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ORIGINAL ARTICLE
ORİJİNAL ARAŞTIRMA

Care Burden and Psychological Resilience of Mothers Accompanying Their Children with Chronic Illnesses Hospitalized in Pediatric Wards

Pediatri Servislerinde Kronik Hastalık Tanısı ile Yatan Çocuklarına Refakat Eden Annelerin Bakım Yükü ve Psikolojik Dayanıklılıkları

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ABSTRACT

Aim: Psychological resilience plays a pivotal role in managing the caregiving burden experienced by mothers of hospitalized young children with chronic illnesses. The resilience of these mothers is not only critical for their own mental health but also for the well-being and development of their child. This study aimed to determine the caregiving burden and psychological resilience of mothers accompanying their children aged 0-2 years who are hospitalized due to chronic illness.

Material and Method: The participants included 134 mothers of hospitalized children. Data were gathered utilizing a personal information form, the Zarit Burden Interview, and the Brief Resilience Scale.

Results: Working mothers with a bachelor's degree had higher Zarit Burden Interview scores than non-working mothers. Mothers of children with epilepsy and neurological diseases had higher Zarit Burden Interview scores than those with other chronic diseases. Mothers receiving instrumental and spiritual support had significantly higher Brief Resilience Scale scores. Among mothers who accompany their children with a chronic illness diagnosis in the hospital, those who are university graduates, employed, or have children diagnosed with epilepsy and neurological diseases are particularly at risk in terms of the burden of care and psychological resilience.

Conclusion: Physicians and especially pediatric nurses can enhance the psychological resilience of these mothers identified as a risk group in this study and alleviate their care burden by providing instrumental and moral support in the clinical setting. The support given to these accompanying mothers can contribute more significantly to the quality of life and care of the child.

Keywords: Care burden, chronic diseases, resilience, pediatrics, mothers

ÖZ

Amaç: Psikolojik dayanıklılık, kronik hastalığı olan hastanede yatan küçük çocukların annelerinin yaşadığı bakım yükünü yönetmede çok önemli bir rol oynar. Bu annelerin dayanıklılığı sadece kendi ruh sağlıkları için değil, aynı zamanda çocuğun iyilik hali ve gelişimi için de kritiktir. Bu çalışmanın amacı, hastanede kronik hastalık nedeniyle yatan 0-2 yaş arasındaki çocuklarına refakat eden annelerin bakım yükü ve psikolojik dayanıklılık durumlarını belirlemektir.

Gereç ve Yöntem: Katılımcılar, hastanede yatmakta olan çocukların annesini (134 kişi) içermektedir. Veriler, kişisel bilgi formu, Zarit Bakım Yükü ve Kısa Dayanıklılık Ölçeği kullanılarak toplanmıştır.

Bulgular: Çalışan ve lisans mezunu olan annelerin bakım yükü puan ortalamaları çalışmayan annelerden daha yüksek bulunmuştur. Epilepsi veya nörolojik hastalık tanısı ile izlenen çocukların annelerinin bakım yükü puan ortalamaları, çocukları diğer kronik hastalıklara sahip olan annelerden daha yüksek çıkmıştır. Araçsal ve manevi destek alan annelerin psikolojik dayanıklılıkları, bu desteği almayanlardan anlamlı olarak daha yüksek bulunmuştur. Kronik hastalık tanısı ile izlenen çocuklarına hastanede refakat eden anneler arasında özellikle; lisans mezunu, çalışan, epilepsi ve nörolojik hastalık tanısı ile izlenen çocuğa sahip anneler bakım yükü ve psikolojik dayanıklılık bakımından risk grubundadır.

Sonuç: Hekimler ve özellikle de pediatri hemşireleri, bu çalışmanın sonucunda risk grubu olarak belirlenmiş annelere klinik ortamda araçsal ve manevi destek sağlayarak, annelerin psikolojik dayanıklılıklarını artırabilir ve bakım yükünü hafifletebilirler. Refakatçı annelere verilen bu destekle çocuğun yaşam kalitesi ve bakımına daha fazla katkı sağlayabilirler.

Anahtar Kelimeler: Bakım yükü, kronik hastalık, dayanıklılık, pediatri, anneler

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INTRODUCTION

Chronic illnesses, often known as noncommunicable diseases, last for a long time and progress slowly. Pediatric chronic diseases are caused by genetic, physiological, environmental, and behavioral factors. These diseases impact people of all ages, locations and countries (1). Caring for a child with chronic illness poses substantial challenges for families, with mothers often bearing a significant emotional, physical, and psychological burden (2,3). Parents of children with chronic diseases experience denial, depression, loneliness, difficulty making decisions, and uncertainty, which negatively affect their quality of life (4-5). Mothers want to give birth to healthy children, however, they experience psychological problems, especially in the first years following birth, when caring for children with chronic diseases (6). The constant demands of maintaining the child's health, combined with significant financial constraints and upheavals in family dynamics, increase the impact.

