BRIEF REPORT



The Burden of Care and Burnout in Individuals Caring for Patients with Alzheimer's Disease

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Abstract

Alzheimer's disease imposes a severe burden upon patients and their caregivers. We examined the relationship between the sociodemographic factors, burden of care and burnout level of 120 of 203 professional caregiving staff dealing with Alzheimer's disease patients in eight geriatric care centers in Istanbul/Turkey. The Zarit Caregiver Burden Scale was used to measure the level of burden of care, and the Maslach burnout inventory to measure the level of burnout. High levels of emotional exhaustion were present in 25% of our sample, and depersonalization was found in 30% reduced personal accomplishment was present in 26% of the caregivers.

Keywords Burnout syndrome · Alzheimer's disease · Caregiver · Dementia

Introduction

Alzheimer's disease is the most common form of dementia, representing between 50 and 70% of all cases. The numbers of rest homes, geriatric care centers and daytime hospitals planned for Alzheimer's patients in Turkey are inadequate. Elderly Alzheimer's patients are generally cared for by primary relatives, and at home. Some patients, particularly those with advanced functional loss, are cared for by caregivers working in health institutions and rest homes. Informal caregiving is based on a preexisting personal relationship

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between the caregiver and the patient, and no payment is offered for the time and money spent. Formal care is the ordinary health care or community-based support offered to persons defined as patients or clients (Hickman et al. 2016).

'Staff Burnout' is a phenomenon appearing in the form of personnel becoming insensitive to others because of the work they do, of feeling emotionally exhausted and absence of feelings of personal success and sufficiency that is most frequently observed in occupations requiring the establishment of face-to-face relations with other people. Burnout has three dimensions-'emotional exhaustion,' 'depersonalization' and 'reduced personal accomplishment.' Emotional exhaustion is the first dimension of burnout syndrome and represents the stress dimension. In emotional terms, staff working to an intensive pattern is exposed to overloading and intense expectations from others. An individual encountering such a situation feels hopeless, trapped and deprived of energy. Depersonalization is the second dimension of burnout and shapes communication between individuals. Depersonalization refers to staff being reluctant to see noteworthy characteristics of people with whom they interact, failing to show them the requisite level of attention and avoiding closeness with them. A feeling of reduced personal accomplishment constitutes the third dimension of burnout and it can be described as feeling unsuccessful and inadequate in the face of various events resulting from self-assessment and self-ideation assuming a negative character (Polatçı et al. 2014). Various environmental

factors can be cited, including the use of a criticizing style that is not just or constructive, the lack of unbiased rewarding tools, unfairness in rewarding and criticizing workers, workers feeling insecurities in their professional careers, the lack of a management conception that attaches importance to workers' needs, an excessive workload, constantly working with the same type of patient or client, constantly doing the same work, constantly working with clients or patients making slow and heavy progress, long working hours and work being of a routine nature (Taycan et al. 2013; Dikmetaş et al. 2012).

According to information from the Research on Family Structure in Turkey, 63% of elderly people continue living independently in their own homes, while 36% live with their children, and only 1% live in care centers (ASAGEM 2010; Çınar et al. 2012). Since professional care and support systems for dementia patients are inadequate, and costs are high, many families are unable to access such professional care systems. Home care services are only newly being developed, and the organizational structuring of such services is still very limited (Cinar et al. 2012). Such limitations applying in Turkey suggest that individuals caring for dementia patients are under a greater burden of care than those in other countries, leading them to experience psychological stress and emotional problems. The factors shaping burden of care include the characteristics of the patient, the disease and the care-giver, the sociodemographic characteristics of the individual providing the care and the conditions in the community concerned (Yu et al. 2015).

Deleterious process in individuals caring for Alzheimer's patients frequently gives rise to burnout by impacting on all areas of life, including relations with family and friends, working life and physical and psychological health. Caregiving relatives of demented patients suffer from high levels of burden of care, but the literature is sparse regarding the prevalence and predictors of burnout in this group. Identifying the vulnerabilities may help us in effectively directing support systems in order to prevent demoralization and burn out which is common in mental health care (Gabel 2012). The caregiving burden may be influenced by cultural aspects and differences in family and societal structures in different countries (Truzzi et al. 2012). This study is one of the a few studies to examine determinants of subjective caregiving burden and burnout in formal caregivers of a Turkish cohort using a prospective method. The aim of this study was to examine the relationship between sociodemographic factors, burden of care and burnout level of 120 professional staff dealing with Alzheimer's disease patients in eight geriatric care centers in Istanbul. In line with recent study results from other countries; we hypothesize that caregiver burden will be correlated with burnout levels and caregiver burden and burnout levels will be correlated with careers' age, sex, education and marital status.

