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Interaction between the Caregiver Burdens and Spiritual Orientations of the Families of Children Receiving Home Care Services

Evde Sağlık Hizmeti Alan Çocukların Ailelerinin Bakım Veren Yükleri ve Manevi Yönelimleri Arasındaki Etkileşim

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Abstract

Objective: The permanent nature of possession of children receiving home care services (HCS) can represent a severe caregiver burden for parents. The purpose of this study was to examine the relationship between these parents' caregiver burdens and spiritual orientation.

Materials and Methods: The parents of 118 children receiving HCS participated in this cross-sectional, descriptive study. Data were collected using a Sociodemographic Information Form, the Spiritual Orientation Scale (SOS), and the Zarit Caregiver Burden Scale (ZCBS).

Results: The mother was the caregiver for 39.8% of the children receiving HHS, while both parents provided care for 55.9%. Income was lower than expenditure among 65.3% of caregivers, and 80.5% were housewives. The parents of children aged 1-6 years exhibited lower spiritual orientation levels and a higher caregiver burden than those with older children. Spiritual orientation levels were higher among parents with low education levels and income lower than expenditure.

Conclusion: Parents with high spiritual orientation scores were found to perceive a lower caregiver burden. This indicates the need for activities aimed at providing spiritual support for parents.

Keywords: Caregivers, Caregiver Burden, Home Care Services.

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Öz

Amaç: Evde sağlık hizmeti (ESH) alan çocuklara sahip olmak bu durumun geçici olmaması ebeveynler için ciddi bakım yükü oluşturabilir. Çalışmada bu ebeveynlerin yaşadığı bakım yükü ile manevi yönelim arasındaki ilişkiyi incelenmesi amaçlamaktadır.

Gereç ve Yöntemler: Kesitsel tamamlayıcı çalışmaya 118 ESH alan çocuğun ebeveyni katılmıştır. Verilerin toplanmasında "Sosyodemografik Bilgi Formu", "Manevi Yönelim Ölçeği (MYÖ)", "Zarit Bakım Veren Yük Ölçeği" (ZBYÖ) kullanıldı.

Bulgular: Evde bakım hizmeti alan çocukların %39,8'nin bakım vereni sadece anne olup hem anne hem babanın bakım verme oranı %55,9 idi. Bakım verenlerin %65,3'nün geliri giderinden az, %80,5'i ev hanımı idi. Bir-altı yaş arası çocuğu olan ebeveynlerin daha büyük yaş grubunda çocuğu olanlara göre daha düşük manevi yönelim düzeylerine ve daha yüksek düzeyde bakım yüküne sahip oldukları belirlendi. Eğitim durumu düşük geliri giderinden az olan ebeveynlerin manevi yönelim düzeyleri yüksekti.

Sonuç: Araştırmada manevi yönelim puanı yüksek olan ebeveynlerin daha az bakım yükü algıladıkları ortaya çıktı. Bu bulgular ebeveynlere manevi destek sağlamaya yönelik etkinliklerin uygulanmasının gerekliliğini ortaya koymaktadır.

Anahtar Kelimeler: Bakım Veren, Bakıcı Yükü, Evde Bakım Hizmetleri.

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Introduction

An individual who cares for someone with difficulty in performing daily living activities due to a physical or mental disorder is known as a 'caregiver' (1). Disease survival times and average life expectancy have increased in line with advances in technology, the improvement of health services, and easier access to such services, and this has in turn led a rise in the numbers of individuals in need of care (2). Home care services (HCS) are a service provided by health personnel within the home for patients and relatives and are intended to increase patients' quality of life (3).

Children as well as adults receive HCS, and the concept of the caregiver is also an important one for these patients (3). Care services are not limited to providing medication and maintenance of treatment in terms of health, but also involve meeting personal care needs, such as washing and using the toilet. Despite entailing positive aspects such as increasing emotional communication with patients and providing psychosocial satisfaction, HCS also involve various downsides and difficulties (1,4). The physical and psychological health of parents must also be preserved while the child's needs are being met (5).