The way in which caregivers provide care is affected by numerous factors, including level of education, uncertainties, a child's pain, adverse effects of the treatment, disease characteristics, the necessity for long periods of hospitalization, financial difficulties (7-9). This adverse situation affect mothers of children with chronic diseases. These mothers are supposed to be psychological resilience strong to cope with and adapt this situation. In the context of caring, resilience is not simply a desirable trait, but also a requirement, allowing caregivers to traverse the emotional, physical, and financial complexity of their duties (10). The substantial demands of caring frequently put mothers' resilience to the test, making it an important topic of study to understand how they manage, adjust, and protect their well-being in the face of such challenges.

Psychological resilience allows caregivers to deal with disease-related problems positively (11). Psychosocial support services help such parents experience fewer problems, adapt to their child's illness, and build psychological resilience (12).

The present study aimed to contribute to and understanding of the effect of sociodemographic factors and psychological resilience on the burden of care in mothers of 0-2-year-old children with chronic diseases. Many factors affect the burden of care. But we wanted to understand the care burden and psychological resilience experienced by mothers who are taking care of their children hospitalized due to chronic illness. The current research focused on the association between psychological resilience and burden of care, hypothesizing that the findings will help healthcare professionals formulate and implement interventions to help mothers of babies/infants with chronic diseases increase their psychological resilience and develop effective coping strategies to minimize the burden of care.

MATERIAL AND METHOD

The study was carried out at the pediatrics inpatient clinic of an university hospital between April and August 2021. This pediatric hospital has important population including families from urban and rural districts. The children with chronic diseases are treated and followed up in this inpatient clinic. We invited to participate the mothers of children who are receiving treatment aged 0-2 years with chronic diseases at the inpatient clinic. The sample size of 128 mothers was determined to have 0.80 power to detect an effect size of 0.20 according to Cohen's d. The final target sample of 134 mothers was selected to allow for an estimated for possible losses. The inclusion criteria were (1) mother of a child receiving treatment with a chronic disease aged 0-2 years in the inpatient clinic, (2) literate in Turkish, (3) absence of any problems that prevent communication. The mothers were selected with the convenience sampling approach. The mothers completed the personal information form, the Zarit Burden Interview, and the Brief Resilience Scale at the inpatient clinic. The mothers were provided with information related to the study. Ethical approval for the research was obtained from the ethics committee of the university (Approval date:1 March 2021; no: 496). In addition, the hospital where the study was conducted received institutional permission, and the participants gave written and verbal consent.

Personal Information Form

The personal information form was developed based on previous survey, conducted by the researchers (13-16). The form included 23 items on mother sociodemographic characteristics (age, gender, marital status, level of education, employment status, health insurance, migration status, place of residence, number of children, the child's chronic diseases, other children and relatives, habits, and social isolation), children's sociodemographic characteristics (gender, diagnosis of chronic disease, and time of diagnosis), and identifying information about caregiving (area of care, duration of caregiving, presence of the other caregiver, material/financial, emotional and spiritual support during caregiving).

Zarit Burden Interview (ZBI)

ZBI was developed by Zarit et al (17). and adapted to Turkish by Inci and Erdem (18) The instrument assesses caregiver burden of care. The 22-item scale does not

have a cut-off score or subscales. The 5-point Likert-type response scale ranges from never (0) to nearly always (4). The total score ranges from 0 to 88, with higher scores indicating higher burden of care (0-21: little or no burden; 21-40: mild to moderate burden; 41-60: moderate to severe burden; 61-88: severe burden). In this study, the scale demonstrated a Cronbach's alpha of 0.874.

Brief Resilience Scale (BRS)

BRS was developed by Smith et al. (19). and adapted to Turkish by Doğan (20). The scale's six items are scored on a 5-point Likert scale, from strongly disagree (1) to strongly agree (5). Items 2, 4, and 6 are scored in reverse. The scale has no cut-off score or subscales. The total score varies between 6 and 30, with higher levels suggesting greater resilience. The scale had a Cronbach's alpha of 0.95, indicating that it was an appropriate instrument for this investigation.

Data Analysis

The data were analyzed with IBM SPSS Statistics for Windows v.26.0 (IBM Corp., Armonk, NY), using a significance level of p=0.05. Descriptive analysis including median, range percentages was used to define the sample's characteristics. Nonparametric tests were employed because the data obtained from the study did not follow a normal distribution.

