Year (Yıl) : 2019
Volume (Cilt) : 6
Issue Number (Sayı) : 1
Doi : 10.5455/JNBS.1548016538

Received/Geliş 19.11.2018
Accepted/Kabul 25.12.2018
JNBS, 2019, 6(1):21-27

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THE EVALUATION OF CAREGIVER BURDEN OF ELDERLY PSYCHIATRIC PATIENTS

PSİKİYATRİK HASTALARA BAKIM VERENLERİN YÜKÜNÜN DEĞERLENDİRİLMESİ

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Abstract

The number of studies evaluating caregivers in the elderly psychiatric population is insufficient. This study aims to determine the caregiver burden and related factors in elderly psychiatric patients' caregivers. This is a descriptive cross-sectional study. The study was carried out on caregivers who applied to Private Adana Hospital psychiatry clinic. The study included 230 caregivers of psychiatric elderly patients (≥60 years). Demographics questionnaire form (for the elderly and caregivers) and the Zarit Burden Interview were used to collect data. Independent t-test, analysis of variance (ANOVA) and Scheffe post-hoc test were used for statistical analysis. Caregivers' burden had a meaningful association with type of psychiatric disorder in elder patients (p=0.005). Post-hoc test showed caregivers' burden was higher in caring for schizophrenic patients and then obsessive-compulsive, bipolar disorder, depression, and anxiety disorders, respectively. The results denoted that care giving hours per week (p=0.003) and additional psychiatric patients number in the family (p=0.004) had an association with care giving burden. Results showed that greater care giving hours/week was associated with higher care giving burden. It is seen that caregiving hours, type of the patient's mental illness and presence of an additional psychiatric patient in a family increases the burden of the caregiver. Caregivers' high care burden can overshadow the quality of care the psychiatric elderly patients and expose the caregivers' psychological health to danger.

Keywords: burden; caregiver; elderly; psychiatric disorder

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Öz

Yaşlı psikiyatrik popülasyondaki bakıcıları değerlendiren çalışmaların sayısı yetersizdir. Bu çalışma yaşlı psikiyatri hastalarının bakım verenlerinde bakıcı yükünü ve ilişkili faktörleri belirlemeyi amaçlamaktadır. Tanımlayıcı kesitsel bir çalışmadır. Çalışma, Özel Adana Hastanesi psikiyatri polkliniğine ayaktan başvuran psikiyatrik yaşlı hastalara (≥60yaş) bakım veren 230 kişi üzerinde yapıldı. Demografik anket formu (yaşlılar ve bakım verenler için) ve Zarit Bakım Yükü Ölçeği verileri toplamak için kullanıldı. İstatistiksel analiz için bağımsız t-testi, varyans Analizi (ANOVA) ve Scheffe post-hoc testleri kullanıldı. Bakım verenlerin yükü, yaşlı hastalarda psikiyatrik bozukluk tipi ile anlamlı bir ilişki göstermiştir (p=0.005). Post-hoc testi bakıcıların yükünün şizofreni hastalarına bakım yapmada sırasıyla obsesif-kompulsif, bipolar bozukluk, depresyon ve anksiyete bozukluklarından daha yüksek olduğunu göstermiştir. Sonuçlar, saatte/haftada saat verilen bakımın (p=0.003) ve ailedeki ek psikiyatrik hasta sayısının (p=0.004) bakım yükü ile ilişkili olduğunu göstermiştir. Bakım saatlerinin, hastanın ruhsal hastalık türü ve ailede ek bir psikiyatri hastasının varlığının bakıcının yükünü arttırdığı görülmektedir. Bakım verenlerin yüksek bakım yükü, psikiyatrik yaşlı hastaların bakım kalitesini düşürebilir ve bakıcıların psikolojik sağlığını tehlikeye maruz bırakabilir. Bu nedenle, yükü azaltmak ve hastaların aileleri gibi gayri resmi bakıcılar tarafından uzun vadeli bakım kalitesini artırmak için toplum odaklı müdahalelerin gerekli olduğu görülmektedir.

Anahtar Kelimeler: *yük; bakım veren; yaşlı; psikiyatrik bozukluk*

1. Introduction

One of the greatest perspectives on the health of older people is their mental health, which deserves more attention (Mirzaee & Shams 2010). The outbreaks of psychiatric disorders with increasing age are cognitive (i.e. dementia) and mental disorders such as schizophrenia, mood disorders (bipolar and major depressive disorders) (Buldukoğlu et al., 2011).

