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Research Article

The Experiences of Mothers With Bedbound Children: Care Burden

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Abstract

This study was carried out to evaluate the problems experienced by mothers with bedridden children and to determine the effects of care burdens on mothers.

The study was carried out on mothers who had a bedridden child who was in the Neurology Service between November 2016 and May 2017. The data were collected through a 19-question introductory form and the caregiver burden scale developed by Zarit. The data were evaluated using a computer. In statistical analysis, t-test, analysis of variance and chi-square test were used in independent samples. A p-value less than 0.05 was considered statistically significant.

The moderate age of 200 mothers participating in the study was found to be 30.8 ± 7.0 years, and the moderate care burden score was found to be 35.1 ± 24.3 , and it was evaluated as mild to moderate. It was found that the younger the mother's age and the age of the child cared for, the greater the burden of care, and the longer the duration of care, the higher the burden of care. Being widowed, having a job and not having social security are factors that increase the burden of care. The effect of all these variables on burden of care was not statistically significant. The main problems that mothers experience while providing care are psychological problems and musculoskeletal problems.

In order to minimize the burden of care for mothers with bedridden children, other family members should be included in the care, and parents should be supported psychologically.

Keywords: Bedbound, Care Burden, Care Burden Scale.

Yatağa Bağımlı Çocuğa Sahip Annelerin Yaşadıkları Bakım Yüğü

Öz

Bu çalışma, yatağa bağımlı çocuğa sahip annelerin yaşadıkları sorunları değerlendirmek ve bakım yüklerinin annelere etkilerini belirlemek amacıyla gerçekleştirilmiştir.

Araştırma, 2016 Kasım-2017 Mayıs tarihleri arasında Nöroloji Servisinde yatan ve yatağa bağımlı çocuğa sahip olan annelerde gerçekleştirildi. Veriler 19 soruluk tanıtıcı form ve Zarit tarafından geliştirilen bakım verme yükü ölçeği aracılığıyla toplandı. Veriler bilgisayar yardımıyla değerlendirildi. İstatistiksel analizde bağımsız örneklerde t testi, varyans analizi ve ki kare testi kullanıldı. $P < 0,05$ değeri istatistiksel olarak anlamlı kabul edildi.

Araştırmaya katılan 200 annenin yaş ortalaması 30.8 ± 7.0 yıl, bakım yükü puan ortalaması 35.1 ± 24.3 bulunmuş ve hafif orta düzeyde olarak değerlendirilmiştir. Anne yaşı ve bakım verilen çocuğun yaşı ne kadar genç ise bakım yükünün o kadar arttığı, bakım verilen süre arttıkça bakım yükünün arttığı tespit edilmiştir. Annenin dul olması, bir işte çalışıyor olması ve sosyal güvencesi olmaması, bakım yükünü arttıran faktörlerdendir. Tüm bu değişkenlerin bakım yüküne etkisi istatistiksel olarak anlamlı bulunmamıştır. Annelerin bakım verme sırasında yaşadıkları başlıca sorunlar psikolojik problemler ve kas/iskelet sistemi sorunlarıdır.

Yatağa bağımlı çocuğa sahip annelerin bakım yükünü en aza indirmek için diğer aile üyelerinin de bakıma katılması sağlanmalı, ayrıca ebeveynler psikolojik açıdan desteklenmelidir.

Anahtar kelimeler: Bakım Yüğü, Bakım Yüğü Ölçeği, Yatağa Bağımlılık.

INTRODUCTION

Bedbound can be defined as the inability of the individual to perform some or all of the activities of eating, dressing, moving, meeting bathroom and toilet needs. A bedbound person cannot often perform communication activities (Zaybak et.al., 2012).

Individuals become bedridden due to some diseases, congenital anomalies, accidents, traumas and abuse (Demir and Aysoy, 2009). In addition to those who receive care due to being bedridden, caregiving personnel or family members also experience various difficulties. According to research studies, the family members who provide care are sleep deprived, have financial difficulties, cannot adequately care for themselves and other family members, and therefore experience a sociocultural burden.

In addition, the insufficient knowledge of caregiving family members about caregiving causes additional health problems for those given home care shortening their quality of life and duration (Bahar and Parlar, 2007; Yıldız et. al., 2016; Işık and Erci, 2018). There are various scales prepared to assess the burden caused by bedbound patients (İnci and Erdem, 2008; Pandey et.al., 2019). However, it is also noted that these burdens may differ in the cultural characteristics of societies.