Spearman's Rho coefficient was used to determine the relationship between the ZBI and BRS. Mann-Whitney U test was used to determine the significance of the mothers' health insurance, employment, presence of another caregiver, spiritual and material support on the mother's resilience and caregiver burden. The Kruskal-Wallis H Test was used to compare the significance of the mother's age, education, number of children on the mother's resilience and caregiver burden.

RESULTS

85.1% of the children of were first diagnosed 6 months ago. The rate of the mothers who had been giving care to their child during this period was 85.1% (**Table 1**). Majority of the children (32.8%) had a diagnosis of respiratory system diseases

Table 2 shows the distribution of ZBI and BRS scores according to the mothers' sociodemographic characteristics. Mothers with a bachelor's degree had a significantly higher mean ZBI score than those with lower levels of educational (p=0.013). Working mothers had a significantly higher mean ZBI score than their non-working counterparts (p=0.001). Participants that received material and spiritual support had a significantly higher mean BRS score than those that did not (p=0.019 and p=0.021, respectively).

Table 1. Characteristics about the mothers and their children

Mothers	**n (134)**	**%**
Age (years) median (19-44)		
≤29	64	47.8
30-34	33	24.6
≥35	37	27.6
Marital Status		
Married	130	97.0
Single	4	3.0
Level of Education		
Primary school	52	38.8
High School	35	26.1
Bachelor's Degree	47	35.1
Number of children		
1	55	41.0
2	45	33.5
≥3	34	25.5
Employment Status		
Unemployed	93	69.5
Employed	41	30.5
Job		
Housewife	93	69.4
Employee	10	7.5
Official	31	23.1
Health insurance		
Yes	108	80.6
No	26	19.4
Presence of another caregiver		
Yes	72	53.7
No	62	46.3
Spiritual (emotional etc.) support for care		
Yes	68	50.7
No	66	49.3
Material (financial etc.) support for care		
Yes	59	44.0
No	75	56.0
Children		
Sex		
Girl	52	38.8
Boy	82	61.2
Diagnosis of the children		
Cardiovascular diseases	34	24.6
Chronic respiratory diseases	44	32.8
Epilepsy and neurological disease	34	25.4
Metabolic disease	23	17.2
Kidney disease	17	12.7
Immunologic and hematologic disease	34	25.4
Time of diagnosis (month)		
6	114	85.1
6>	20	14.9
Period of the mother caregiving duration (month)		
<6 months	114	85.1
≥6 months	20	14.9

Table 2. Distribution of ZBI and BRS scores according to the mothers' sociodemographic characteristics and presumed social support

The mother's sociodemographic characteristics and details of the presumed social support	n(134)	ZBI Median	Statistical Analysis-ZBI	BRS Median	Statistical Analysis-BRS
Age (years)			0.941[a]		0.822[a]
≤29	64	45.00		12.00	
30-34	33	43.00		13.00	
≥35	37	49.00		13.00	
Level education			0.013[a]		0.562[a]
Primary school	52	42.50		12.50	
High school	35	44.00		12.00	
Bachelor's Degree	45	51.00		13.00	
Employment status			0.001[b]		0.281[b]
Unemployed	93	42.00		13.00	
Employed	41	51.00		12.00	
Health insurance			0.960[b]		0.082[b]
Yes	108	45.00		13.00	
No	26	44.50		12.00	
Number of children			0.773[a]		0.966[a]
1	55	46.00		13.00	
2	45	45.00		13.00	
≥3	34	43.00		13.00	
Presence of another caregiver			0.286[c]		0.363[b]
Yes	72	47.00		13.00	
No	62	43.50		12.00	
Spiritual (emotional etc.) support for care			0.801[d]		0.019[b]
Yes	68	46.00		13.50	
No	66	44.50		12.00	
Material support for care			0.898[d]		0.021[b]
Yes	59	46.00		14.00	
No	75	45.00		12.00	

[a]Kruskal-Wallis H test. [b]Mann-Whitney U test. [c]Independent 2-group t-test (Levene's test [p=0.646]). [d]Mann-Whitney U test (p<0.05).

Table 3 shows the distribution of ZBI scores according to the children's chronic characteristics. Mothers caring for children with epilepsy and neurological diseases had a significantly higher mean ZBI score than those caring for children with other chronic diseases (p<0.001).

Table 3. Distribution of mother's ZBI scores according to their children's chronic diseases characteristics.

