



Care burden and burnout levels of individuals caring for homecare patients

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Abstract

Aging is an important problem. Nowadays life conditions have become more sophisticated. Homecare services include people with old age, disabilities, chronic illnesses, or individuals in recovery. We all have to support our elderly people's life feel more comfortable but should not forget the difficulties of caregivers in life. In this study, we aimed to evaluate that may occur in our elderly population as well as their relatives. This is a descriptive cross-sectional study. The sociodemographic characteristics of the participants, the General Health Questionnaire – 28 (GHQ-28), Maslach Burnout Inventory (MBI), and Zarit Caregiver Burden Scale (ZCBS) were analyzed. SPSS 24.0 program was used for the analysis. Of the 150 caregiving people included in the study, 67.3% of the caregivers were first-degree relatives. The main disease of 65.3% of the patients who were cared for was neurological. Caregivers who performed care over two years had higher scores on the ZCBS and MBI, but it was only ZCBS that was statistically significant in this group ($p=0.16$). It may be a support method for both parts to reduce the burden of care of individuals who care for their patients at home and to contribute to their social lives.

Keywords: Homecare services, geriatrics, burden of care, Maslach Burnout Inventory, Zarit Caregiver Burden Scale

Introduction

Aging is a natural process of life, and it is the irreversible loss of physical and mental powers of people. Physical and spiritual losses add to social field losses with time. The aging of the population is an important problem for society. Living conditions have become more sophisticated in our day. The education level of the society has increased, and brought along the developments in health and technological fields. Thus, both the ratio of the elderly to the general population and the survival rates of the elderly has increased. All these situations brought some new problems. Although these new global problems vary according to the cultural differences between countries and other situational factors, they have many common grounds. A study in Canada found that patients who died and their families had many unmet needs [1]. Although every elderly patient aged 65 and over does not need care, their need for help increases due to the risk of diseases and physical inadequacies [2-4].

According to the 2022 data of the Turkey Statistical Institute

(TSI-TUIK), the population projections, the rate of the elderly population is over 8 million in 2022. It will projected 12.9% in 2030, 16.3% in 2040, 22.6% in 2060, and 25.6% in 2080. According to official estimates, the population of 65-year-old and above will increase from 87.5 million in 2010 to 152.6 million in 2060 in Europe [5,6].

Homecare services include people with old age, disabilities, chronic illnesses, or individuals in recovery. Physical, social, emotional, economic, and environmental factors of the individual and his/her family should include a holistic teamwork approach. The primary purpose here is to support people in their familiar environment and to facilitate their adaptation to social life. These psycho-social, physiological, and medical support services and the integrity of social services that are offered to individuals and their families define homecare services. In homecare services, patients may have the right to choose their treatment alternatives, caregiver, the place they want to receive the treatment, and the person to give the treatment [7,8]. While this service is provided,

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a medical team consisting of physiotherapists, social workers, dieticians, and other specialists is needed as well as the doctor and nurse [9].

It is seen that homecare services have started in the form of nursing services from past to present, and they have been carried out in this way for many years. If we take a look at the history of homecare services first of all the family members looked after the patients. Afterward, homecare services have come to this day with small nursing agencies, private nurses, patient caregivers, with or without family members [10]. Poland is the country that needs the least amount of homecare among European countries, where family's younger individuals are primarily responsible for supporting the elderly [6].

When examining the structure of the homecare service in Turkey, it is seen that mostly relatives of people use the hospital supported delivery models in their own homes. Besides, there has been an increase in homecare services provided by some private companies independent of hospitals and financed by out-of-pocket payments [11]. Obtaining continuous service, visiting on certain days/hours, and arrangements regarding treatment/care can be made instantly. In this way, an important aspect of the psychological problems is prevented, but not completely [12,13].

Homecare services have lower costs compared to inpatient treatment services [14]. Worldwide, healthcare providers have been investigated by financial managers and researchers in order to see whether there is an alternative to hospitals in terms of the cost and quality of homecare services, and it is foreseen that the cost of homecare and health services should be publicly sourced as a necessity of social governmental structure. Treatment services continue in homecare services as they are used to daily life conditions. The aim is to minimize the effects of the disease and not to decrease the quality of life [15].

The needs of the person are determined integratively. It is aimed to ensure that the elderly individual lives as independently as possible with the combination of family, friends and/or professional assistants, whether or not there is a payment under social insurance. At the same time, personal care taken by the individual in his/her own home contributes to the acceleration of the healing process [7]. Due to the septic conditions that severely affect survival today, the protection of homecare from hospital originated infections is perhaps the biggest medical gain.

In our study, it is aimed to raise awareness of all kinds of health problems that may occur in our elderly population as well as their relatives.