Families with bedbound children often take on the role of primary care. They take a large part in the care that will be given to the child. Maintaining treatment and care needs for such children can be challenging. Families may be adversely affected physically and mentally while providing care to the child. Families may experience problems such as social isolation, burnout, inadequacy and fatigue (Yotani et.al, 2014; Brehaut ve et.al., 2004). This study was carried out to evaluate the problems experienced by mothers with bedbound patients children and to determine the effects of care burdens on mothers.

METHODS

Type of Research

This study was conducted as a descriptive research.

Sample Group

The study was carried out on mothers who were hospitalized in Erciyes University Children's Hospital, Pediatrics Neurology Service in Kayseri between November 2016 and May 2017 and had a bedbound patients child. The universe of the study consists of the mothers of the children who were hospitalized (N= 290) between these dates. In this study, it was aimed to reach the entire universe, not choosing a sample. A total of 90 mothers did not agree to participate in this study, and the study was completed with 200 mothers who agreed to participate in this study.

Data Collection

In order to evaluate the burden of caregivers to individuals in need of care, a 19-question descriptive form was created by the researchers using the caregiver burden scale developed by Zarit et al. by reviewing the literature. The data was collected with the help of a scale developed by İnci et al whose Turkish translation, validity and reliability analyses were performed by İnci and Erdem (2008) .

The scale consists of 22 statements that determine the effect of caregiving on an individual's life. The scale is evaluated as "never", "rarely", "sometimes", "often", "always" using the 5-point Likert scale, and the scores are obtained by giving points ranging from 0 to 4, respectively. Total score is evaluated as 88-61 severe burden, 60-41 average severe, 40-21 mild- average, those less than 21 are considered as little or no burden, high scale score indicates that the problem experienced is high. The highest score is 88, the minimum is zero.

In this study, Cronbach alpha value of the Care Delivery Burden Scale was found to be 0.65. In the study where İnci and Erdem (2008) evaluated the difficulties experienced by the caregivers of the elderly, the Cronbach Alpha internal consistency coefficient was found to be 0.95.

Data Analysis

Data were analyzed by using SPSS statistical software version 20.0 on Windows. In statistical evaluation, Chi-square test was used for comparison of qualitative data, t-test and analysis of variance were used for comparison of quantitative data, and $p < 0.05$ was considered significant.

Ethical Consideration

The research was carried out in accordance with the Declaration of Helsinki. Ethics committee approval was obtained from Erciyes University clinical research ethics committee before starting the study. In addition, voluntary informed consent forms were filled out by mothers who agreed to participate in the study (Decision no: 20161600/ Date: 18.11.2016).

RESULTS

The moderate age of the mothers that participated in the study was 30.8 ± 7.0 . It was found that most of the mothers were primary school graduates (41.5%), not working (87.5%) and housewives (89.5%). The mothers do not have social security (28.0%), stated that their income is less than their expenses (47.5%). The mothers are not satisfied with care (2.5%) and the mothers only have received training in caregiving (17%).

The mothers have a chronic disease (11.5%). It was found that 23.5% of the health problems occurred during the care, and the health problems that occurred were psychological problems (40.4%) and low back pain/herniated disc (38.3%).

When the care giving periods of the caregivers were examined, it was found that 73% of them gave care for less than 5 years. The proportion of those who provided daily care over 8 hours is 84.0%. It was found that 42.5% of the caregiving mothers received help while giving care and the majority of those who helped them (44.7%) were their mothers. Mothers' moderate score of care burden was found to be 35.1 ± 24.3 and it was determined to be mild to average.

As the age of the caregiving mothers increased, the burden of care decreased, but the difference was not statistically significant ($F=1.796$ $p=0.169$). Care burden decreased as the number of children in the family increased ($F= 0.456$ $p=0.634$). It was found that as the number of sick children in the family increased, the burden of care increased ($F=1.082$ $p=0.341$).

It was found that as the age of the sick child reduces, the burden of care increases ($F=0.660$ $p=0.518$). It was observed that as the duration of care for the sick child decreased, the burden of care also decreased ($F=0.266$ $p=0.767$). It was found that as the number of hours of taking care of the patient daily decreased, the burden of care decreased ($F=0.406$ $p=0.667$). The difference between these variables was not statistically significant (Table 1).