Chronic Diseases		n	ZBI Mean±SD	Median	Statistics p[a]
Heart disease	Yes	33	44.39±11.09	45.00	0.967
	No	101	43.57±14.40	45.00	
Respiratory system disease	Yes	44	42.41±13.62	42.00	0.353
	No	90	44.44±13.65	46.00	
Epilepsy and neurological disease	Yes	34	50.82±11.84	55.00	<0.001
	No	100	41.38±13.41	43.00	
Metabolic disease	Yes	23	47.13±11.18	49.00	0.233
	No	111	43.08±14.02	45.00	
Immunologic and hematologic disease	Yes	34	43.38±14.19	47.50	0.931
	No	100	43.91±13.50	45.00	

[a]Mann-Whitney U test.

Table 4 shows the distribution of BRS scores according to ZBI scores of the mothers'. The mothers with mild to moderate burden of care had a significantly higher mean BRS score than those with moderate to severe burden of care (p<0.001).

Table 4. Distribution of BRS scores according to ZBI scores.

BI Score levels	n	BRS Scores Mean±SD	Median	p[a]
Mild to Moderate burden of care	49	19.71±6.14	23.00	<0.001
Moderate to severe burden of care	85	12.14±2.31	12.00	<0.001

[a]Mann-Whitney U test.

Sperman's correlations are presented in **Table 5**. Sperman correlations revealed negative links between the BRS and ZBI. There was an inverse correlation between the ZBI and BRS scores (r=–0.650; p=0.001).

Table 5. Spearman's Rho Correlations

Scales and corelations	BRS	ZBI
Spearman's Rho coefficient		
BRS correlation coefficient	-	-0.650**
Sig	-	.000
N	134	
ZBI correlation coefficient	-0.0650**	-
Sig	.000	-
N	134	

**p<0.01

DISCUSSION

The present study examined the effect of sociodemographic factors and psychological resilience on burden of care in mothers of children with chronic diseases. The findings show that the mothers had moderate to severe burden of care. The mothers with a bachelor's degrees had a significantly higher mean ZBI score than those with lower levels of education. Working mothers had a significantly higher mean ZBI score than their non-working counterparts. The mothers caring for children with epilepsy and neurological diseases had a significantly higher mean ZBI score than those caring for children with other chronic diseases. Moreover, the findings show that the level of psychological resilience is lower in mothers who report greater burden of care. Other research shows that mothers that care for children with chronic diseases have moderate and severe burden of care (21-24).

In the present study level of education, employment status, type of chronic disease, and level of psychological resilience were associated with the level of burden of care. Burden of care rankings in the current study were higher than those previously reported (5,8,16,25-26) which might be because the presented sample consisted of mothers of hospitalized infants aged 0-2 years. Even healthy babies require a great amount of care; therefore, caring for infants with chronic diseases increases the burden of care. Mothers of hospitalized infants are faced with extra high burden of care because those infants are in the active period of disease. In accordance with our observations, the reasons for the increase in mothers' caregiving burden can include factors such as polypharmacy, complications, frequent changes in basic self-care needs (nutrition and excretion), physical dependence, finances problems, emotion and feeling of inadequate in responding to the needs of their children. Some Turkish studies report low mean burden of care scores, which is probably because Turkish people do not consider care to be a burden (18,27). Although Turkish people perceive caregiving as a form of help, physical and psychological factors increase their burden of care, because balancing work and home life becomes difficult when a child is chronically ill. More highly educated women are participating in the workforce in Turkey than ever before, and due to the dual responsibilities of work and home women caring for children with a chronic illness are expected to have an increased burden of care (25).

Researchers focusing on the relationship between level of education and burden of care have reported inconsistent findings. Turan and Yayan reported that university graduates had a high burden of care (23). On the other hand, Alahan et al. reported that parents with a primary school degree had higher mean burden of care scores than others (27). Çalışır et al. reported that there isn't a relationship between burden of care and level of educational (22). The researchers that reported parents with a bachelor's degree have a lower burden of care attributed this finding to the assumption that the burden of care may decrease as the level of knowledge increases. Mothers in the present study with a bachelor's degree had a higher mean ZBI score than those with primary and high school degrees, which might have been due to 3 things. First reason; mothers with a bachelor's degree may be more aware that their children with chronic diseases have specific needs that need to be met, and therefore, they can feel the burden of care more intensely than those with lower levels of education. Second reason; On one hand, the responsibilities brought by working life, and on the other hand, accompanying a child hospitalized and taking care of responsibilities at home, when experienced together, can increase the mother's caregiving burden. Third reason; educated mothers can gather information about the complications of their illnesses from a variety of information sources, therefore they may feel the responsibilities that come with knowing more intensely.

