caregivers with psychological morbidity and higher stress are more likely to have poor physical health and a higher risk of mortality [19,23]. Furthermore, regarding physical health, there is an increased risk of cardiovascular problems, lower immunity, higher levels of chronic diseases etc. [19,24,25].

Close relationship observed between Burden and QOL, with the increased burden leads to degradation of QOL for caregivers but also for patients [12,17,26,27,28,29,30]. Burden and QOL also have been associated with shorter institutionalization for patients [2,9,31,32,33,34,35] and premature mortality for caregivers [36].

As the main predictor of burden, as shown by the literature is gender, men caregivers of patients with dementia, usually spouses and children do not experience high burden rates in relation to women [2,37,38,39].

2 Methods

A cross-sectional study was conducted. The study sample consisted of 102 family caregivers of patients with dementia residing in a city of Peloponnese, Greece. The population was derived from the records of Neurological Clinics of Primary Health care of city's Health Unit. The selection criterion for carers was to have the main responsibility and most frequent contact with the patient (with any type of dementia) from all other family members.

In order to conduct the study was used the scale measuring burden "The Zarit Burden Interview" [40,41], which was translated and adapted into Greek population.

Initially, a preliminary pilot study was held to investigate the internal consistency and reliability of measurements of psychometric instruments of research. The sample of the study were twenty-two (22) carers. The reliability coefficient Cronbach's alpha was 0.91 which indicates excellent internal consistency (Table 1).

Table 1: Reliability Statistics (Pilot Study)

Cronbach's Alpha	N of Items
,913	22

Thereafter, the reliability factor was estimated Cronbach's alpha for the total of 102 caregivers study. The reliability coefficient Cronbach's alpha was 0.93 which indicates excellent internal consistency (Table 2).

Table 2: Reliability Statistics

Cronbach's Alpha	N of Items
,937	102

3 Main Results

Study showed that the majority of individuals provided care for people with dementia were women at 77.5%, while male rate was 22.5%. A 41.2% of caregivers were children with sons to be the minority (6.9 %, n = 7), while siblings was 5.9% with the brothers at 2%. The mean age of all caregivers were 60.6 years and they had provided care for an average of 5.4 years. Results showed that 57.8% of all carers had high burden and 33.3%, had moderate to severe, with men suffer less. It is noteworthy that only men showed little or no burden but also mild to moderate.

3.1 Profile of Male Carers

Profile carers with a little or no burden

Little or no burden showed up 2,9% of caregivers (n = 3). These are three men, of which two were friends with the patient and one was son. They do not live with the patient, had high education, high income over 12,000 euros, with no health problems, and none of them had attended a training program for dementia care.

Profile carers with mild to moderate burden

Mild to moderate showed 7.8 % of caregivers (n = 8). These are caregivers with close family relationship with the patient, husbands (n = 2), sons (n = 4) and grandsons (n = 2). Most of them not stayed in the same place with the patient, their education was moderate to high, with a moderate to high income and little or no health problems. Health problems reported only by the elderly husbands of the patients (cardiovascular). None of the caregivers had not attended any training program for dementia care.

Profile caregivers with moderate to severe burden

Moderate to severe burden presented 2.9 % (n = 3) of caregivers. These are elderly husbands with a mean age of 80 years, who took care of the patient 6.3 years. They lived in the same house with the patient, had low education and low income. Reported health problems as hypertension and cardiovascular and stated that they had not attended a training program for dementia care.

Profile caregivers with severe burden

Severe burden presented 8.8 % (n = 9) of caregivers. The mean age of men caregivers with severe burden was 76.1 years and years of care 8.1. The majority was living in the same house with the patient ((n = 8), and all had close family ties with the patient, with husbands prevail over (n = 5), and follow brothers (n = 2) and sons (n = 2). The majority of them had low to moderate income and education level from secondary education to no education, except one who had higher education (son). In health problems reported outmatched hypertension and cardiovascular, while reported musculoskeletal problems and diabetes.

Burden levels with the percentages of male caregivers are presented in Table 3.

Table 3: Burden of Men Carers

Burden	Percentage %	Population (n)
little or no	2,9 %	3
mild to moderate	7,8 %	8
moderate to severe	2,9 %	3
Severe	8,8 %	9
Total	100 %	23

Table 4 shows the correlations between all demographics and the burden rating scale.