Elderly people with psychiatric disorders often require daily activities supported by caregivers (Tel et al., 2013). Family caregivers are taken into account as a part of the informal support system principally in charge of the patient without receiving any financial provision (Carra et al, 2012). Approximately 10% of individuals with chronic mental illness need long-term care and live mostly with their families or other related caregivers. The patient's relatives have become primary caregivers and have adopted the approach of treating the patient in the community and within their own environment and increased the responsibilities of caregivers (Tel et al., 2010). This situation has brought a number of problems. Chronic mental disorders in the elderly lead to disturbances in individuals' feelings, thoughts and cognitive abilities, changes in their personality and individual habits, and social and economic losses (O'Hara et al, 2010; Vina et al, 2007).

Family caregivers are vulnerable and require special attention like the elderly (Çetinkaya Duman & Bademli, 2013; Settineri et al, 2014). Besides physiological and biological damage, stress and long-term caring effect on the caregivers causes at least fatigue (Schulz & Beach, 1999), and presumably decreased social and job activities and disconnected relationships with the environment including family and friends (Kuipers, 1993). A study found that an old person's physical disease leads to increased stress, anxiety, and financial burden in the caregivers' personal lives (Garlo et al, 2010). Another study showed that caring of psychiatric elderly patients leads to problems, such as personal life stress, additional financial burden and feeling guilty for the caregivers, losing one's job resulting in the caregiving burden (Limpawattana et al, 2013; Schulze & Rössler, 2005) Caregiving burden is masked in nature which means that the patient and the caregivers are both in suffering and pain and strongly need to be socially supported and understood (Milbury et al, 2013). The type, duration, and severity of the mental disorder, the caregiving period, the incidence of problematic behaviors on the patient's side, reduced social protection, and negative feelings can lower quality of life and bring about further burden (Saunders, 2003; Zendjidjian et al, 2012). Under the best conditions and circumstances, caregivers are affected by the burden (Grover & Dutt, 2011; Magliano et al, 2006; Tel et al., 2010).

Studies on the care burden of psychiatric disorders in the literature mostly focuses on caregivers of schizophrenia patients. However, the number of studies evaluating caregivers in the elderly psychiatric population is insufficient. This study aims to determine the caregiver burden and related factors in elderly psychiatric patients' caregivers.

2. Materials and Methods

The study was a descriptive cross-sectional study. The participants were composed of caregivers (n=230) of the elderly patients (≥60 years) who applied consecutively to the outpatient clinic and agreed to participate in the study. The study was carried out between 1 June 2018 to 1 January 2019 at Private Adana Hospital outpatient psychiatry unit. Study was approved by the Ethics Committee of Çukurova University and this study complies with the Declaration of Helsinki Research Ethics.

The study included the caregivers of elderly patients (≥60 years) that applied consecutively who gave informed written consent and accepted to participate in the study and filled out the forms.

Caregivers with active bipolar disease, active psychosis, dementia, mental retardation, Parkinson's disease, degenerative diseases, neurological diseases such as multiple sclerosis, SLE, chronic renal failure and those with systemic chronic disease were excluded from the evaluation. The exclusion criteria were defined as having any neurological or physical disease and cognitive deficits which may cause problems in understanding the research guidelines and filling in the forms.

The persons who had not accepted to participate in the

study (n=13) and had cognitive disorders (n=6), history of brain injury (n=4), neurologic disorders (n=9) were excluded from the study (total excluded n=32) . The reasons for the absence of caregivers who did not agree to participate in the study were determined by the time, the concern about the passing of their names in the study and the response from the family.

2.1. Tools

All caregivers were diagnosed using the Structured Clinical Interview for DSM-IV Disorders (SCID-I) (First et al, 2002).

The demographics form of the elderly included gender, marital status, education, the psychiatric disorder type, the disorder duration, job status and insurance, and that of the caregivers covered age, gender, marital status, relation, education, economic status, employment status, the number of psychiatric patient members in the family, and care giving hours per week. The economic level was determined by the amount of yearly household income (> 20,000 = poor, 20,000-40,000 = average, ≥40,000 = good) (1$=5,30 at 14.02.2019).

Zarit Burden Interview: This is the most established tool that evaluates the perceived burden of family caregivers and questionnaires is filled out by the caregiver (Zarrit et al, 1980). This inventory discovers negative mental, physical, social, and economic impacts of care giving on the life of the caregiver. The inventory comprises 22 questions in a 5-point Likert scale and each question has 5 choices given scores as "never (0), almost (1), sometimes (2), often (3), and always (4)". Total scores represents the care giving burden. Scores of less than 30 were defined as mild burden, 31 to 60 as average burden, and 61 to 88 as severe burden. The scale was translated into Turkish (Özlü et al., 2003).

