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RESEARCH

BURDEN OF FAMILY CAREGIVERS OF THE ELDERLY AND FACTORS AFFECTING THEIR BURDEN

ABSTRACT

Introduction: This study aims to analyze the burden of family caregivers of the elderly and the factors affecting their burden.

Materials and Method: This descriptive study was conducted on families providing home care for 270 people above the age of 60 who were registered to the elderly care unit of Yenierenköy Medical Center in Northern Cyprus. The sample consisted of 242 family caregivers who agreed to participate in our study. We used a descriptive questionnaire and the Zarit Burden Interview for data collection. The data were collected between February and May 2017.

Results: Of the participants, 32.2% were between the ages of 31 and 40, 69.8% were female, 79.8% were married, and 30.2% were high school graduates. In addition, 52.5% were the children of the elderly people they cared for and 58.3% had been providing home care for the elderly for six or more years. The income of 60.7% of the participants was insufficient to meet their expenses, 83.5% had one or more children, and 28.2% had chronic illnesses. We found that Zarit Burden Interview scores were higher for caregivers who were below the age of 30, had lower income, and who did not have children or chronic illnesses.

Conclusion: Further qualitative studies must analyze the impact of burden of care on the quality of caregiving for elderly people.

Keywords: Aged; Caregivers; Nursing.

ARAŞTIRMA

YAŞLI BİREYE BAKIM VEREN AİLE ÜYELERİNİN BAKIM YÜKÜ VE ETKİLEYEN FAKTÖRLER

ÖZ

Giriş: Bu çalışma; yaşlı bireye bakım veren aile üyelerinin bakım yükü ve etkileyen faktörlerin incelenmesi amacıyla gerçekleştirilmiştir.

Gereç ve Yöntem: Tanımlayıcı tipteki araştırma, Kuzey Kıbrıs'ta Yenierenköy Sağlık Merkezi'ne bağlı yaşlı bakım ekibi tarafından hizmet götürülen 60 yaş ve üzeri 270 yaşlıya evde bakım veren bireyler ile gerçekleştirilmiştir. Örneklemini ise araştırmaya gönüllü katılan 242 bakım veren oluşturmuştur. Veri toplama aracı olarak 'Tanıtıcı Bilgi Formu" ve 'Zarit Bakım Verme Yükü Ölçeği' kullanılmıştır. Veriler Şubat-Mayıs 2017 tarihleri arasında toplanmıştır.

Bulgular: Bakım veren aile üyelerinin %32.2'si 31-40 yaş arası, %69,8'i kadın, %79.8'i evli ve %30.2'si lise mezunudur. Bakım verenlerin %52,5'inin yaşlı bireyin çocuğu olduğu, %58.3'ünün 6 yıl ve üzeri süredir yaşlıya bakım verdiği saptanmıştır. Bakım verenlerin %60.7'sinin gelirlerinin giderlerini karşılamadığı, %83.5'inin çocuk sahibi olduğu ve %28.2'sinin kronik bir hastalığının olduğu belirlenmiştir. Otuz yaş ve altında olan, gelir düzeyi düşük, çocuk sahibi olmayan ve kronik hastalığı olmayan bakım vericilerin bakım yüklerinin yüksek olduğu belirlenmiştir.

Sonuç: Gelecek çalışmaların nitel çalışma deseninde ve hissedilen yükün bakımın kalitesine olan etkisinin incelenmesi yönünde yapılması önerilmektedir.

Anahtar Sözcükler: Yaşlı; Bakım verenler; Hemşirelik.

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INTRODUCTION

Advancements in health care services have resulted in increases in life expectancy and proportions of the elderly in populations, in turn, paving the way for new aging-related physical, economic, and psychosocial problems (1). Among these, elderly care is perhaps the most important social problem.

Despite the changes in the social structure of Turkish society, family relations still hold an important place. Besides, family members play an important part in the process of caregiving for dependent elderly people (2). This is not unique to Turkey; families have been primarily responsible for long-term caregiving for the elderly and people with chronic diseases in most societies. However, family members may find it difficult to carry the burden of caregiving owing to various economic, demographic, social, and epidemiologic factors. Therefore, family members who provide caregiving services need to be supported and guided in order to maintain their functions (3).

While care is a basic need for all humans, caregiving is a primary responsibility. Caregiving may be defined as "everything we do directly to help individuals to meet their basic needs, develop or maintain their basic capacities, and live as much as possible free from suffering, so that they can survive and function at least at a minimally decent level" (4).

