

The Burden and the Levels of Anxiety and Depression in Caregivers of Patients with Dementia

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Abstract

The literature suggests that dementia has been associated with high levels of burden, anxiety and depression for family carers of patients. The aim of this study is to investigate these three dimensions by focusing on the differences in caregivers based on degree of kinship and age on the one hand, and on the association between burden and anxiety and burden and depression on the other hand. The sample of the study consisted of 101 family caregivers of dementia patients from the Day Centers of the Athens Association of Alzheimer's Disease and Related Disorders and its educational seminar cycle as well as from the Agios Eleftherios Memory Centre of the Nestor Psychogeriatric Association. Participants were administered the Greek version of the Zarit Burden Interview (Papastavrou et al., 2006), which assesses four dimensions, and the Hospital Anxiety and Depression Scale (Michopoulos et al., 2007). The results showed that caregiver spouses are more burdened, anxious and depressed than children caregivers, with this difference in the case of anxiety and depression being statistically significant. In addition, higher levels of burden and depression were shown by older caregivers, with this difference being statistically significant in the latter case, while in terms of anxiety higher levels were shown by the second age group of the survey. Finally, it was confirmed that the higher the burden, the higher the anxiety and the depressive symptoms. The findings are discussed in relation to the international literature and ideas for future research are suggested.

Key words: dementia, family caregivers, burden, anxiety, depression

Introduction

In modern times and having now entered a new decade, it is worth noting the progress in the field of Medicine and pharmaceutical care that contribute to improving the quality of life. Life expectancy has increased rapidly and, consequently, so has the elderly population. Today, 703 million people worldwide are aged 65 or over (World Population Ageing, 2019). However, the more the elderly population increases, the more the population suffering from dementia increases (Heese, 2015). Especially in Greece, there are approximately 200.000 dementia patients (Athens Association of Alzheimer Disease and Related Disorders, 2015).

Due to the increased number of dementia patients in Greece, the disease is becoming a focus of studies, as it affects a huge percentage of people directly and indirectly. Approximately 90% of patients suffering from the disease receive care at home from their families, and as a result, caregivers are also affected by the disease (Athens Association of Alzheimer Disease and Related Disorders, 2015).

It is possible that the caregiver may develop mental and physical symptoms, resulting in the caregiver being called a hidden (De Fazio et al., 2015) or invisible second patient (Brodaty & Donkin, 2009). Family care, therefore, for dementia patients imposes significant costs on the caregiver. Financial, emotional (Torti et al., 2004; Revenson et al., 2016), social (Torti et al., 2004; Zacharopoulou et al., 2015), physical health costs (Revenson et al., 2016), mental morbidity and burden (Zacharopoulou et al., 2015). The psychologically debilitating situation of caring for a relative affects the caregiver to such an extent that, if he/she is not helped to heal the wounds caused by the burden one bears, it is likely that in the future he/she will become a patient with dementia himself or herself (Πετρούνης, 2013).

Burden Factors

In terms of age, Springate and Termont (2014) reported that younger caregivers are affected to a greater extent in their lives by caring for their dementia patient relative compared to older caregivers. Chiao et al. (2005) confirmed this view, stating that the younger the caregiver and therefore with less experience, the higher the levels of burden. Conversely, later research found that, as the age of the caregiver

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increases, the higher levels of burden the caregiver experiences (Vorvolakos et al., 2020). The authors explained that this is because, on the one hand, the older the couple is in age, the greater the caregiver spouse's need for help from another person, and on the other hand, the older patient makes the caregiving task more difficult, so that the caregiving role becomes a greater burden.

With regard to caregiver's relationship to patient, it was observed that the type of relationship between patient and caregiver indeed influences the levels of burden (Chiao et al., 2015; Springate & Termont, 2014; Torti et al., 2004). More specifically, in a study by Springate and Termont (2014), spouses showed lower levels of burden than adult children, which is related to the direct impact of the caregiving role on the former's lives. The authors explained that adult children often try to balance the demands of parental caregiving with those of their children, and further noted that perhaps the difference between the marital and parent-child relationship plays a role in the differences observed regarding burden levels (Springate & Termont, 2014).