Table 1. Comparison of Socio-Demographic Characteristics According to Moderate Care Burden Score

Socio-Demographic Features	No maintenance burden (Number = 13)	Mild to moderate maintenance burden (n = 125)	Moderate care burden (n = 62)	Statistical assessment	
	Mean \pm SD*	Mean \pm SD*	Mean \pm SD*	F	p
Age	33.77 \pm 6.88	30.20 \pm 6.95	31.32 \pm 7.15	1.796	0.169
Number of children	2.54 \pm 1.13	2.26 \pm 0.97	2.27 \pm 1.074	0.456	0.634
Number of sick children	1.00 \pm 0.00	1.04 \pm 0.19	1.08 \pm 0.27	1.082	0.341
Sick child age	6.54 \pm 5.64	5.21 \pm 4.29	5.12 \pm 3.43	0.660	0.518
Patient care time	3.54 \pm 3.97	4.32 \pm 3.85	4.24 \pm 3.21	0.266	0.767
Daily maintenance hour	17.85 \pm 7.23	19.26 \pm 7.38	18.42 \pm 7.67	0.406	0.667

* Arithmetic mean and standard deviation

Considering the care burden scores of the mothers participating in the study according to their age groups in Table 2, it was found that the mild to average care burden was higher in the 25 and below age group and the difference between the groups was not statistically significant ($p > 0.05$).

Considering the care burden scores of the mothers participating in the study, it was found that the mild to average care burden was higher in those who graduated from primary school, but there was no significant difference between the groups ($p > 0.05$). Considering the care burden scores of the caregiving mothers according to their marital status, it was found that the mild to average care burden was higher in the widows and the difference between the groups was not statistically significant ($p > 0.05$). When the care burden scores of the mothers participating in the study were examined, it was found that the mild to average care burden was higher in the employees, but the difference between the groups was not statistically significant ($p > 0.05$) (Table 2).

Table 2. Comparison of Care Burden Scores According to the Socio-Demographic Characteristics of Caring Mothers

Socio Demographic Feature		No Maintenance Burden	Mild to Moderate Maintenance Burden	Moderate Care Burden	Statistical assessment	
		Number (%)	Number (%)	Number (%)	χ^2	p
Age	25 and below	2 (3.0)	46 (69.7)	18 (27.3)	3.082	0.214
	Over 25	11 (8.2)	79 (59.0)	44 (32.8)		
Education Status	Primary school	5 (6.0)	50 (60.2)	28 (33.7)	7.361	0.289
	Middle School	4 (6.7)	38 (63.3)	18 (30.0)		
	High school	2 (4.2)	30 (62.5)	16 (33.3)		
	University	2 (22.2)	7 (77.8)	0 (0.0)		
Marital status	Married	12 (6.7)	110 (61.8)	56 (31.5)	2.902	0.574
	Widow	1 (11.1)	7 (77.8)	1 (11.1)		
	Divorced	0 (0.0)	8 (61.5)	5 (38.5)		
Working Status	Yes	1 (4.0)	16 (64.0)	8 (32.0)	0.294	0.863
	No	12 (6.9)	109 (62.3)	54 (30.9)		
Profession	Housewife	12 (6.7)	111 (62.0)	56 (31.3)	5.712	0.222
	Officer	1 (8.3)	10 (83.3)	1 (8.3)		
	Worker	0 (0.0)	4 (44.4)	5 (55.6)		

Social security	Having	10 (6.9)	87 (60.4)	47 (32.6)	0.959	0.619
	Not having	3 (5.4)	38 (67.9)	15 (26.8)		
Income status	Less than income	4 (4.2)	57 (60.0)	34 (35.8)	3.201	0.525
	Income is equal to expenses	8 (9.0)	57 (64.0)	24 (27.0)		
	More than income	1 (6.3)	11 (68.8)	4 (25.0)		

When the care burden scores of the mothers participating in the study were compared according to the status of receiving help while giving care, the mild to average care burden rate was found to be higher in those who did not receive help while providing care, but the difference between the groups was found to be statistically insignificant. Considering the care burden point rates of the mothers who participated in the study, the rate of mild to average care burden was found to be higher in those who did not receive training for care, and the difference between the groups was not statistically significant ($p > 0.05$) (Table 3).