Studies have shown that the caregiver burden emerges as a multidimensional reaction resulting from psychological, physical, emotional, social, and economic problems deriving from caregiving (6). Adverse factors such as burnout-like states, a gradual decline in physical health, and depression may be seen because of long-term caregiving (6, 7).

HCS improves patients' quality of life by allowing them to live independently in their own living areas. Although the difficulties faced by the parents of children receiving this service are well-known, there are still gaps concerning effective strategies for overcoming them. The purpose of this study was to examine the relationship between spiritual orientations and the caregiver burden in parents of children receiving HCS. Examining the role of spiritual orientation in the context of difficulties encountered by the parents of these children, who may be described as 'special,' can yield valuable information for future research and play an effective role in meeting families' needs.

Materials and Methods

Pediatric patients registered with the HCS unit of a tertiary training and research hospital were included in this descriptive, cross-sectional study. The study was approved by the University of Samsun non-interventional Clinical Research Ethical Committee (date: 20.02.2023 and approval number: SÜKAEK-2023-4/8). Caregivers were contacted by telephone and informed about the aim of the study. Verbal consent was obtained from parents of children aged 0-18 registered with the HCS system and who agreed to participate. One hundred twenty-four parents of 181 patients registered with the HCS consented to take part. However, six parents were excluded due to deficient responses to questions or communication problems. Sample calculation performed using OpenEPI showed that 105 individuals would be sufficient with a 99.90% confidence interval and a 5% margin of error.

The first part of the research involved a sociodemographic information form investigating data such as age, sex, education, marital status, profession, number of years spent as a caregiver, the age of the child, presence of a diagnosed disease, and the number of drugs used.

The second part consisted of the Zarit Caregiver Burden Scale (ZCBS) developed in 1980 by Zarit, Reever, and Bach-Peterson. This 22-item scale is used to evaluate stress experienced by the caregivers of the elderly or others needing care. It employs a four-point Likert-type scale – never, rarely, often, or almost always (1). The reliability and validity study of the Turkish-language adaptation was performed in 2008 by İnci and Erdem (8). Possible scores range between 0 and 88, with higher scores indicating greater distress (1).

In the third part, the Spiritual Orientation Scale (SOS) was employed as a data collection tool. The SOS was developed by Kasapoğlu in 2015 for the purpose of evaluating the individual's spiritual orientations. A scale consisting of 16 items and a single dimension emerged as a result of validity and reliability studies. The lowest possible core on this seven-point Likert-type scale is 16, and the highest is 112. Higher scores indicate higher spiritual orientation (9).

Statistical Analyses

Statistical analysis was performed on Statistical Package for the Social Sciences for Windows version 20.0 software. Descriptive analyses were employed in data distribution and frequency analyses. Chi-square tests were applied to determine relationships between the caregiver burden and parameters such as patients' diagnoses, economic status, education levels, and the sex of the caregiver. Normality analysis was applied to continuous variables. Normally distributed data were analyzed using Pearson's correlation analysis and non-normally distributed data using Spearman's correlation analysis. The independent t-test was used to compare the means of two independent groups, and one-way analysis of variance (ANOVA) for comparing means of more than two independent groups. P values <0.05 were regarded as significant for all analyses.

Results

The parents of 118 children registered in the HCS system were included in the study. The mother alone was the caregiver for 41.6% of children receiving HCS, and both the father and mother for 56.9%. Mean ages were 30 ± 7.3 years (min 22, max 60) for the mothers and 41.2 ± 7.3 years (min 25, max 65) for the fathers. Thirty-nine percent of the participants were elementary school graduates and 18.6% were university graduates, while housewives represented the largest occupational group (80.5%). Analysis showed that 65.3% of parents regarded their income as lower than their expenditure. A chronic disease was present in 26.3% of the parents taking part in the survey. The mean age of the children receiving care was 10.4 ± 4.4 years (min 1, max 17). Analysis of causes of sequelae showed that 93.2% of patients had a congenital disease, the most common being cerebral palsy (34.7%).