The concept of care burden refers to the physical, psychosocial, or material problems that may be encountered during the process of caregiving. Care burden is directly related to care needs (5).

Various studies have analyzed the effects of caregiving burden on caregivers of the elderly. Ay et al.'s study found that anxiety and depression levels of caregivers of the elderly were significantly high (5). Kalınkara and Kalaycı found that caregivers experienced 50% burnout, which increased as the maintenance load increased (6). Njoku's study on the effects of caregiving on caregivers' stress levels found that they were faced with not only stress but also depression, anxiety, anger, despair, and hopelessness (7). Similarly, Kim et al.'s study on caregivers of individuals with dementia found that caregiving burden led to depression and deterioration of their physical, emotional, psychological, and functional status (8).

The aims of elderly care include not only treatment but also improving the quality of life by maximizing their physical, mental, and psychological functional capacity, enabling them to be independent and healthy (9). However, the caregiving role may have both positive and negative effects on caregivers. The caregiving experience may provide a new perspective on life and access to social support, contribute to personal development, and improve self-esteem, satisfaction and the relationship between the elderly and their caregivers. However, there are many difficulties caregivers can experience (10).

Increases in the proportions of the elderly among their populations have led various countries to address the need of caregiving for the elderly. Home care for the elderly is among the most important problems. The government of the Turkish Republic of Northern Cyprus (TRNC) provides health and social services for the elderly through public and private nursing homes, rehabilitation centers, and residential homes. Despite these facilities, the responsibility of caregiving for the elderly mostly falls upon family members. If nurses support and encourage family members who carry the burden of caregiving, the quality of care may improve.

Identification of the problems related to caregiving for elderly people is essential to find solutions and improve the quality of elderly care. However, the number of studies defining the problems faced by family caregivers is limited. Factors that may affect the burden of care should be identified in order to determine possible problems and to take the necessary measures. Besides, identification of the burden of caregivers and taking the necessary steps may empower caregivers and increase their capacity to cope with the side effects of caregiving for elderly people.

This study is an attempt to answer the two questions: "What are the care burden levels of the caregiving families?", and "Is there a relationship between the descriptive characteristics of the caregiving families and their care burden levels?".

MATERIALS AND METHOD

Aim of the study

This descriptive study aims to identify the burden of caregivers of elderly people and the factors affecting their burden.

Population and sample

The population of the study consisted of families providing home care for 270 elderly people above the age of 60 who were registered to the elderly care unit of Yenierenköy Medical Center in the TRNC in 2017. The final sample comprised 242 family caregivers after excluding 15 Greek caregivers who did not know Turkish and 13 caregivers who refused to participate.

Inclusion criteria

Family caregivers who met the following inclusion criteria were included in the study:

- Providing home care to elderly family members who were at least 60
- Had spent at least three months living with the elderly people they cared for
- At least 18 years of age
- Able to communicate with the elderly people they cared for

Data collection tools

Descriptive questionnaire

The questionnaire prepared by the researchers included questions on the caregivers' descriptive characteristics such as gender, age, educational level,the marital status, number of children, income, chronic illnesses, and health status.

Zarit Burden Interview

The Zarit Burden Interview (ZBI), developed to evaluate caregiver burden (11), has 22 items scored on a five-point ordinal Likert-type scale (0: never, 1: rarely, 2: sometimes, 3: frequently, and 4: nearly always). Scores range between 0 and 88, with higher scores indicating higher social and emotional burden experienced by the caregivers. Evaluating the reliability and validity of the Turkish version of the ZBI, İnci and Erdem found a Cronbach's alpha of 0.95. In our study, Cronbach's alpha was 0.914 (12).

Data collection process

The data were collected between February and May 2017 through home visits. Prior to face-to-face interviews with the caregiving family members, we informed the participants about the aim and scope of the study and obtained written informed consent. The data collection process took about 15 minutes per participant.

Statistical analysis

The collected data were analyzed by SPSS version 24.0. In order to determine the hypothesis tests that will be used to compare the findings of the ZBI according to the descriptive characteristics of the caregiving families, we first analyzed the normality of the data distribution by Kolmogorov-Smirnov (significant: .046) and Shapiro-Wilk tests (significant: .001), Q-Q plot, and skewness and kurtosis values. Since the caregivers' ZBI scores did not follow a normal distribution, we used nonparametric hypothesis tests. We used the Mann-Whitney U test for independent variables with two categories and the Kruskal-Wallis (K-W) test for independent variables with more than two categories. In case there were differences between the independent variable categories on the K-W test, the Mann-Whitney U test was conducted to determine the category that caused the difference. $P<0.05$ was considered statistically significant.