Table 3. Comparison of Care Burden Scores According to Care Giving Features of Care Giving Mothers

Care Features		No Maintenance Burden	Mild to Moderate Maintenance Burden	Moderate Care Burden	Statistical assessment	
		Number (%)	Number (%)	Number (%)	χ^2	p
Having a Separate Room	Yes	2 (3.4)	41 (69.5)	16 (27.1)	2.307	0.316
	No	11 (7.8)	84 (59.6)	46 (32.6)		
Giving Care	Satisfied	13 (6.7)	120 (61.5)	62 (31.8)	3.077	0.215
	Not Satisfied	0 (0.0)	5 (100.0)	0 (0.0)		
Assistance in Giving Care	Receive	6 (7.1)	54 (63.5)	25 (29.4)	0.169	0.919
	Does not receive	7 (6.2)	70 (61.9)	36 (31.9)		
Maintenance Training Status	Yes	1 (2.9)	24 (70.6)	9 (26.5)	1.498	0.473
	No	12 (7.2)	101 (60.8)	53 (31.9)		

The mild to average care burden rate was found to be higher in patients with chronic disease when examining a chronic disease status according to the care burden scores, but the difference between the groups was not statistically significant ($p > 0.05$) (Table 4).

Table 4. Comparison of Care Burden Scores According to Health Features of Mothers Giving Care

Health Features		No Maintenance Burden	Mild to Moderate Maintenance Burden	Moderate Care Burden	Statistical assessment	
		Number (%)	Number (%)	Number (%)	χ^2	p
Chronic Illness	Yes	1 (4.3)	17 (73.9)	5 (21.7)	1446	0485
	No	12 (6.8)	108 (61.0)	57 (32.2)		
Health problem	Formed	4 (8.5)	29 (61.7)	14 (29.8)	0418	0812
	No Occurrence	9 (5.9)	96 (62.7)	48 (31.4)		

DISCUSSION

The child's dependence on the bed can cause emotional, social and economic problems, disruption of the relationship between the spouses and affect the family life. In this study, the effect of care burden on family life was evaluated by interviewing 200 mothers who had bedbound patients children.

In the study, care burden scale was used to determine the care burden of mothers who care for the bedbound patients child. In the evaluations about the care burden, the care burden scale mean score was found to be mild (35.1 ± 24.3). In the studies conducted by Zaybak et al. on the patients' relatives in the orthopedics, physical therapy and neurology service, the care burden scale mean score was found to be 24.91 ± 7.05 . The probable reason for having a lower moderate score compared to this study may be that in the study of Zaybak et al. (2012), care is usually given for certain hours, while there is no such time limit in this study. In the study conducted by Özdemir et al. (2009), on mothers with cancer children, the mean care burden score was found as 21.26 ± 12 . According to this study, the lower moderate burden score is probably due to the fact that fewer people were enrolled in the study and the duration of care was different.

In the study of Tang et al. (2013) on caregivers for demented patients, the mean score of the care burden scale was found to be 26.6. Possible reasons for this lower moderate compared to this study may be due to more mobilization of dementia patients and shorter maintenance times. In the study conducted by Fertelli and Tuncay (2019) on the caregivers of stroke patients using the same scale, the mean burden of care was found to be 36.2. As a probable result of the characteristics of the research group in this study being similar, the mean load score like our study was found.

In our study, it was found that 97.5% of the caregiving mothers were satisfied with the care. In the study conducted by Alpteker (2008) with caregivers for patients aged 65 and over, 88.4% of the caregivers were satisfied. According to the study of Alpteker, the high rate of satisfaction may be due to the fact that the mothers in our study tolerate the problems more easily because they care for their own children.

It was found that 57.5% of the mothers with a bedbound patients child did not receive any assistance while providing care, and 73% gave care for 1-5 years. Akyar and Akdemir (2009) found that 50% of caregivers provided care for 1-5 years in their study on caregivers of Alzheimer's patients. Care time in the elderly is shorter than the care periods given to children, probably because the care delivery process is shared (Zaybak et.al., 2012). The results of the study are in line with the findings of this study, but 78% of them got help while giving care which differs with our study. This difference is probably because there are more sources of support during the care given to the elderly. In the literature, there is a study showing that the social support systems of Turkish society are strong and the care burden given to the elderly is shared (Fertelli and Tuncay, 2019). While the support resources in the care to be given to children are limited only to the immediate environment of the parents, these resources are more diverse in the care to be given to the elderly.