Tracheostomy cannulae were present in 12.7% of the patients, and 7.6% were attached to a domestic-type ventilator. Percutaneous gastrostomy catheters were present in 5.1% of patients. In addition, 53.4% of the children receiving HCS were also receiving special education, and 43.2% were receiving physiotherapy exercises from a physiotherapist. Parents reported good oral hygiene at a level of only 32.2%, and 41.3% of patients were using four or more drugs. All recipients of HCS received a monthly home care support payment. The demographic data of the participants and the children receiving HCS are shown in Table 1.

Table 1

The Participants' Demographic Data

	N	%
Gender		
Male	64	45.8
Female	54	54.2
Special education		
Yes	63	53.4
No	55	46.6
Type of sequelae		
Congenital	110	93.2
Acquired	8	6.8
Individuals caring for the child		
Mother+Father	66	56.9
Mother only	49	41.6
Father only	3	2.5
Child's disease		
Cerebral Palsy	41	34.7
Metabolic Diseases	22	18.6
Congenital CNS deformities (Spina Bifida, CNS Defects/Microcephaly)	14	11.9
Refractory Epilepsy / Epileptic Encephalopathy	11	9.3
Chromosomal Diseases	10	8.5
Muscular Diseases (Duchene Muscular Dystrophy/Spinal Muscular Atrophy)	6	5.1
Post-Infection/Intoxication	5	4.2
Congenital Heart Diseases	4	3.4
Non-Vehicle Traffic Accident/Trauma	3	2.5
Chronic Pulmonary Diseases	2	1.7

Marital Status		
Married	115	97.5
Divorced	3	2.5
Duration of weekly care		
Certain days a week	2	1.7
Every day	116	98.3
Place of residence		
City	83	70.3
Outlying district	22	18.6
Small town-village	13	11.0
Education		
Elementary school	46	39.0
Middle school	20	16.9
High school	30	25.4
University and above	22	18.6
Employment status		
Mother+Father	8	6.8
Father only	85	72.0
Mother only	1	0.8
Both unemployed	24	20.3
Occupation		
Housewife	95	80.5
White collar	6	5.1
Self-employed	9	7.6
Health worker	3	2.5
Education/training	2	1.7
Private sector	3	2.5
Income		
Income less than expenditure	77	65.3
Income equal to expenditure	35	29.7
Income exceeding expenditure	6	5.1
Number of children in the home		
1	14	11.9
2	51	43.2
3	41	34.7
>=4	12	10.1
Home owner		
Yes	51	48.3
No	61	51.7
Presence of tracheostomy		
Yes	15	12.7
No	103	87.3
Domestic type ventilator		
Yes	9	7.6
No	109	
Percutaneous gastrostomy		
Yes	6	5.1
No	112	94.9
Number of drugs used		
0	16	13.6
1	16	13.6
2	15	12.7
3	22	18.6
4	15	12.7
5	14	11.9
6	9	7.6
>=7	11	9.1
Chronic disease in caregiver		

Yes	31	26.3
No	87	73.7
Physiotherapy		
Yes	51	43.2
No	67	56.8
Oral hygiene		
Yes	38	32.2
No	80	67.8

The present study examined the relationships between the sociodemographic features of the parents of children receiving HCS and their spiritual orientations and caregiver burden. The results showed that the parents of children aged 1-6 years had lower spiritual orientations than those of parents of children in the older age group (F= 3.288, p = 0.041) and a greater caregiver burden (F = 8.139, p=0.000). Mothers with a low level of education also exhibited higher levels of spiritual orientation (KW = 3.007, p= 0.033), but no significant association was observed with caregiver burden (KW=0.333, p=0.801) (Table 2). A high caregiver burden was also detected in the parents of children with sleep disorder (KW = 31.088, p= 0.000), but no significant difference was observed between their SOS scores (KW=0.573, p=0.565). Parents with income lower than expenditure registered low ZCBS scores (KW=3.337, p=0.039) and significantly high spiritual orientation scores (KW=3.188, p=0.045). Significant elevation in SOS scores was observed in the parents of children with good oral hygiene compared to those without (KW=5.177, p=0.025). Number of children, special education, performing physiotherapy exercises at home, and the presence of tracheostomy had no effect on the ZCBS or SOS. However, the families of children with percutaneous gastrostomy registered low ZCBS scores.