Method

This is a descriptive study with cross-sectional design. The inclusion criteria for caregivers were as follows: (a) age \geq 18 years; (b) ability to communicate in Turkish; and (c) providing written informed consent. All participants were informed about the aims of the study and gave their consent to participate in the face-to-face interviews. Questionnaires used to investigate the burden of care and burnout levels in personnel caring for Alzheimer's patients were applied to personnel in identified care centers, and the results were analyzed. This survey study was performed in August 2016. The Ethics Committee of the Beykent University at Istanbul gave approval for the study. Informed consent were given by the participants of the study.

All rest and care centers in the Büyükçekmece district of Istanbul were included in the study. The study population consisted of 203 personnel caring for Alzheimer's patients in the Beylikdüzü Rest Home, Hayat Private Rest Home, the Care for the Aged Center, the Yuvam Care Center, the Altınçağ Rest Home, the Ay Yaşam Rest Home and the Gülşah Rest Home. At the time of the study, 29 staff was working in the Beylikdüzü Rest Home, 15 in the Hayat Private Rest Home, 15 in the Care for the Aged Center, 50 in the Yuvam Care Center, 25 in the Altınçağ Rest Home, 32 in the Ay Yaşam Rest Home and 17 in the Gülşah Rest Home.

We endeavored to contact all 203 caregiving personnel in the study. Of these, 51 were unavailable for various reasons, and 32 declined to participate as they did not want to consent to any research studies. One hundred twenty personnel participated represent the final research sample.

A six-item "personal information form" for eliciting sociodemographic data, the "Zarit Caregiver Burden Scale" and finally the "Maslach Burnout Inventory" were used as data collection tools.

Personal Information Form

Data concerning gender, age, education status, marital status, number of children and other information were recorded.

Zarit Caregiver Burden Scale

A 22-item Likert-type scale used to assess the burden experienced by caregivers. A high score is associated with a high caregiver burden and consequent distress. The scale was developed by Zarit et al. (1980), it has cross-cultural use (Tang et al. 2017) The reliability and validity of the Turkishlanguage version were established by Ash et al. (2009). It is scored on a scale from zero to 88 (9). The raw scores from this measure can be analyzed as a numeric variable, and they can also be categorized into four groups that reflect increasing caregiver burden (0–20: little or no burden; 21–40: mild to moderate burden; 41–60: moderate to severe burden, and 61–88: severe burden).

Maslach Burnout Inventory

A 22-item Likert-type scale. Scores on the burnout scale range between 1 and 5. This interval has a 4-point width. This is divided into five equal bands, 1.00-1.79 "very low," 1.80-2.59 "low", 2.60-3.39 "moderate", 3.40-4.19 "high" and 4.20-5.00 "very high." High scores indicate increased occupational burnout (Maslach and Jackson 1986). Maslach and Jackson (1986) also claimed that for the subscale scores; the level of burnout was high if emotional exhaustion score was \geq 27, personal accomplishment score was \leq 21, and depersonalization was \geq 13 and the burnout was low if low if emotional exhaustion was ≤ 16 , personal accomplishment was \geq 39, and depersonalization was \leq 6. The inventory was adapted into Turkish by Ergin (1996). The inventory is divided into three components, emotional burnout, depersonalization and a feeling of reduced personal accomplishment. During score evaluation, the higher the emotional burnout and depersonalization scores and the lower the personal accomplishment scores, the greater the burnout.

Statistical Analysis

The data obtained were analyzed on SPSS for Windows 22.0 software. Number, percentage, mean and standard deviation

Table 1Sociodemographiccharacteristics of caregivers

were used during analysis. The Mann Whitney U test was used to compare quantitative constant variables between two independent groups and the Kruskal Wallis test to compare quantitative constant variables between more than two groups. The Mann Whitney test was used as a complementary technique to determine variations after the Kruskal Wallis test. Spearman correlation and regression analysis was applied between constant variables. Correlation analysis is performed in order to determine the power (degree) and direction of linear relations between constant variables. Regression analysis was applied in order to determine causal relations between constant variables and to confirm dependent variable values difficult to obtain with the help of independent variables. The Kruskal Wallis (H) H-test was used to investigate the relation between care giving and burnout levels and sociodemographic data, and the Mann Whitney U test was applied to identify the group representing the source of variation. Data findings were interpreted at a 95% confidence interval and at a 5% significance level.