Material and Methods

The data of this descriptive, cross sectional study was collected from the patients registered in Sisli Hamidiye Etfal Training and Research Hospital Homecare Unit. The study was based on voluntary participation. The participants were informed that their names were taken only to reach the information, and at the end of the study, their identity information would not be disclosed under any circumstances. The participant had the right to quit the questionnaire and discontinue when s/he started to answer the questionnaire. The study did not bring any costs to the social

security institution or the researcher. Participants were personally visited at their houses, and both verbal and written consent to participate in the study was obtained.

Sociodemographic characteristics (age, gender, marriage, etc.) of the participants were recorded and General Health Questionnaire - 28 (GHQ- 28), Maslach Burnout Inventory (MBI), and Zarit Caregiver Burden Scale (ZCBS) were also applied. GHQ-28, which is a screening test developed by David Goldberg for the screening of general mentally specified in health screenings and patient groups, is classified as 12,28,30 and 60 questions. The internal consistency of GHQ-28, which was shown to be valid and reliable by Cengiz Kılıç, was found to have 0.84 internal consistency, 0.74 sensitivity, and 0.70. There are 28 questions in total, under 4 titles in 4 main topics [16]. MBI developed by Maslach and Jackson (1981) and passed to the literature under the name of Maslach was adapted to Turkish by Burhan Çapri, who also reported its validity and reliability study. The questionnaire has 23 questions, and participants were asked to indicate how often they experienced the specified situation. Likert scale was used (1=Never, ... 5=Always) [17].

Adaptation of the ZCBS to Turkish and validity and reliability study of the scale was performed by Fadime Hatice İnci. The participants were asked 22 questions that determine the effect of giving care to the individual's life on the scale, and the participants were asked to express their feelings with the frequency expression of "never," "rarely," "sometimes," "quite often" and "almost always" concerning the individual they were responsible. It has a Likert type rating ranging from 0 to 4 [18].

The study was approved by İstanbul Sisli Hamidiye Etfal Ethical Committee. Despite descriptive statistical analysis Independent sampling t-tests and Mann - Whitney U test was used for the quantitative data, and the chi-square test for qualitative data. SPSS 24.0 program was used for the analysis.

Results

Of the 150 caregiving people included in the study, 120 were female (80%), and 30 were male (20%). The age range was between 17-83 years and 16.7% (n=25) were in 21-40 age group while 66.7% (n=100) were in 41-65 years age group, and 16% (n=24) were over 65 years old. The mean age was 53.25±14.08, 10% were illiterate, 72% were graduated from high school. 90.7% (n=136) of the caregivers' do this service as a profession and 18% (n=27) of the group worked only as caregivers. 67.3% of the caregivers were first degree relatives, and 80% (n=120) were not payed for this service. The main disease of 65.3% patients was neurological, such as Alzheimer's, Dementia, Cerebrovascular Disease (CVD), 8% was malignancy, 5.3% was a hip fracture, muscular dystrophy, and muscular-skeletal system originated problems, also 52.7% (n=79) had both nutritional and incontinence problems. A total of 93 caregivers (62%) were doing this service for ≥2 years. Most of the caregivers (61.3%) were expected also to help houseworks and 68% worked alone (nobody helped for patient care). 88% served for 24 hours and 66.7% (n=100) could not leave their patients alone, even for a short time. 25.3% of the caregivers did not know what to do in case of an emergency (Table 1).

Table 1. Sociodemographic features

Mean age	53.25±14.08
Gender (F/M)	120 (80%)/30 (20%)
Educational status	
Low	70 (46.7%)
High	80 (53.3%)
Any kinship	120 (80%)
Average of care duration	59.36±57.80
The additional disease of caregiver (+)	65 (43.3%)
Another caregiver (+)	48 (32%)
Can leave the patient for a short time	50 (33.3%)

Whole groups' mean score of ZCBS was 29.22±16.63 (min 2–max 80), MBI 36.57±10.87 (min 11-max71) and GHQ-28 was 2.82±3.55 (min 0-max16). ZCBS scores and the MBI scores were lower among people who earn money from this job and doing this service professionally than the other group (p<0.05) Those who performed care over two years had higher scores on the ZCBS (p=0.016) and MBI (p>0.05). In terms of age and gender education, there was no difference between the groups(p>0.05). Age and gender of the caregiver, patient's incontinance or nutritional problems did not effect the scores significantly. The results of the general health questionnaire were similar with the ZCBS and MBI. Although GHQ-28 scores were lower in those who performed care professionally and earned money from the service there was no statistically significant difference between the groups (Table 2).