Table 2

Relationships Between Sociodemographic Findings and The SOS and ZCBS

	ZCBS		SOS	
	Mean+SD	Test (p)	Mean+SD	Test (p)
Child age group				
1-6 years	54.68±12.92	8.139 (.000)	64.92±13.99	3.288 (.041)
7-12 years	52.49±13.31		68.68±14.19	
13-17 years	43.54±11.63		73.59±13.30	
Maternal age group				
20-35 years	50.53±13.44	0.124 (.883)	69.02±13.16	0.104 (.902)
36-45 years	49.17±14.29		70.24±15.67	
46-60 years	49.77±10.79		69.10±11.33	
Education status				
Elementary school	48.52±13.84	0.333 (.801)	74.21±14.35	3.007 (.033)
Middle school	49.85±13.95		68.60±13.62	
High school	50.05±12.77		66.60±12.86	
University equivalent	52.00±13.41		65.13±13.78	
Number of children				
1	53.07±12.88	0.339 (.797)	65.57±11.67	0.575 (.632)
2	49.68±12.92		69.29±14.54	
3	48.95±14.96		70.85±14.95	
>=4	49.05±11.10		71.66±12.15	
Sleep disorder				
Yes	56.80±11.30	31.088 (.000)	62.03±11.76	0.573 (.565)
No	44.41±12.42		75.41±13.33	
Special education				
Yes	48.71±13.40	0.305 (.738)	71.39±12.39	2.145 (.148)
No	50.98±14.24		67.61±15.73	
Physiotherapy				

Yes	47.50±11.58	2.187 (.142)	71.17±12.38	0.895 (.346)
No	51.22±14.33		68.65±15.11	
Oral hygiene				
Yes	52.71±12.81	2.736 (.101)	65.42±12.99	5.177 (.025)
No	48.37±13.52		71.63±14.25	
Place of residence				
City	50.31±13.84	0.305 (.738)	68.74±12.62	0.573 (.565)
Outlying district	49.18±12.90		72.13±13.33	
Village	47.30±11.89		71.07±14.11	
Sex				
Male	50.25±12.62	0.177 (.675)	69.02±13.62	0.282 (.596)
Female	49.20±14.37		70.38±14.76	
Tracheostomy				
Yes	50.80±12.40	0.100 (.752)	67.73±13.75	0.310 (.579)
No	49.62±13.59		69.91±14.20	
Domestic-type ventilator				
Yes	51.24±12.36	0.145 (.518)	68.12±13.91	0.302 (.582)
No	49.81±13.64		69.27±14.09	
Percutaneous gastrostomy				
Yes	44.56±11.97	6.134 (.021)	73.86±14.27	2.102 (.155)
No	51.12±13.74		68.74±14.56	
Income				
Lower than expenditure	48.03±12.92	3.337 (.039)	71.37±14.13	3.188 (.045)
Equal to expenditure	51.71±13.72		67.88±12.74	
Greater than expenditure	61.16±12.38		57.50±16.59	

Abbreviations: SOS, Spiritual Orientation Scale; ZCBS, Zarit Caregiver Burden Scale.

Discussion

This study investigated the spiritual orientations and caregiver burden of parents of children receiving HCS.The woman generally assumes the primary role in the context of elderly individuals receiving HCS, with spouses or daughters acting as caregivers (10). Although this may vary depending on cultural and social conditions, children's caregivers are generally their mothers (11). The majority of caregivers in the present study were also mothers.