Results

The study included 120 individuals. Characteristics of the caregivers are shown in Table 1. High levels of emotional exhaustion were present in 25% of our sample, high levels of depersonalization was found in 30% and reduced personal accomplishment was present in 26% of the caregivers. High emotional exhaustion and low reduced personal accomplishment were found in 5%, high emotional exhaustion and

Variables	Groups	Frequency (n)	Percentage (%)
Gender	Female	62	51.7
	Male	58	48.3
Age	20-30	62	51.7
	31–40	28	23.3
	Over 40	30	25.0
Level of education	Literate	10	8.3
	Primary school	16	13.3
	Middle school	24	20.0
	High school	50	41.7
	University	20	16.7
Marital state	Married	60	50.0
	Never married	36	30.0
	Widow	8	6.7
	Divorced or separated	16	13.3
Children	Present	72	60.0
	None	48	40.0
Professional experience	1-3 years	36	30.0
	4-6 years	52	43.3
	More than 6 years	32	26.7

depersonalization in 17%, and high depersonalization and low reduced personal accomplishment in 9% of the caregivers. In the 120 caregivers, 46% did not experience any clinically significant (high level) of burnout dimension.

73% of the sample had mild to moderate burden, 21% of the sample had moderate to severe burden and %2 of the sample had severe burden based on the Zarit Caregiver Burden Scale scores. The mean "caregiver burden" of the caregivers in the study was 35.3 (SD=9.92), the mean "emotional burnout" level was 2.36 (SD=0.80), the mean "depersonalization" level was 1.93 (SD=0.67) and the "personal accomplishment" level was 2.54 (SD=0.87).

Genders were equally represented in the sample (51% female, n = 62). Most caregivers in the study were aged between 20 and 30 (51%, n = 62), 23% of the participants were aged 31–40 (n = 28) and 25% of the participants were aged over 40 (n = 30). Educational levels of the participants were as follows; literate (8%, n = 10), primary school (13%, n = 16), middle school (20%, n = 24), high school (41%, n = 50) and university graduates (16.7%, n = 16). Most of the participants had children (60%, n = 72). A higher proportion of the participants were married (50%, n = 60), 30% of them were never married (n = 36), and 6% of them were widowed (n = 8), 13% of them were divorced or separated (n = 16). The professional experience levels of the participants were as follows; 1–3 years (30%, n = 36), 4–6 years (43%, n = 52), more than 6 years (26%, n = 32).

Relations Between Burnout Subscales and Caregiver Burden

A positive, significant correlation was determined between emotional burnout and caregiver burden (r=.41; p < .001). A positive, significant correlation was determined between depersonalization and caregiver burden (r=.38; p < .001). A positive, significant correlation was determined between reduced personal accomplishment and caregiver burden (r=.25; p=.006). A positive, significant correlation was determined between depersonalization and emotional burnout (r=.48; p < .001). A positive, significant correlation was determined between reduced personal accomplishment and emotional burnout (r=.19; p=.034). A positive, significant correlation was determined between reduced personal accomplishment and depersonalization (r=.30; p=.001).

Regression analysis was performed and the relationship between caregiver burden and emotional burnout that was statistically significant (F=16, 229; p < .001); the relationship between caregiver burden and depersonalization was statistically significant (F=15, 148; p < .001); but relationship between caregiver burden and a feeling of reduced personal accomplishment was not statistically significant (F=3, 062; p=.083). A correlation was observed with caregiver burden variables as a determinant of emotional burnout level ($R^2 = 0.113$). Caregivers' burden of care levels showed increase with increasing emotional burnout levels ($\beta = 0.028$). A correlation was determined with caregiver variables as a determinant of depersonalization levels ($R^2 = 0.106$). Rising burden of care levels occurred with increasing depersonalization levels ($\beta = 0.023$).

Relations Between Caregiver Burden, Burnout Levels and the Sociodemographic Data

Married subjects' and widowed subjects' mean emotional burnout scores (M=2.49, SD=0.91 and M=3.02 SD=0.59 respectively) were higher than those subjects who had never married (M=2.06, SD=0.51) and were higher from divorced or separated subjects (M=2.22, SD=0.70). Accordingly, being married was associated with higher emotional burnout (p=.007, H=12.181) and depersonalization scores (p<.001, H=19.047). No significant correlation was determined between caregiver burden and marital status (p=.536, H=2,182). No significant correlation was determined between personal accomplishment and marital status (p=.228, H=4.325).