Table 4: Correlations between demographic characteristics and rating of the burden scale

Feature	Mean (standard deviation)	Value p
Gender		0,05^a
Male	53,7 (20,4)	
Female	62,8 (12,6)	
Age	0,18 ^b	0,08^b
Marital Status		0,3 ^a
Married	61,2 (15,1)	
Unmarried	58,2 (15,1)	
Children		0,4 ^a
Yes	61,2 (15,2)	
No	58,8 (14,8)	
Number of the Family living	-0,06 ^γ	0,6 ^γ
Place of residence		0,07^a
In the same house with the patient	62,4 (13,7)	
In a different house from the patient	56,4 (17,7)	
Educational level	-0,35 ^γ	<0,001^γ
Employees		<0,001^β
Yes	57,8 (16,1)	
No (household unemployed)	67,8 (9,5)	
Income	-0,26 ^γ	0,009^γ
Years of care	0,17 ^γ	0,1^γ

Degree of kinship with the patient		0,3 ^a
Spouse / son / daughter / brother/sister	61,6 (13,8)	
Other	57,7 (19,1)	
Health problems		<0,001^a
Yes	63,0 (14,0)	
No	47,2 (14,7)	
Attending training program for patient care		0,05^a
Yes	50,6 (12,5)	
No	61,6 (15,1)	
Age of patient	-0,03 ^b	0,8 ^b
Gender of patient		0,4 ^a
Male	62,4 (14,5)	
Female	60,0 (15,5)	
Types of Dementia		0,4 ^δ
Parkinson	57,5 (19,9)	
Alzheimer's	64,3 (13,9)	
Strokes (vascular dementia)	59,1 (16,8)	
Other dementia syndromes	59,9 (16,8)	

^a Testing *t*

^b Pearson's correlation coefficient

^γ Spearman's correlation coefficient

^δ Analysis of variance

After the bivariate analysis statistical relationship arose at the level of 0,20 ($p < 0,20$) between the score on the scale burden and 9 demographic characteristics. For this reason was applied multivariate linear regression, the results of which shown in Table 5.

Table 5: Multivariate linear regression with dependent variable score in burden scale

Characteristic	Coefficient b	95% confidence interval for b	P Value
Females compared to males	8,0	1,9 έως 14,2	0,01
Health problems related to the absence of health problems	12,9	5,5 έως 20,3	0,001
Educational level	-3,2	-5,2 έως -1,2	0,002

According to the results of multivariate linear regression:

- Men had a lower burden in relation to women.
- Carers with health problems had a higher burden than carers without health problems.
- Higher levels of education were associated with reducing the burden.

These variables explain 30% of the variability in burden score scale.

4 Discussion

The study showed that the care of patients with dementia continues to be a primary responsibility of women agreeing with other studies, although men caregivers increasing rapidly [2,38,42,43,44]. The researchers suggest that because women are socialized to the home and family, consider care as a continuation and expansion of their responsibilities, unlike men who are socialized in order to focus on the outside world, thus disclaim from responsibility of caring, a role which they consider stranger to the male model with which they have grown up [15,45].

Furthermore, this study showed that the most important factor that can predict the burden of family caregivers is gender, with men experiencing lower burden confirming previous studies and reviews [2,15,37,38,39]. Women and men caregivers differ in conception and approach to the role of care and react differently to it [15,46].

At the men caregivers 'sense of coherence' in other words a person's ability to cope with various situations of life, was higher than women [47].

Much of the literature shows that there is a big difference in the care coping strategy in both genders. Men focus on problem solving and the fulfilment of the tasks and activities of daily living, while women focus more on the quality of execution of work and emotional support [48-51]. According to Cooper et al., (2007), coping strategies based on emotion which adopt women, lead to a higher burden, as opposed to those which focus on the problem [52]. By contrast, the adoption by men of practical solutions to problems that occur during care and mechanisms that help to create an emotional distance from the patient, causes them less stress for the care and helps them to become better adapted to their new role [15]. It has been suggested that the previous experience of men in paid employment has enabled them to develop a strong and broad repertoire in management techniques, and a more positive approach to problem solving [53]. Thus, men (particularly husbands) respond to challenges care in a more practical way than women, have less emotional involvement and use mechanisms that create a psychological distance. Even with regard to personality changes (aggressiveness) of the patient they can better handle an aggressive spouse in spite women a violent man [15].