In contrast, a study by Brodaty and Donkin (2009) showed that the female spouses of dementia patients who have taken the care were more burdened, while it was later shown that the patient's spouse was more burdened regardless of gender (Zacharopoulou et al., 2015).

Burden, Depression and Anxiety in Carers

A significant association was shown to exist between caregiver's burden and caregiver's depression (Liew et al., 2019; Sherwood et al., 2005). Specifically, caregiver's burden appeared to act as a predictor, because as its levels increased, depressive symptoms tended to increase (Sherwood et al., 2005).

The fact that the duration of care in dementia patients is longer than in other patients may explain why these caregivers are more vulnerable to developing a mental disorder (Joling et al., 2014). Thus, the pressure experienced by the caregiver may manifest as mental illness, which includes depression and anxiety (Brodaty & Donkin, 2009). These psychological morbidities include «somatization, interpersonal sensitivity, depression, anxiety, stress, distress, burden, obsessive-compulsiveness, hostility, phobia, paranoia, psychoticism, and development of dementia» (Hopkinson et al., 2019, p.344). In conclusion, caring for a dementia patient has been associated with levels of depression or depressive symptoms and anxiety, worry or stress (Mahoney et al., 2005; Σαμπάνη, 2013).

Regarding the relationship to patient, it was observed that spouses often showed depressive symptoms, less happiness, joy and hope for the future (Adams, 2008). In fact, in some studies they showed higher levels of depression and anxiety than the adult children of dementia patients (Piercy et al., 2013; Pinquart & Sorensen, 2011). With regard to age, opinions are divided, i.e. higher depressive symptoms are displayed by either younger (Pinquart & Sorensen, 2011) or older (De Fazio et al., 2015) caregivers.

Aim

The purpose of this study is to detect and measure the burden placed on family carers of dementia patients, and to monitor the levels of depression and anxiety to which this leads.

The initial aim is to study the correlation between caregiver's burden, depression and anxiety and certain demographic factors. More specifically, there will be investigated "how burden and levels of depression and anxiety vary according to the degree of relationship to the patient and to the age of caregiver". Another important objective is to investigate "how caregiver's burden is related to depressive symptoms and anxiety".

Method Sample

101 family caregivers of dementia patients from Athens participated in the survey. The 41 caregivers in the sample came from the Day Centers of Athens Association of Alzheimer's Disease and Related Disorders. In addition, 41 caregivers came from the cycle of educational seminars for caregivers («school for caregivers of people with dementia») conducted by Athens Association of Alzheimer's Disease from 4/11 to 9/12 in 2019. Furthermore, eight family caregivers from the Memory Centre of Agios Elefterios of the Nestor Psychogeriatric Association participated. The rest of the sample, 11 caregivers, were people from the researcher's social circle. The main criterion for the selection of participants was that they were informal caregivers who have undertaken the care of the patient either due to kinship or close relationship. Professional caregivers were excluded from the sample.

Measurement Tools

Demographic Data Questionnaire. A questionnaire, designed for the needs of this study, was used to address the social and demographic data of caregivers. It contained 22 close-ended questions and the information obtained was related to gender, age, marital status, educational level, professional life, type of employment, annual income, degree of kinship with the patient, place of residence in relation to the patient, years of diagnosed dementia of the patient, years of caring for the patient, the average hour per day spent caring, whether or not they are supported by a health professional, the reason for being a carer, whether or not they attend a training program for caring for the patient, whether or not they receive psychological support, as well as the patient's age, gender and form of dementia. For the needs of the present study only the age of the carer and the degree of kinship with the patient were correlated with burden, depression and anxiety.