The emotional burnout scores of subjects with 4–6 years' professional experience (M=2.59, SD=0.91) were higher than those of subjects with 1–3 years' experience (M=2.08, SD=0.64) and more than 6 years' experience (M=2.31, SD=0.67). No significant correlation was determined between caregiver burden and professional experience (p=.592, H=1,049).

Caregiver burden scores of subjects aged between 31 and 40 years (M = 39.0, SD = 12.5) were higher than those of subjects aged 20–30 years (M = 33.1, SD = 7.01). Being in 31-40 years of age was associated with higher caregiver burden than being in 20–30 years of age (p = .031, H = 6.976). Depersonalization scores of subjects aged over 40 years (M = 2.26, SD = 0.71) were higher than those of subjects aged 20–30 years (M = 1.77, SD = 0.60). Depersonalization scores of subjects aged over 40 years (M = 2.26, SD = 0.71) were higher than those of subjects aged 31-40 years (M = 1.91, SD = 0.67). Older age was associated with higher depersonalization (p = .005, H = 10.630). Feelings of reduced personal accomplishment of subjects aged 20–30 years (M = 2.69, SD = 0.87) were higher than those of subjects aged over 40 years (M = 2.18, SD = 0.78). Being between 20 and 30 years of age was associated with higher personal accomplishment scores than being over 40 years of age (p = .043, H = 6.293). Accordingly, caregiver burden and depersonalization scores tended to rise with age, while feeling of reduced personal accomplishment scores were higher in younger subjects. No significant correlation was determined between emotional burnout and age (p = .477,H = 1.482).

Caregiver burden, emotional burnout and depersonalization scores were higher in subjects with an education level of literacy compared to all the groups with higher levels of education. This was particularly pronounced in the caregiver burden among all the groups. Caregiver burden scores of merely literate subjects (M = 46.4, SD = 4.6) were higher than of subjects with primary school education (M = 37.0,SD = 15.1), middle school education (M = 31.0, SD = 9.10), high school education (M = 34.1, SD = 8.09), and university education (36.5, SD = 7.84). Emotional burnout scores of merely literate subjects (M = 3.40, SD = 0.25) were higher than of subjects with primary school education (M = 2.31,SD = 0.65), middle school education (M = 2.22, SD = 0.79), high school education (M = 2.28, SD = 0.86), and university education (M = 2.25, SD = 0.58). Lower education level was associated with higher caregiver burden (p = .000, H = 21.107), emotional burnout (p < .001, H = 20.038) and depersonalization (p = .001, H = 19.801) levels. No significant correlation was determined between personal accomplishment and education level (p = .063, H = 8.928).

In terms of distribution by gender, women had higher depersonalization scores (M = 2.05, SD = 0.67) than men (M = 1.80, SD = 0.66); with statistical significance revealed with Mann Whitney U test (p = .033, U = 1394.0). No significant difference was determined according to gender in terms of mean caregiver burden (p = .066), emotional burnout (p = .269) or personal accomplishment (p = .728). Subjects with children had higher emotional burnout (M = 2.47, SD = 0.83) and depersonalization (M = 2.03, SD = 0.71) scores than those without children (M = 2.20, SD = 0.73 and M = 1.76, SD = 0.58, respectively), while no significant difference was observed in terms of caregiver burden (p = .479) and personal accomplishment (p = .076).

Discussion

We observed that more than half of our sample had moderate or severe burden. Also high levels of emotional exhaustion, depersonalization and reduced personal accomplishment were present in the caregivers. Not unexpectedly, our data show that caregiver burden was significantly correlated with levels of burnout, indicating that tailored interventions that target individual caregiver needs could be developed. Most of the studies found that lower caregiver burden was associated with higher caregiver mental functioning. Recently, a study conducted by Takai et al. (2009) found that caregiver burnout and depression were the most significant factors associated with the caregiver's low quality of life. It was also shown that reducing caregiver burden may increase the likelihood that caregivers will remain engaged and supportive of patient recovery. Similar to other study findings emotional exhaustion was the most pronounced dimension in our sample. Matsuda (2001) and Takai et al. (2009) also found higher levels of emotional exhaustion in their sample of familial caregivers of patients with dementia. A Finding of high levels of emotional exhaustion is important, since emotional exhaustion is the main burnout dimension and reflects the stress dimension of this syndrome. Strenuous physical and emotional demands that dementia caregivers face due to the caregiving tasks appear to drain their emotional resources and may ultimately lead to feelings of energy depletion.