Ethical dimensions

We obtained permission from the Scientific Research and Publication Ethics Board (approval number: 2016-3418) and TRNC Ministry of Health General Directorate of Basic Health Services. Informed consent was obtained from all participants. We obtained permission to use the ZBI from the author of the scale via e-mail.

RESULTS

Among the caregivers, 32.2% were between 31 and 40, 69.8% were female, 79.8% were married, and 30.2% were high school graduates. In addition, 52.5% of the participants were children of the elderly people they cared for and 58.3% had been providing home care for the elderly for six or more years. Further, 60.7% of the participants stated that their income was insufficient to meet their expenses, 83.5% had one or more children, and 28.2% had chronic illnesses.

The participants' average ZBI score was 36.92±17.33 and the scores ranged between 2 and 81 (Table 1). Analysis by age group revealed that the care burden of caregivers aged 30 or below was significantly higher than that of other age groups ($p<0.05$) (Table 2). However, we did not find any statistically significant relationship between the ZBI scores of the caregivers and their gender, marital status, educational level, relationship with the elderly, and time spent on elderly care ($p>0.05$). Besides, we found that caregivers whose income was not enough to cover their expenses and who did not have any children had a higher burden of care ($p<0.05$) (Table 2). Finally, the ZBI scores of the caregivers without any chronic illness were significantly higher than those of caregivers with chronic illnesses ($p<0.05$).

DISCUSSION

Studies on the burden of care for elderly people underline the negative effects of caregiving, including psychiatric and psychosomatic problems, stress, depression, and social isolation (13-15). Our study found that family caregivers obtained an average score of 36.92±17.33 on the ZBI, which indicates medium levels of burden (Table 2). Studies on Turkish caregivers of people with chronic illness found that they had low levels of burden (16-17). However, studies conducted on caregivers of elderly people found low to medium levels of burden (18,19). Compared to these, Loureiro et al.'s study found a high prevalence of burden (84.6%) among caregivers of elderly residents in Brazil (14). Similarly, Salama and El-Soud analyzed the burden of care among caregivers of the elderly and found that the majority of caregivers (63.9%) experienced severe burden (20). The difference between the findings of our study and those of others regarding the burden of care may be explained by two factors. Firstly, regular health and social services provided by the elderly care units of the municipalities in the TRNC may have decreased the burden of family caregiving for the elderly population. Secondly, Turkish people may consider elderly care an ethical duty rather than a burden. In order to verify these explanations, we need further studies that analyze the impact of Turkish cultural values on the caregiving role.

ZBI scores differed according to the characteristics of the caregivers. Our study

Table 1. ZBI scores obtained by the caregivers (N=242).

	n	$\overline{X}$	s	Min	Max
ZBI score	242	36.92	17.33	2	81

Table 2. Comparison of ZBI scores of caregiving families according to their descriptive characteristics (n=242).

Variable	**n**	$\overline{X}$	**s**	**Median**	**Mean Rank**	X^2	**p**	**Difference**
Age group								
30 and below	61	45.34	17.39	45.00	154.32	19.180	0.000*	1-2
31-40	78	32.44	15.77	31.50	103.78			1-3
41-49	43	35.56	17.73	35.00	115.91			1-4
50 and above	60	35.18	16.34	33.00	115.18			
Educational level								
No education	37	38.89	16.11	37.00	130.85	7.354	0.118	
Primary	66	31.97	15.05	29.00	101.80			
Secondary	38	39.11	18.04	36.00	129.53			
High School	73	38.90	18.03	38.00	129.39			
University	28	37.89	19.84	39.00	124.11			
Relationship with elderly								
Spouse	44	36.64	16.42	34.50	121.31	4.138	0.247	
Child	127	35.85	17.95	35.00	116.54			
Daughter-in-Law	47	36.66	15.52	35.00	121.43			
Other**	24	43.67	18.53	46.00	148.23			
Time spent on elderly care								
Less than one year	25	37.96	17.89	39.00	127.42	0.262		0.877
1-5 years	76	36.37	18.56	34.00	119.20			
6 years and above	141	37.04	16.65	35.00	121.69			
Gender								
Female	169	34.58	16.50	34.00	122.30		-0.234	0.815
Male	73	42.36	18.09	41.00	120.12			
Marital status							-0.408	0.683
Married	193	35.80	17.13	34.00	123.01			
Single	49	41.37	17.60	41.00	119.28			
Income								
Income matches expenses	95	32.17	17.05	32.00	103.29		-3.254	0.001*
Income does not match expenses	147	40.00	16.87	37.00	133.27			
Having a child								
Yes	202	35.56	17.05	34.00	115.98		-2.757	0.006*
No	40	43.80	17.34	43.50	149.38			
Having a chronic illness								
Yes	92	32.22	15.27	30.50	103.08		-3.206	0.001*
No	150	39.81	17.93	39.00	132.80			