Zarit Burden Interview (ZBI). To measure burden, the ZBI designed by Zarit and Zarit (as cited by Papastavrou et al., 2006, p.440) was used to assess the subjective burden experienced by American caregivers of dementia patients. Regarding Greece, the questionnaire was translated using the reverse translation method and weighted by Papastavrou et al. (2006). It is a 22-item questionnaire that reflects the feelings of caregivers of elderly people with dementia. For each item, where 0=never, 1=rarely, 2=sometimes, 3=quite often and 4=almost always, participants are asked to indicate how often they have felt what the question states. For scores 61-88 the burden is considered severe, for scores 41-60 moderate to severe, for scores 21-40 mild to moderate and for scores below 21 it is considered none to little according to Zarit & Zarit (as cited by Hebert et al., 2000 p.495-496). From the factor analysis of Papastavrou et al. (2006) four factors emerged for the 22 items of the questionnaire (personal strain, role strain, relationship deprivation and care management), which represent the dimensions of burden and the different aspects of caregiving. From the validity and reliability analyses of Papastavrou et al. (2006) it was proved that the reliability of the questionnaire is excellent ($\alpha=0,93$) as well as the reliability of the factors. The correlation of the first three factors is significant and positive, close to $r=0,7$ for all of them. Thus, if caregivers show high scores on the questions covering the first factor, they will also show high scores on the second and third factor. Only the fourth is not significantly correlated with any of the three (Papastavrou et al., 2006).

Hospital Anxiety and Depression Scale (HADS). To measure depression and anxiety, the HADS, created by Zigmond and Snaith (1983), was used. It has been adapted into Greek by the method of reverse translation by Mystakidou et al. (2004).

The HADS is a 14-item questionnaire, each of which has 4 possible answers and it is completed by the examinee. It is designed to assess anxiety (HADS-A) and depression (HADS-D), (7 items for each condition), with a score range from 0 to 21. The role of the HADS is more probing than diagnostic and the items exploring depression do not include questions about physical symptoms such as insomnia, anorexia, weight loss (Michopoulos et al., 2007). Zigmond and Snaith (1983) and Livingston et al. (2005) have proposed two cut-off scores for detecting anxiety and depression: from 8 to 10 for intermediate-doubtful cases, 11 and above for clinical cases. In another review of research, a cut-off score of 8 was proposed (Bjelland et al., 2002).

The overall Scale showed high internal consistency, 0,845 (Mystakidou et al., 2004) and in the study of Michopoulos et al. (2007) it showed high internal consistency and significant internal and external reliability. The Cronbach's α was 0,884 for the whole scale, 0,829 for the HADS-A and 0,840 for the HADS-D. It showed high values, both in the Cronbach's α (from 0,870 to 0,885) and in the item-scale correlations, from 0,608 to 0,762 for the anxiety items and from 0,540 to 0,804 for the depression items. Furthermore, factor analysis indicated the existence of two factors, anxiety and depression, so that this Scale can measure anxiety independently of de-

pression and vice versa (Michopoulos et al., 2007). Thus, the Greek translation of the HADS is valid, reliable and easy to use for measuring depression and anxiety (Michopoulos et al., 2007; Mystakidou et al., 2004).

Procedure

The survey was conducted from 30 October 2019 to 3 January 2020. The questionnaire took approximately 15 minutes to complete, participation was voluntary and each participant was informed, before agreeing to take part, about the anonymity of the questionnaire, the purposes of the survey and the ethical principles governing it, and that he/she could withdraw if he/she wished to do so.

Participants were either given the option of completing the questionnaire themselves or through a face-to-face interview with the researcher. Of the 101 caregivers, 85 completed the questionnaire on their own, 14 gave their responses in a face-to-face interview and two responded to the questionnaire's questions by telephone.

Statistical Analysis

All variables were assumed with the use of descriptive statistics (frequencies, means, standard deviations) and then using the independent samples t-test, Kruskal-Wallis H non parametric criterion, one-way analysis of variance (ANOVA), multiple comparisons with Bonferroni's post hoc criterion, Pearson's Correlation and Regression Analysis.