2.2. Procedure

After exclusion of the caregivers which are not appropriate or unwilling for aforementioned reasons (n=32), informed written consent was taken from the rest of the caregivers of the elderly (n=230) that accepted to participate in the study. Sociodemographic form was filled out by the staff, and ZBI was filled out by the caregivers. Data obtained from the results are analyzed by the eligible statistical tests.

2.3. Anaylysis

The SPSS 22 software was used to analyze the date with descriptive and inferential statistics such as analysis of variance (ANOVA), independent t-test, and Scheffe Post hoc test.

3. Results

Caregivers aged between 22 and 70 years (Mean±SD=50.78±12.76). Forty percent of the caregivers were male, 91.0% (n=209) married, and 52.2% (n=120) of them were in the age group of 40 to 59 years old. The majority of the caregivers were the children of the patients (n=105, 45.7%) followed by spouses (n=67, 29.1%). Education of caregivers was similar in illiteracy (25.2%), primary 29.6%), secondary (25.6%) and high school (19.6) levels. More than half (66.5%) of them had an average economic status. Around 86.4% of them only had cared for one psychiatric elderly and 13.6% took care of another psychiatric patient at home in addition to the psychiatric elderly. The highest care-giving hours per week was 35 to 44 hours (Mean±SD=34.32±23.98, Min=14, Max=56) (Table 1).

Table 1. Demographic Characteristics of Caregivers of Psychiatric Elderly Patients

Demographic Data		N (%)
Gender	Male	92 (40.0)
	Female	138 (60.0)
Age (years)	>40	38 (16.5)
	40-59	120 (52.2)
	60-70	72 (31.3)
Education	Illiterate	58 (25.2)
	Primary	68 (29.6)
	Secondary	59 (25.6)
	High	45 (19.6)
Marital Status	Single	21(0.9)
	Married	209 (91.0)
Economic Status	Poor	9 (3.9)
	Average	153 (66.5)
	Good	68 (29.6)
Employment status	Housewife	45 (19.6)
	Farmer	41 (17.8)
	Self-employed	38 (16.5)
	Job holder	69 (30.0)
	Retired	37 (16.1)
Another psychiatric disorder in family	No	184 (80.0)
	Yes	46 (20.0)
Weekly Patient Care (hours)	<24	38 (16.5)
	24-34	76 (33.0)
	35-44	86 (37.4)
	>44	30 (13.1)
Relation to patient	Spouse	67 (29.1)
	Child	105 (45.7)
	Child in law	29 (12.6)
	Other Relatives	29 (12.6)

In addition, the results showed the mean age of patients was 71.79±2.31 years, ranging from 60 to 92 years; 48.7% were male, 53.5% married, and 44.8% of them were jobless with no income; about 40.9% had a psychiatric disorder for 10 to 19 years. In patients, psychiatric disorders were found as anxiety in 7.8%, bipolar disorder in 21.3%, schizophrenia in 27.8%, and depression in 31.3% (Table 2).

Table 2. Demographic Characteristics of The Psychiatric Elderly Patients

Demographics		N (%)
Gender	Male	112 (48.7)
	Female	118 (51.3)
Age (years)	60-69	102 (44.3)
	70-79	95 (41.3)
	≥80	33 (14.4)
Education level	Illiterate	77 (33.5)
	Primary	67 (29.1)
	Secondary	49 (21.3)
	High	37 (16.1)
Marital Status	Single	14 (6.0)
	Married	123 (53.5)
	Widow	93 (40.5)
Emplaoment status	Jobless	103 (44.8)
	Farmer	55 (23.9)
	Self-employed	8 (3.5)
	Retired	64 (27.8)
Duration of disase(years)	<10	40 (17.4)
	10-19	94 (40.9)
	20-29	62 (26.9)
	≥30	34 (14.8)
Psychiatric disorder type	Schizophrenia	64 (27.8)
	Anxiety disorders	18 (7.8)
	Bipolar disorder	49 (21.3)
	Derpression	72 (31.3)
	More than one	27 (11.8)

It was found that 33%, 55%, and 14% of caregivers had mild, average, and severe burden, respectively. The mean scores of personal, emotional, social, and economic caregivers' burden were 15.61±5.62, 13,61±1.03, 4.81±33.29, and 4.79±1.52, respectively. The results showed that caregivers' burden had a meaningful association with type of psychiatric disorder in elder patients (F=4.330, df=4.174, and p=0.005). Post Hoc test showed caregivers' burden was higher in caring for schizophrenic patients and then obsessive-compulsive disorder, bipolar disorder, depression, and anxiety disorders, respectively. Psychiatric distribution of caregivers was found as follows: 7.8% schizophrenia (n=18), 8.3% bipolar disorder (n=19), 38.3% anxiety (any) (n=88), 33.0% depression (n=76) and 12.6% obsessive compulsive disorder (n=29). The results denoted that caregiving hours per week (t=2.89, df=31.49, and p=0.003) and additional psychiatric patients number in the family (t=2.89, df=31.49, and p=0.004) had an association with care giving burden. Post-hoc test showed that greater caregiving hours/week was associated with higher care giving burden (Table 3).