When husbands take on the role of caregiver, receive more recognition and support from the community, as opposed to women of which expected to provide care based on their traditional role [54]. Studies have suggested that male spouses who are the primary caregivers, often have the additional support by the women of the family which are not the primary carers of the patient, such as daughters, the nieces, daughters-in-law, etc., thus contributing to reducing the burden [15,55,56]. This is one of the reasons that husbands manage to maintain a relatively high level of well-being, despite the challenges posed by the new situation partly because of additional support in everyday activities regarding the care [49].

In fact women who cared for their husbands with Alzheimer's in an advanced stage, they reported that they received little support from family and friends, in contrast to men caregivers in similar circumstances, and this was associated with impairment of physical and mental health [56]. Those who reported that they received additional informal support from other family members or friends, they noted that the level of assistance was not enough to reduce the burden experienced [57].

Reasons that men undertake caring of the dementia patient are many. For some husbands taking care can be considered a natural consequence, confirming the traditional role as the patron of the family [58]. For Russell et al. (2007), husbands undertake caring from a

sense of duty, which was later replaced by loyalty and despite the initial description of the assumption of care as something frightening and unknown, then devote themselves and undertake tasks everyday life but also the complicated procedures required by this [59]. Sons of caregivers take over the care from duty, love and gratitude to their parents [60]. Friedemann & Buckwalter (2014) suggested that the percentage of unmarried caregivers is higher among male adult children, because fewer family responsibilities could be a determining factor for the sons to become carers [57]. However sons of caregivers in the study of Stewart et al., (2014), report less distress than husbands, but there was no difference in the burden concept based on the type of relationship [37].

Health problems in our study were associated with burden. It is remarkable that all men caregivers with serious burden reported no mental health problems (depression, anxiety), but only physically (cardiovascular, hypertension, diabetes, musculoskeletal).

And other studies have found that male caregivers do not face such high levels of stressors and depressive symptoms, have more social resources and report higher levels of mental and physical health [15,37,55].

According to Papastavrou et al. (2009), the differences observed may be the result of prejudice, answer to which women and men may have similar levels of mental morbidity, but men are less likely than the women report in surveys that they experience emotional distress [55]. Generally there is a tendency for women to be willing to report health problems, mentally and socially, especially if it relates to chronic stress and be more aware of their problems [61]. Similar findings were obtained by Pöysti et al., (2012), who reported that elderly men caregivers experienced significantly lower burden and depressive symptoms, no matter how serious the cognitive impairment of their wife and although the highest level of concomitant disease [38]. Particularly as regards the mental health, that in most studies has been associated mostly with females [42,62].

A third factor was associated in our study with the burden was the level of education. The highest level of education was associated with reducing the burden. The majority of men in the study with high burden reported low level of education, while caregivers with low or no burden reported a high level of education. This is consistent with other studies in which higher levels of education were associated with fewer depressive symptoms and less burden [63]. Contrast results showed that the highest level of education may be associated with higher burden and this because these caregivers have higher expectations of themselves [64]. Also the study of Pöysti et al. (2012), comparing the gender differences concerning burden factors to spouses caregivers, was found that the low level of men education was associated with less burden. This could be explained by the satisfaction that can feel a carer who has low education, with simple, daily events, without new experiences, as opposed to a "complicated" way of life pursuing high education caregivers [38].

5 Conclusions

Caregivers of patients with dementia experience high burden, heavily for a small provincial town. Consistently women continue to bear the burden of care but also the burden of mental and physical deterioration. As indicated by this study, caregivers people suffering dementia, experiencing high burden in a large proportion for a small provincial town. Men caregivers, for various reasons still "hold stocks" and affected much less from the burden of care.

6 Limitations of the Study

The small sample size limits the over generalization of our results. An additional negative indicator is the limitation in the geographical location of the sample. The extent to which were the same or different results from a sample from other areas (urban perhaps), is unknown.

Also, researchers can not be absolutely sure about the sincerity of the answers to such sensitive issues as considered the issue of care. This is because the scale is based on self-reports of caregivers about their experiences and ratings reflect the personal perception of caregivers for the burden, perceptions can not be verified objectively.

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