Ören et al. investigated the caregiver burdens of parents of disabled children and determined that maternal caregiver burdens tended to increase with age. In their investigation of the caregiver burden of mothers of children being treated in hospital, Beyzat et al. also determined a significant correlation between age and caregiver burden (12,13). However, maternal age and caregiver burden were negatively correlated in a study by Obrest et al. In contrast, caregiver burdens were parallel in all age groups in the present study (14). Although the caregiver burden was expected to rise with age, ZCBS scores in the present study were also high in younger mothers. Caring for a patient group receiving HCS may be more tiring and difficult. A study from Italy reported that parents devoted approximately nine hours a day to children receiving HCS, suggesting that providing intensive care is difficult and challenging for mothers from all age groups (15). In the present study, ZCGS scores were higher in the presence of percutaneous endoscopic gastrostomy. This may be due to the absence of feeding difficulties in the presence of percutaneous endoscopic gastrostomy, and to children feeding more easily.

In terms of primary diagnoses, neurological diseases, and particularly cerebral palsy, were markedly more common. This is consistent with a study of children receiving HCS from İzmir in Türkiye (16). These diseases are frequently seen in Türkiye due to the widespread nature of consanguineous marriages and persisting high rates of perinatal problems (17). In addition, the majority of neurological, metabolic, or genetic diseases occurring at birth are progressive and irreversible, gradually leading to a decline in all body functions and causing children to become dependent on home care.

Interestingly, although most of individuals in a previous study were caring for patients receiving HCS seven days a week, the caregiver burden decreased as the number of days a week increased (18). The caregivers in the present study cared for their children seven days a week, for which reason no direct comparison was possible. The decrease in the caregiver burden may be associated with the strengthening of bonds with the individual concerned and increased experience on the subject of care provision.

Individuals' spiritual and religious needs are reported to increase in chronic diseases involving increased social support requirements (19). This derives from the unpredictable nature of the disease course and encourages a turning to spiritual matters to make one feel better and more positive (20). The parents of younger children in the present study exhibited low Zarit scores but high spirituality scores. The results of the study showed that there was no association between the carer's education level and the parent's caregiver burden, and that spiritual orientations were higher in parents with lower education levels. Other research findings have suggested no significant relationship between spiritual orientation and education levels (21). Individuals with poorer income levels exhibited lower ZCBS scores but higher SOS scores. Studies have reported that the presence of a disease that requires care increases the family's financial costs and the caregiver burden (22,23). The parents of children with life-restricting or threatening diseases usually have to change jobs. This results in emotional and physical difficulties expressed as the caregiver burden (24). Levels of spiritual well-being are regarded as a factor that facilitates adaptation to physical and psychological problems that lead to chronic diseases (25). High spirituality and a low caregiver burden among parents with low-income levels may be due to the profound and indubitable impact of placing one's faith in God in the face of overwhelming difficulties that leave one bereft of solutions (26). Shaw et al. reported that spiritual orientation can help parents cope better with traumatic experiences (27).

Being in the position of an involuntary and unplanned caregiver for their children leads to an adaptation process in parents (28,29). However, due to the permanent nature of this condition, parents have also been shown to experience anxiety and depression and a decrease in their psychological health (30,31). Even though the diseases and follow-up processes of children receiving care differ, it is more difficult for parents to raise children with special needs compared to their normally developing peers. This emphasizes the need to meet the spiritual support needs of parents primarily responsible for children with chronic diseases, such as those receiving HCS.

The present study has some limitations. First, patients receiving HCS and registered with our hospital were enrolled. The research was conducted with a sample including participants in the Samsun province of Turkey and is not representative of the general population. Biased responses may occur in all survey studies.

Conclusion

Being a parent caring for a chronically ill child represents a significant burden. It is important to identify the difficulties experienced by caregivers, to determine their caregiver burden, to provide the requisite social support to these children's caregivers, and to improve their quality of life in order for these patients to receive a better quality service and to better manage their diseases. This study observed a lower caregiver burden perception among mothers with high spiritual orientations. Various activities are therefore needed to provide spiritual support for these mothers.

Data Availability: All data generated or analyzed during the present study are included in this published article and supplementary information files.

Ethics Committee Approval: The study was approved by the University of Samsun non-interventional Clinical Research Ethical Committee (date: 20.02.2023 and approval number: SÜKAEK-2023-4/8).

Informed Consent: Caregivers were contacted by telephone and informed about the aim of the study. Verbal consent was obtained from parents of children aged 0-18 registered with the HCS system and who agreed to participate.

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