Table 3. Caregivers' Burden Numerical Indicators in Terms of Demographic Data

Demographics		Test Results
Gender	Male	t=1.34, df=198, p=0.181
	Female	
Age (years)	<30	F=0.788, df=1.221, p=0.456
	30-39	
	40-49	
	50-59	
	60-69	
	70-79	
Education	Elementary	F=1.63, df=2.145, p=0.184
	Secondary	
	High	
	University	
Marital Status	Single	t=-0.713, df=17, p=0.477
	Married	
Economic Status	Low	F=2.854, df=2.301, p=0.061
	Average	
	High	
Employment status	Housewife	F=0.202, df=1.273, p=0.937
	Farmer	
	Self-employed	
	Jobholder	
	Retired	
Another psychiatric person in the family	No	t=-2.89,df=31.49, p=0.004
	Yes	
Weekly patient Care (hours)	<24	t=-2.89, df=31.49, p=0.003
	24-34	
	35-44	
	>44	
Caregiver's relation to the patient	Spouse	F=1.363,df=1.432, p=0.255
	Child	
	Child in law	
	Other relatives	
Psychiatric disorder type in the caregiver	Schizophrenia	F=4.330, df=4.174, p=0.005
	Anxiety (any)	
	Bipolar disorder	
	Depression	
	Obsessive-Compulsive Disorder	

4. Discussion

The study findings show a high burden for caregivers. The study was conducted on 230 caregivers; 60% of them were female and 90.9% were married. Half of the caregivers were in 40-59 age range. The educational level distribution of caregivers was found similar (illiterate to

high school). The economic status of two thirds of the caregivers was average (66.5%). Twenty percent (n=46) of the caregivers had another psychiatric patient in their family. With regard to the degree of closeness to patients, the majority of caregivers were children of the patients (45.6%, n=105).

There are limited studies carried out on elderly mental health patients in Turkey. In a study conducted by Kızılırmak & Küçük (2016) using Burden Assessment Scale, they showed that caregivers of patients with mental disorders of any age (n=243, age 35.48±17.00, range min=17, max=90) have a high risk of developing mental disorders including anxiety and depression. In a study with patients diagnosed with Alzheimer's dementia, Akpınar et al. (2011) found that female caregivers had higher burden than males on time dependence, developmental, and social burdens, but no difference was found with respect to emotional burden.

The achieved results in the present study indicated that 33% of the caregivers had mild burden and 69% had average to severe burden. This outcome is compatible with recent studies on caregivers of elderly (Abdulla-pour et al, 2011; Caqueo-Urizar et al, 2011). Another study was not consistent with our result (Limpawattana et al, 2013). Based upon the findings, out of the care giving burden dimensions, only two, including emotional and personal aspects, were correlated with duration of duration in the elderly psychiatric patients. A study on caregiver's quality of life and burden of elderly patients with physical and mental illness also showed emotional, economic, and personal burden correlated with duration of disease in the caregivers (Settineri et al, 2014). Bergvall et al. (2011) in the study of caregivers of Alzheimer's patients, found mild to moderate level of burden. Loi et al. (2015) found that patients with mental illness had moderate to severe, Luchsinger et al. (2015) found high level of burden on caregivers. Our study revealed that the main caregivers were children of the patients followed by spouses. Although the caregiving burden of the children was higher than that of other caregivers (spouse, son-in-law, and daughter-in-law), this difference was not considerable.

Our study showed that almost half of the caregivers were male, the sex of caregivers did not show a significant relationship with the care burden, and the male burden scores were higher than females (as seen in Table 3). Similar to this study, previous studies (Awad & Voruganti, 2008; Caqueo-Urizar et al, 2011; Haresabadi et al, 2012; Shinde et al, 2012) revealed that the average burden of care scores among males were higher than females. However, the current difference may depend on the cultural context of the working environment in Turkish families, such as men's bread winners and their financial role as financial provider and men's ability to physically address patients.