Results

Demographic profile of caregivers

The study included 101 family caregivers. Regarding the gender, the sample consisted of 20 males (19, 8%) and 81 (80, 2%) females. As for their age, one (1%) was in the 20-30 years old category, nine (8, 9%) were between 31-40 years old, nine (8, 9%) were between 41-50 years old, 39 (38, 6%) were between 51-60, 29 (28, 7%) were between 61-70 and 14 (13, 9%) were between 71-80 years old. Regarding the degree of participant's relationship to patient, it was observed that the majority were spouses and children. The 32 participants (31, 7%) were spouses, 43 (42, 6%) were daughters, 16 (15, 8%) were sons. The sample also consisted of one sister (0, 99%), one niece (0, 99%), one granddaughter (0, 99%), four sons' wives (3, 96%), one partner (0, 99%) and two family friends (1,98%).

Scores on outcome variables

The mean score of the caregivers on Zarit Burden Interview (ZBI) was 45,32 (SD=16,44) with 18,74% of caregivers experiencing severe burden, 45,83% moderate to severe, 27,05% mild to moderate and 8,33% little or no burden.

Regarding the Hospital Anxiety and Depression Scale (HADS) the mean score was 17,39 (SD= 8,79). Specifically, for depression the mean caregivers was 7, 70 (SD=4, 60) and for anxiety it was 9, 64 (SD=4, 89). The total score of the participants on the HADS revealed that the majority (73, 2%) of the participants were a clinically significant case with anxiety (45, 5%) predominating over depression (24, 7%).

Differences on outcome variables as to demographic characteristics

Regarding the degree of caregiver's relationship to patient (spouse/partner/adult child), testing of means with the t test for independent samples showed that burden, depression and anxiety were significantly correlated with the type of kinship. Thus, for burden: $t(86,00)=0,87$, $p=0,389$, for anxiety: $t(90,00)=2,35$, $p=0,021$ and for depression: $t(89,00)=3,31$, $p=0,001$ (Table 1). Therefore, the difference in mean spouses and children was statistically significant for anxiety and depression levels, but not for burden.

Although in all three dimensions-burden, anxiety, depression-it was observed that the spouses showed higher levels compared to the patients' sons/daughters, in the case of burden this difference is not statistically significant, since $p=0,389$, while in the case of anxiety ($p=0,021$) and depression ($p=0,001$) it is (Table 1).

As to caregivers' age, there were not found any statistically significant differences in burden through the use of the non-parametric Kruskal-Wallis H criterion (the conditions for equality of variances were not met in order to perform one – way analysis, ANOVA). It was observed that the oldest caregivers, aged 61 to 80 years, had a higher mean burden compared to participants in the other two age groups. However, this difference was not statistically significant, since $p=0,218$.

Using the one-way analysis of variance (ANOVA) between the three age groups (20 to 50 years, 51 to 60 years and 61 to 80 years) with anxiety and depression as dependent variables, it was observed that for the effect of age on anxiety the result is: $F(2, 98)=2,06$, $p=0,133$ (Table 2) and the participants aged 51 to 60 years had higher mean anxiety than the other two age groups (Table 3), but there is no statistically significant difference since $p=0,133>0,05$ (Table 2). For depression the result is: $F(2, 97)=3,89$, $p=0,024$ with the difference being statistically significant ($p=0,024<0,05$), [Table 2]. Therefore, multiple comparisons were made using Bonferroni's post hoc criterion and it was found that the differences in mean depression between the groups 20 to 50 years and 61 to 80 years are statistically significant ($p=0,020$), [Table 4] with the older age group having a higher mean depression (Table 3).

Correlations between variables

Regarding the correlation between family caregivers' burden and levels of anxiety and depression, Pearson r correlation was used between the burden, anxiety and depression scales. All indices were positive and statistically significant. Specifically, a high positive coefficient ($r=0, 58$) and statistically significant ($p<0,001$) was presented for burden and anx-

ety. The same occurred in the correlation between burden and depression, where the coefficient was high positive ($r=0, 61$) and statistically significant since $p<0,001$. The magnitude of the indices ranged from 0,58 ("anxiety" X "burden") to 0,72 ("depression" X "anxiety"). That is, the more positively the participants' scores on the burden scale increased, the more positively their scores on both the anxiety and depression scales increased (Table 5).