The nursing mothers stated of 11.5% that they had a chronic disease. It was found that 23.5% of health problems occurred as a result of providing care, and psychological problems (40.4%) were the most common health problems. Akyar and Akdemir (2009) found that 66% of caregivers had a diagnosed disease in a study they conducted on caregivers of Alzheimer's patients. Alpteker (2008) found that 69.4% of the caregivers had no disease in their study with caregivers aged 65 and over. Tuna and Olgun (2010), in their study on their relatives caring for stroke patients, stated that 51.8% of the caregivers of stroke patients were negatively affected and 57% of them had physical or psychological health problems.

In this study, compared to other research results, the low rate of chronic disease and health problem resulting from care may be due to the low moderate age of the mothers (30.78 ± 7.037). While the caregivers of the elderly are generally at an older age, the moderate age of the mothers who care for their children is smaller and therefore the chance of chronic disease is reduced.

In our study, it was found that as the age of the sick child decreases, the burden of care increases, but the difference was not statistically significant. In a study conducted by Tel et al. (2012) on caregivers of chronic obstructive pulmonary disease patients, they found that as the age of patients increased, the burden of care increased. The result of this study differs with our research. This difference is thought to be due to the low moderate age of the mothers in our study and not having sufficient information about care. In our study, it was found that caregivers in the age group 25 and below had a mild to average care burden, but the difference between the groups was not statistically significant. In the study conducted by Şahin et al. (2009), care burden was found to be higher in the 18-27 age group compared to the other groups, but the difference between the groups was not statistically significant. Our study is in line with this research. In Tülüçe's (2012) study on caregivers of patients with heart failure, it was found that age groups and care burden affect each other and the burden of care increases as age increases. In the research conducted by Remier et al. (1998) on caregivers of stroke patients, it was found that care burden increased with age. In our study, it is thought that the fact that the burden of care is higher in the young age group is caused by the lack of sufficient knowledge and experience of the youth.

When we examined the care burden scores of mothers according to their education status, the mild to average care burden was found to be higher in those who graduated from primary school, but the difference was not statistically significant. In the study conducted by Mollaoğlu et al. (2011), it was found that uneducated individuals had a higher care burden and the difference between education level and care burden was found to be significant. The result of this study is in line with the results of this research. It is thought that this result is due to the insufficient knowledge level of primary school graduates.

In the observation made according to the marital status of the mothers participating in the study, the mild to average care burden was higher in widowed individuals, but the difference between the groups was not statistically significant. The reason why it is high in the widows is that while married people support each other while giving care, widows are thought to be providing care alone. Ma et al. (2014) also showed that the care burden was less in areas of spouse support during care.

In our study, it was found that the mild to average burden was high in those without social security, but the difference between the groups was insignificant. Koçak (2011) found that caregiver burden is higher in individuals who do not have social security in their study of caregivers with stroke patients. Ma et al. (2014) showed that in patients with spinal cord injuries, the burden of care was less in those with social security.

In our study, it was found that mild to average care burden was high in mothers who did not receive help while giving care to their bedbound patients children, but the difference between the groups was found to be statistically insignificant. In a study conducted by Bugge et al. (1999) with caregivers of stroke patients, it was found that caregivers received assistance in care from their family members.

In our study, mild to average care burden was found to be high in mothers with health problems, but the difference between the groups was not statistically significant. In the study of Aşiret (2011) on caregivers of stroke patients, the burden of care was found to be high in those without health problems. The results of this study differ from the findings of our study. The probable reason for this is that the moderate age of the people in the study groups is different.

CONCLUSION

As a result, it was determined that the burden of care was higher for mothers aged 25 and under, widowed and who did not receive help while providing care. The most psychological disorders occur in mothers who have health problems as a result of caregiving, as the age of the sick child decreases, the burden of care for mothers increases.

Suggestions

In order to minimize the burden of care for mothers with bedbound children, other family members can be supported to participate in care. Mothers with bedbound children can be directed to care education programs together with other family members who can participate in care in order to increase the low rate of information about caregiving.

In order to prevent mothers from blaming themselves for their child's condition and to ensure unity and solidarity among family members, it may be recommended to receive family education and psychological support for both parents. Since the CDBS used in the study was used on adults in previous studies, this scale may not be suitable for children. It may be recommended that CDBS be developed for children.

Limitations

This study has limitations, because only participants of Erciyes University Hospitals were included to study. The inaccessibility of the study data on children in the literature constitutes the limitation of the research.

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