Table 2. Intragroup distribution of scales

	MASLACH	P value	ZCBS	P value	GHQ-28	P value
Gender						
Male (n=30)	36.73±10.87	0.842	29.13±17.34	0.855	1.66±2.24	0.097
Female (n=120)	35.93±11.03		29.25±16.52		3.10±3.76	
Age						
50≥ (n:59)	37.33±10.64	0.972	28.59±16.41	0.506	3.15±3.89	0.676
50< (n:91)	36.07±11.05		29.63±16.85		2.60±3.32	
Education level						
High	37.57±11.45	0.795	30±17.67	0.943	3.31±3.89	0.133
Low	35.42±10.13		28.34±15.44		2.25±3.05	
Homecare duration						
≤2 years (n=58)	35.46±10.45	0.185	24.92±15.96	0.016	2.82±3.81	0.959
>2 years (n=92)	36.07±11.05		31.94±16.55		2.81±3.41	
Professional homecare giver						
Yes	30.4±6.24	<0.001	17.98±11.97	<0.001	1.5±2.47	0.002
No	36.37±11.53		30.45±17.64		3.3±2.67	
Earnmoney from the service						
Yes	31.0±5.24	<0.001	19.93±11.57	<0.001	1.3±2.57	0.002
No	37.97±11.47		31.55±19.94		3.2±3.67	
Can leave the patient for a short time						
Yes (n=50)	35.56±11.78	0.359	27.88±17.84	0.869	2.9±3.72	0.886
No (n=100)	37.08±10.41		29.90±16.04		2.78±3.48	

Discussion

Caregiving is an empathetic process for both the caregiver and the patient. Today, as a result of technology, treatment choices, laboratory and economic supports of governments, the expected life span has been extended. This situation has caused an increase in the prevalence of chronic diseases and also an increase the need for homecare.

A study reveals that women constitute 75% of healthcare professionals at the family and individual level. In the study conducted by Çatak et al., 9/10 of the caregivers were women

[19]. In the summary of the report published by the World Health Organization (WHO) in 2009, the emphasis is placed on the roles of women providers in the home and health institutions [20].

In a study carried out by Perez et al. in southern Spain, 79.10% (n: 68) of those who care for their elderly relatives were found to be women [21]. In our study, 80% of the individuals providing care were women. These results show that despite the regional differences, the burden of providing care for women has not changed in different societies.

In the study of Enginyurt and Öngel, the two most common

diseases that need homecare are related with cerebrovascular problems (20.8%) and Alzheimer diseases (16.8%) [22]. In the study conducted by Erkan et al., neurological diseases were the disease group that required the need for home healthcare services the most with 50.31% [23]. In our study, the primary chronic disease of 65.3% of the patients who needed care was neurological, such as Alzheimer's, Dementia, and CVD, while neurological conditions were followed by malignancy (8%), hip fracture and muscular dystrophy (5.3%). This result is consistent with the knowledge of "Although neurological diseases are not common in the society like some other diseases, they appear as common health problems in older ages." according to the Turkey Chronic Diseases and Risk Factors Prevalence study conducted in 2013 [24]. It can be thought biopsychosocial and economical care burden as a result of neurological diseases, preventive medicine should be more foregoing in public health in our country which would be more effective in disease management in early phase of the diseases .

It has been reported that, providing care was accepted as a symbol of sincere relation and that caregivers generally took the responsibility of elderly care for emotional and economic reasons, rather than their skills, or being the most appropriate individual for providing care in our country. Despite the changing social structure, supportive family relationships still exist, and if the elderly people needs care, family members are mostly (approximately 60-80%) responsible with the care [25]. In some studies, it were found that, all of the caregivers were relatives of the patients [26]. In our study, first-degree relatives were caring for 67.3% of the patients. If we take into account both the sociocultural and medical necessities of the burden of providing care in our country with its patriarchal family structure, it is an inevitable reality that the need for care is high. Therefore, we think that the adverse effects of diseases on both patients and caregivers may cause efficiency in morbidity and mortality over time.

Although Karahan and Güven's study provides positive efficiency to the people who care for by their relatives, it shows that caregivers face some problems and are exposed to negative interactions. There are other similar studies in the literature [27]. In our study, caregivers ZCBS, and GHQ scores were worse in those with extended care, even those who could not leave them alone for a short time, and those with chronic disease. However, it was not statistically significant. The reason for this finding is that maybe the participants could not eliminate themselves from the conscientious responsibility of caring for their family members while answering this questionnaire. ZCBS and MBI scores were higher in caregivers of 2 years or more, but only the ZCBS was statistically significant ($p=0.16$) With these data in the literature, we think that when deciding by the clinician, not only the patient to be given homecare, but also the caregiver should be evaluated subjectively. Since the questions asked in ZCBS are more patient-oriented than MBI, such a result may have been obtained. According to Atagün et al., relatives of the patients who care for elderly individuals have been reported

to have difficulties in meeting the care needs of the elderly, managing complaints related to their chronic diseases, and providing emotional support to their patients [28]. In our study, the burden of care was higher in patients with chronic disease, but the difference was not statistically significant.