Several factors have been identified that influence the burden experienced by careers including the age and socioeconomic status of the caregivers. The gender of the caregiver also plays an important role in the amount of burden experienced, with a greater level of burden being experienced by women. In present study women had higher depersonalization scores than men, while there was no difference in terms of other subtypes. Similar to this finding some studies from Turkey have determined greater depersonalization in women than in men (Dikmetaş et al. 2012). Contrary to this finding, some other studies reported that women tend to score higher on emotional exhaustion, whereas men often score higher on depersonalization (Truzzi et al. 2016). They suggested that this difference is probably due to gender role stereotypes, as men appear less likely to express their negative feelings than female caregivers. Algül et al. also observed greater emotional burnout in women and concluded that this was due to greater demands from women both in the home and at work (Purnova and Muros 2010; Adekola 2010). However, the relationship between gender and burnout varies for different samples (Marakoğlu et al. 2013; Erol et al. 2007). For example, in their study in which practitioner physicians participated, Sünter et al. (2006) found no difference according to gender, apart from higher personal achievement scores in men.

The associations between the three burnout dimensions and the caregiver's clinical and sociodemographic characteristics are less studied. A study conducted by Yilmaz et al. (2009) found that the severity of the caregiver's anxiety and the patient's functional decline were the main predictors of emotional burnout. Additionally, a submissive approach by the caregiver, their level of education and caring for a female patient were related to reduced personal accomplishment. Finally, Truzzi et al. (2016) found a significant association between the patient's depression and the caregiver's depersonalization. In present study being widowed and married was associated with higher emotional burnout and depersonalization scores than being not married and separated/ divorced subjects. Also subjects with children had higher emotional burnout and depersonalization scores than those without in this study. Accordingly, Algül et al. (2016) found

that not having children was correlated with low burnout (depersonalization) scores in caregivers.

In our research, the severity of emotional burnout increased with professional experience, which may be associated with this protective effect of increased professional experience not being seen in non-physician health personnel. This suggests that the professional conditions enjoyed by non-physician health workers do not increase sufficiently in line with seniority.

Caregiver burden and depersonalization scores increased with age; burnout related to feelings of reduced personal accomplishment was also encountered more frequently in caregivers with older age in our study. Inconsistent with this finding, some studies have reported a negative correlation between age and emotional burnout (Brewer and Shapard 2004; Maslach et al. 2001). There are also studies showing that depersonalization decreases with age (Antoniou et al. 2006; Randall 2007). In agreement with our study, there are epidemiological studies suggesting the opposite. Two studies among manual workers in Finland and Sweden reported that burnout tended to increase with age (Kalimo 2000; Ahola et al. 2000; Lindblom et al. 2006). It is unclear which factor predicts the relationship between age and burnout, but various factors have been implicated, including; professional advancement, organizational loyalty, increased income and social support systems (Ramirez et al. 1996; Erol et al. 2007; Algül et al. 2016).

According to our study results caregiver burden, emotional burnout and depersonalization increase as education levels decrease. A gradual relation is particularly marked in caregiver burden. No significant difference was determined between the groups in terms of feelings of reduced personal accomplishment by education levels. It may be hypothesized that caregivers with a high level of education have greater capacities to cope with the caregiver burden (Atagun et al. 2011).

The present study bears some limitations. The basic limitation is that it cannot draw any definitive conclusions about cause and effect relationships and, therefore, only informed assumptions can be made for the underlying relationships that affect caregivers' levels of burnout and care burden. Furthermore, the absence of a control group in our sample prevents further comparisons. Also, caution should be taken while generalizing our conclusions, since our data were representing the eight geriatric care centers in Istanbul.

Conclusion

We observed that most of the subjects had moderate or severe caregiver burden and high levels of burnout symptoms in our sample. Targets must be identified with an increase in studies along these lines, and measures must be taken to facilitate initiatives aimed at reducing personnel burnout.

As formal caregivers play such a crucial role in the care of patients with Alzheimer's dementia, development of appropriate management strategies that incorporate interventions which address the specific correlates of burden deserves special attention. Addressing the specific factors that are associated with caregivers' stress may have important humanitarian and economic implications.

We think that in addition to preventing progression of the disease in the treatment of patients with Alzheimer's dementia, treating the psychological and behavioral symptoms that occur in the condition can also help preventing caregiver burden and burnout. Development and application of measures to preserve and improve patients' functioning can also reduce the burden and burnout experienced by caregivers.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval The study has been approved by the appropriate institutional ethics committee and have been performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or compatible ethical standards.

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