*p<0.05 ** Aunt, uncle etc.

found that ZBI scores of participants below the age of 30 were significantly higher than those of participants from other age groups. Against our findings, Öksüz et al.'s study on caregivers of chemotherapy patients found that ZBI scores did not vary according to age groups (21). However, Salama ve El-Soud found that older caregivers had a higher perception of burden (20). Contrary to the literature, we found that perceived burden was higher for younger caregivers. This finding may be related to the tensions between the expectations of the younger caregivers and the difficulties of caregiving, lack of knowledge and information, and the conflict between the burden of working and caregiving. Besides, limitations in the social life of younger caregivers and their social isolation may have led to a higher perception of burden.

The literature suggests that educational status is an important factor that determines the perceived burden of care. Orak and Sezgin found that caregivers with lower educational status faced problems while receiving help from health professionals regarding caregiving (22). Salama and El-Soud's study found that burden of care decreased parallel to the decrease in caregivers' educational status (20) Contrary to this, Loureiro et al.'s study in Brazil found that burden of care was higher for caregivers with lower educational status (14). However, our study did not find any association between the educational status of caregiving families and burden of care ($p>0.05$) (Table 2). Similarly, various studies on Turkish caregiving families found no association between caregivers' educational status and their perceived burden of care for the elderly (17, 22, 23).

Various international studies found that insufficient financial resources are among the key factors that affect burden of care for elderly people (14, 24). Our study found that burden of care was higher for the caregivers whose income did not match their expenses. In a similar vein, Yeşil, Uslusoy and Korkmaz's study on caregivers of patients with chronic illness found a negative relationship between burden of care and income status (23). Two further studies conducted in Egypt and Pakistan found that caregivers' insufficient financial resources are inversely related with their perceived burden of care (20,24). Caregivers with lower income may face difficulties in meeting the costs of family caregiving or may not be able to access financial resources. This, in turn, increases the perceived burden of care and stress among caregivers.

Our study found that family caregivers without children had higher ZBI scores ($p<0.05$) (Table 2). Similarly, Özdemir, Şahin and Küçük's study found a statistically significant relationship between the number of children a caregiver had and the burden of care (25). Having a child may be considered a means of socialization. Therefore, caregivers of elderly people who do not have a child may perceive themselves as isolated. Besides, caregivers who prioritize providing care for elderly people may neglect their personal lives. This, in turn, may result in a perception of burden of care.

In our study, 71.8% of the caregiving families did not have any chronic illness. We found that ZBI scores were higher for caregivers without chronic illnesses ($p<0.05$). However, two studies on the burden of caregivers in Turkey found that caregivers with health problems experienced a higher burden of care (17). This difference may be explained with reference to the possibility that caregivers without health problems may feel insufficiently equipped to cope with illness owing to a lack of personal experience. On the contrary, caregivers with chronic illness may be more experienced to cope with not only their problems but also those of the elderly. However, further studies with a higher number of participants should be conducted in order to verify our explanation and make a substantial contribution to the literature.

Based on our findings, we can conclude that the analysis of factors that influence the burden of caregiving and personalized support provided to caregivers may reduce the burden of care on caregivers of elderly people. Sociodemographic and economic characteristics of caregivers may have an important effect on the management of care provided to elderly people. We suggest the requirement of the development of new policies and guidance services that target younger caregivers and those with lower income. Finally, further studies must analyze the impact of burden of care on the quality of caregiving.

CONFLICT OF INTEREST

The authors declare no conflict of interest related to this study.

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