The vast majority of the participating caregivers in the present study was married, which may represent economic security and a sense of responsibility compared to single individuals; marital status did not reveal any considerable relationship with the caregiving burden. Married caregivers had a higher mean load score than single caregivers. Average levels of burden was found in very high, particularly for mothers, In addition, the average burden scores of caregivers aged between 45 and 65 were reported more than in other age categories. However, this age difference was not considerable. It has been reported that married people, regardless of disability level, provide the most consistent and most reliable care for elderly patients. In addition, the placement of unmarried patients in nursing homes is shorter (Cantor & Little, 1985). Horowitz & Dobrof (1982) documented the primary role of spouses in providing the primary responsibility for care work, household responsibilities, and medical supervision of the elderly person. The importance of the primary roles of spouses compared to other family members was emphasized and it is referred to the additional role of family members compared to the primary role of spouses in caring in later life. In fact, it has been reported that some elderly women have reduced their health problems by their spouses in the caregiver role in long-term marriages (Motenko, 1988).

Based on the post-hoc test, the average care burden scores according to the perceived economic situation showed that the care burden was higher in low-income caregivers. The above findings are consistent with some previous studies (Abdulla-pour et al, 2011; Limpawattana et al, 2013; Settineri et al, 2014).

This finding showed that the economic situation plays an important role in the care of patients. This study also revealed that elderly caregivers have hour/weekly and additional family psychiatric members and have a significant relationship with the care burden of the type of psychiatric disorders in the elderly. The present study findings are consistent with the results of these studies (Garces et al, 2009; Settineri et al, 2014).

In addition, the presence of another psychiatric patient in the family together with the elderly psychiatric patient has imposed a burden on caregivers. Other studies (Andren & Elmstahl, 2007; Carretero et al, 2009) have shown that long-term care of elderly Alzheimer's patients leads to a reduction in burden on caregivers. The difference in these studies can be justified in some way according to adaptability, individual characteristics, cultural and traditional beliefs of caregivers; Apparently, higher adaptation capabilities and responsible caregivers of the current conditions experienced less burden, while those with lower adaptations reported a higher burden (Lautenschlager et al, 2013). Findings showed that the caregiver burden had significant difference according to the type of psychiatric disorder seen in elderly patients.

The caregivers of schizophrenia patients suffered a higher burden. This result was consistent with other studies (Hou et al, 2008; Kuipers, 1993). The results showed that older male patients were more burdensome to their caregivers than female patients. However, this difference was not statistically considerable. The results are similar to some other studies (Awad & Voruganti, 2008; Haresabadi et al, 2012; Roick et al, 2007). This

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may show a worse prognosis for psychiatric disorders in males than females and a greater resistance to treatment in male patients (van Wijngaarden et al, 2000).

4.1. Limitations and strengths

The study carried out by a self-reported interview can prevent the results to come out objectively. Another limitation is that caregivers have been evaluated once. The treatment of caregivers was not evaluated in the study. There is a relationship between the burden of caregivers and the methods of coping with stress. The caregivers' ways of coping with stress were not investigated.

As a consequence, the data obtained from the self-report criteria and the analysis should be interpreted carefully. However, the use of an instrument with validated psychometric properties confirms that the variables are measured correctly. Adequate sample size also supports findings to establish a real relationship between burden among patient and caregivers. This study directly focused on the caregivers of the elderly mental health patients with different psychiatric diagnoses (≥60 years), which is the first for our contry. In this study, results reflect the burden of caregivers of elderly psychiatric patients of a province located in the east of Turkey. It is clear that it will not show or reflect results in general for other regions and cultures in the country.

4.2. Conclusions and Recommendations for Forthcoming Studies

In summary, the findings indicate that there is a high burden on caregivers of elderly patients in a Turkish sample, so families need to promote their knowledge and awareness to reduce the burden of long-term care. In addition, the evidence showed that the burden of elderly psychiatric caregivers was related to care factors. Counseling services, cooperation between public and private institutions, training programs and temporary care implementation by the national media are recommended to alleviate the burden of caregivers between the psychiatric elderly caregivers. Therefore, family caregivers are taken into acccount to be the most important preventive system, and it can be seen that the perceived burden on caregivers can play a decisive role in caregiving. The idea behind mental health is to focus on directing activities in vulnerable populations, to prevent mental illness. For this purpose, it is necessary to evaluate the burden of care in family caregivers.

Based on the findings, forthcoming researches should address these questions: i) what are the predecessors or moderators of the burden of caregivers of the elderly psychiatric patients? ii) does psychoeducation interventions ease the caregiver burden? iii) can positive psychological characteristics in elderly patients or caregivers alleviate caregiver burden? iv) what are the specific factors related to the load by type of psychiatric disorders? v) how does cultural differences effect caregiver burden?

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