In the study conducted by Feldman et al., it was determined that 36% of the caregivers were insufficient to provide care. Long-term care, self-health problems, advanced age, and lack of social support causes caregivers to experience various social, physical, spiritual, and economic problems. It is reported that the freedom of caregivers is restricted, their mental states are negatively affected, they experience stress, and they become depressed [29]. According to Kalinkara and Kalaycı, chronic discomfort ($p<0.05$), dissatisfaction with the caregiving to the elderly ($p<0.05$), feeling insufficient in care ($p<0.001$), negative effects of family life and social life due to care ($p<0.001$) increases the burden [30]. It was reported that the difficulties experienced by patient relatives might be affected by the sociodemographic and clinical characteristics of the elderly individual, as well as the caregiver's characteristics such as age, gender, kinship degree to the patient, level of education, and the state of receiving support from their relatives [28,31]. In our study, there was no statistically significant difference in cases such as the age, gender, intimacy, education levels, and support status of the caregiver, and incontinence and nutritional disorders that put a burden on caregivers during care. The ZCBS score was lower, the MBI score was less, and the overall health was better in professional caregivers and for caregivers who earn income from this, the results were statistically significant generating income from care, even they are family members, encouraged caregivers. We think that the differences between the studies may be due to the geographical and cultural differences of the regions, as well as the fact that the participants did not answer some questions completely objectively. On the otherhand feedback that can be considered positive, such as earning money for the service provided. In the study conducted by Hirono et al. in Japanese, the ZCBS was found as 28.6 ± 15.3 (SD) [32]. From the studies conducted in our country, Zaybak et al. determined that this score was 27.71 ± 8.85 (SD), the highest score was 52, and the lowest score was 6 [33]. Sağlam et al. found as 30.7 ± 13.6 (SD). They found 28.54 ± 9.20 in women and 24.91 ± 7.05 in men, and although they could not find a statistically significant difference between the groups ($p=0.84$, $t=1.744$), also they found higher ZCBS scores for female caregivers than male caregivers [34]. In our study, we calculated this score as 29.2 ± 16.63 (SD), the highest was 80, and the lowest was 2. According to gender, 29.13 ± 17.34 in male caregivers and 29.25 ± 16.52 in female caregivers, and gender-dependent care burden scores of caregivers were not statistically significant. Although statistically significant results were not obtained, the most important reason for the high results of the survey scores in women in studies conducted in our country may be the traditional structure of the society. While the woman is responsible for all of the child&elderly care, the layout of the house, the determination of all the needs and to supply them, the

man is obliged to earn money. In summary, while the man exerts only physical power, the woman exerts both physical and mental strength, but this situation is generally perceived as the opposite by the society. These reasons may cause the scores to be higher. These results are compatible with the literature. It seems that the feelings of care burden result in the same way all over the world.

The lowest score that can be obtained by evaluating the MBI is 22, and the highest score is 110. In our study, the MBI was found to be 71 the highest and 11 the lowest 11 as the average was 36.57 ± 10.87 (SD). In the study of Kalinkara and Kalaycı, this average was found to be 54.928 ± 0.678 , and they interpreted that the burnout level of the caregivers was high, with a rate of 50% [30]. This study in the literature is a national as our study, and we think that the mean scores coming in such a different way may be since individuals who provide paid-professional care services to the elderly are excluded from the research. Our limitation in this work is: This work is done in middle income family place. It does not indicate the conditions experienced by low-income families.

Conclusion

According to all the data we obtained from our study, it may be a support method for both parts to reduce the burden of care of individuals who care for their patients at home and to contribute to their social lives. So, a healthcare application where caregivers can make an appointment at any time they wish to share their caregivers with their relatives, their expenses will be covered by the state, and assistant healthcare professionals will provide them at home without changing the physical conditions of the care recipient. This situation will prevent the vicious circle that causes the bedridden patient to socialize only with family members, and will also enable the caregiver to socialize and thus provide more quality care to their relatives.

Conflict of Interests

The authors declare that there is no conflict of interest in the study.

Financial Disclosure

The authors declare that they have received no financial support for the study.

Ethical Approval

The study was approved by İstanbul Sisli Hamidiye Etfal Ethical Committee. (Date: 19.08.2014/Decision No: 344)

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