Predictors of anxiety and depression in relation to burden

In order to test the ability to predict anxiety and depression based on burden, multiple regression analysis was conducted. Thus, burden was used as a predictor variable. The multiple correlation index in the case of anxiety is equal to 0, 58 and the adjusted coefficient R² is equal to 0, 32. That is, 32% of the dispersion of anxiety can be explained by the effect of burden. In the case of depression, the first index is equal to 0, 61 and the second is 0, 37. That is, 37% of the dispersion of depression can be explained by the effect of burden. The slope of the regression line is significantly different from zero in both cases. Specifically, for anxiety it is $F(1,94)=46,47$, $p<0,001$ and for depression: $F(1,93)=55,58$, $p<0,001$. From the review of the regression's coefficients we ascertain that burden contributes significantly to both anxiety ($\beta=0, 58$, $t=6, 82$, $p<0,001$) and depression ($\beta=0,61$, $t=7,46$, $p<0,001$) prediction. That is, the greater the burden, the greater the levels of anxiety on the one hand, and the greater the levels of depression on the other (Table 6).

Discussion

The present research suggests an interplay between caring for dementia beloved patients either relatives or close friends and levels of burden, depression and anxiety. Indeed, it was found that the majority of participants experience moderate to severe burden and the levels of anxiety and depression experienced suggest the existence of a clinical case with anxiety predominating.

With regard to demographic factors and specifically the degree of kinship between caregiver and patient, the findings of the present study suggest that spouses of dementia patients have higher levels of burden than adult children who have taken on the caregiving role. Specifically for anxiety and depression, this difference is also statistically significant.

Regarding the age of caregivers, the findings of this study show that older caregivers, aged 61 to 80 years, had a higher burden than younger caregivers, aged 20 to 50 and 51 to 60 years. In terms of stress levels, it shows that caregivers aged 51 to 60 years experience more stress than younger caregivers aged 20 to 50 years and older caregivers aged 61 to 80 years. In terms of levels of depression, it emerges that higher depressive symptoms are experienced by the oldest group, aged 61 to 80 years, compared to the youngest age group in the survey, 20 to 50 years, with this difference being statistically significant. It is worth noting that this is linked to the finding for caregivers' spouses, as, in this survey, the older age group was mostly made up of spouses, while the

younger group was made up of only adult children.

Regarding the correlation between burden and anxiety on the one hand and burden and depression on the other hand, the findings of the present study highlight the existence of a strong correlation between burden and anxiety and also burden and depression, with burden contributing significantly to the prediction of both.

Burden, as observed from the literature and the present research, is significantly correlated with caregivers' depression (Liew et al., 2019; Sherwood et al., 2005) and acts as a predictor of depressive symptoms (Sherwood et al., 2005) and excessive stress leading to anxiety (Μεσσήνη, 2013).

In this research, the spouses of the patients and the older age group are particularly stressed, anxious and depressed. This can be said to be linked to the fact that the carer spouse resides in the same house as the patient, as opposed to the adult children who probably have a family of their own. Indeed, as observed, cohabitation with the patient brings a higher burden on the caregiver (Chiao et al., 2015; Torti et al., 2004) and stress (Livingston et al., 2005). In the present study, all spouse caregivers live with the patient, while as for adult children, only some live in the same house. The higher levels of burden, depression and anxiety in spouses can be explained by the fact that the spouse is the closest person to the patient. He or she is the person with whom the patient has probably created a family. Indeed, the majority of the participant spouses have children and from the age of the children we ascertain that the caregiver has shared a large part of his/her life with the patient. Therefore, he/she may experience all the changes in his/her life partner more intensely.

Since the older the caregivers are, the more likely they are to be the patient's spouse rather than the patient's child, as shown in the study, it is reasonable to expect higher levels of burden, anxiety and depression in older caregivers. This difference can also be explained by the fact that the older the age of the couple, the more the caregiver spouse needs help from a third party, because the older patient makes the caregiving role more difficult (Vorvolakos et al., 2020) and the caregiver spouse has less strength due to age.

The study of family caregivers of dementia patients is of paramount importance and further studies should be done. It would be appropriate to pay particular attention to the benefits of psychological support for carers and how this helps to reduce burden, anxiety and depression. Family caregivers may thus be encouraged to seek help, to take part in psychotherapy groups for this purpose, to exchange views with people experiencing similar situations and to express their feelings. As they are a highly burdened population living in obscurity, it is important to create a more optimistic future for those who sacrifice a great deal in order to stand by their sick person.

Limitations of research

Although the present study highlights important findings on burden, anxiety and depression among family caregivers of dementia patients, some limitations should be noted.

- The sample of 101 participants is small but also unequal between the two degrees of kinship and between the three age groups
- The survey was conducted in Athens, so it is difficult to draw conclusions about the total population of caregivers of dementia patients
- The majority of the sample consisted of caregivers whose patient used to spend some time in a Day Centre of Athens Association Alzheimer's Disease and Related Disorders or the Nestor Psychogeriatric Association. Thus, it is likely that the levels of burden, anxiety and depression experienced by the caregiver are lower compared to those who do not receive any help for the patient
- In terms of sampling, there was a difference in the time available for each caregiver to complete the questionnaire
- As to the content of the demographic questions, information about the patient's behavioural changes is missing, as the way the patient behaves affects the burden on the caregiver and the levels of depression and anxiety he/she experiences

Appendix

Table 1

T-test on the Scales under study on the degree of caregiver's relationship to patient

	Burden		Anxiety		Depression	
	Equal variances assumed	Equal variances not assumed	Equal variances assumed	Equal variances not assumed	Equal variances assumed	Equal variances not assumed
	F		F		F	
	Sig.		Sig.		Sig.	
Levene's Test for F		1,78		1,55		,08
Equality of Variances Sig.		,188		,217		,782
t-test for Equality of Means	t					
	df	88,00	55,85	90,00	73,70	89,00
		61,44				
	Sig. (2-tailed)	,389	,413	,021	,017	,001
	Mean Difference	3,17	3,17	2,40	2,40	3,11
	Std. Error Difference	3,86	3,84	1,02	,98	,94
	95% Confidence Interval of the Difference					
	Lower	-4,11	-4,53	,37	,44	1,24
	Upper	10,45	10,87	4,43	4,36	4,97

Table 2

ANOVA

	df	F	Sig.
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Table 3

Means and Standard Deviations of the Age Groups from Analysis of Variance

		Anxiety		Depression		Anxiety		Depression	
Age Groups		20-50		51-60		61-80		Total	
N		19	19	39	39	43	42	101	100
Mean		7,63	5,42	10,28	7,56	9,98	8,86	9,64	7,70
SD		4,36	4,18	5,15	4,48	4,73	4,59	4,89	4,60
Std. Error		1,00	,96	,82	,72	,72	,71	,49	,46
95% Confidence.									
Interval	Lower Bound	5,53	3,41	8,59	6,11	8,52	7,43	8,68	6,79
	Upper Bound	9,73	7,44	11,93	9,02	11,43	10,29	10,61	8,61
Min		2,00	,00	,00	,00	,00	1,00	,00	,00
Max		16,00	13,00	19,00	19,00	21,00	19,00	21,00	19,00

Table 4

Multiple Comparisons Post Hoc Analysis for Depression

	(A) Age group	(B) Age group	Sig.
Bonferroni	20-50	51-80	,270
		61-80	,020
	51-60	20-50	,270
		61-80	,590
	61-80	20-50	,020
		51-60	,590

Table 5

Pearson's Correlation (Pearson r) between Burden, Anxiety and Depression

	1	2	3
1. Burden	1,00		
2. Anxiety	0,58***	1,00	
3. Depression	0,61***	0,72 ***	1,00

Note: * $p < 0,05$. ** $p < 0,01$. *** $p < 0,001$.

Table 6

Regression Analysis for the Statistical Prediction of Anxiety and Depression by Burden (N=101)

Predictive Factor	B	Std. Error B	Beta
Burden in case of Anxiety	0,17	0,03	0,58***
Burden in case of Depression	0,17	0,02	0,61***

Note. For Anxiety: $R^2=0,53$. Adjusted $R^2=0,52$.

For Depression : $R^2=0,37$. Adjusted $R^2=0,37$.

**** $p<0,001$.*

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