In the present study working mothers had a significantly higher mean ZBI score than their non-working counterparts, which is consistent with the literature (15,28). On the other hand, some studies observed that non-working mothers had a significantly higher mean ZBI score than their working counterparts (25,29). Caring for a child with a chronic disease requires constant attention, emotional support, and medical management, which can significantly strain the mother's psychological well-being. Balancing these responsibilities with work demands can exacerbate burden care of the mothers. The mother's responsibilities at the workplace and increased roles can increase the burden of care. Also the type of work, duration and intensity of work, work-related physical and mental fatigue, stress, and the distance between the workplace and home are among the factors that affect work and burden of care (29).

Mothers in the present study whose children had epilepsy and neurological diseases had a significantly higher mean ZBI score than those whose children had other chronic diseases. Earlier research also shows that caregivers of children with epilepsy and neurological diseases have more burden of care than those whose children has other chronic diseases (22,30). It was further suggested that a child with epilepsy's seizure frequency, response to treatment, and need for prolonged and frequent hospitalization, and the fact that the child's mental functions are negatively affected increase burden of care.

In the present study there was a negative correlation between the ZBI and BRS scores; as the ZBI score increased the BRS score decreased, as previously reported (31-33). High-level psychological resilience

has a significant positive effect on the perception of burden of care, as compared to low-level resilience. Psychological resilience plays a role in mobilizing functionality used to solve problems. Mothers with chronically ill children need support to overcome illness-associated adversity; therefore, it is necessary to develop intervention strategies for strengthening psychological resilience (14). Positive results are expected when resilience development strategies are used with mothers that have low-moderate-level psychological resilience. In addition to improving psychological resilience, it can also decrease the burden of care. The mothers in the present study that received material and spiritual support had a significantly higher mean BRS score than those that did not. Earlier research shows that parents that receive social support have higher levels of psychological resilience and lower burden of care than those that do not (34-37). Positive social relationships are critical to psychological resilience and social support positively affects parents' maintenance of positive relationships and psychological resilience (38).

The present findings show there is a significant relationship between burden of care and psychological resilience. Mothers reporting, mild to moderate burden of care had higher levels of psychological resilience than mothers reporting moderate to severe burden of care. Mothers reporting, mild to moderate burden of care had higher BRS scores than those reporting moderate to severe burden of care. These findings are similar to previous studies that interventions to improve psychological resilience might also decrease burden of care (30,39-40). They also indicate that chronic diseases in children, especially those requiring continuous care in hospital, can negatively affect parents' psychological resilience because they require medication and multiple forms of treatment, and a high level of care. A study conducted on caregivers of children with chronic illness reported that the level of psychological resilience varied according to being a parent or not and that the level of psychological resilience in non-parents was higher than that in parents (37). The first years of parenthood (in the case of a child with a chronic disease) might negatively affect psychological resilience due to the challenges of the required high level of caregiving. Up to a certain point, mothers may employ coping mechanisms and resilience strategies effectively to manage the stress and demands of caregiving. However, as the burden intensifies, these mechanisms may become overwhelmed, leading to a decrease in resilience. Several factors might account for the relationship between the burden of care and resilience ratings. Firstly, individuals with a light to moderate caregiving load might have better access to support networks like family, community resources, and healthcare services, which can help them maintain their resilience. Secondly, the intensity and length of the caregiving situation can greatly affect resilience; those with moderate to severe caregiving duties might face longer-term, more demanding responsibilities, which can hinder their ability to recover from stress. Lastly, personal traits such as optimism, coping skills, and past experiences with adversity can also play a role in determining resilience levels.

Limitations

The present study was initially designed to be conducted in outpatient and inpatient clinics but was conducted only in inpatient wards due to the ongoing COVID-19 pandemic and the closure of outpatient clinics. The results are obtained from a small size of companion mothers from the inpatient pediatric clinics and, therefore whether these results can be replicated in general in large sample remains to be clarified. In this study, only the caregiving burden and resilience of mothers who provide care was examined.

CONCLUSION

In this study, which examines the care burden and resilience of mothers accompanying children aged 0-2 who are receiving treatment in hospitals, it has been found that the mothers' care burden is high. In addition, the burden of care was higher in the mothers that had a bachelor's degree, were employed, and had children with epilepsy and neurological diseases. Based on these findings, we think it is essential to initiate interventions to increase psychological resilience in these mothers, so as to decrease their burden of care.

Working mothers had a higher level of burden of care than non-working mothers. Identification of the factors associated with work-related stress in mothers of children with chronic diseases and interventions directed towards those factors are recommended. The burden of care in the present study's mothers of children with epilepsy and neurologic diseases was higher than in the mothers of children with other diseases. These mothers face an immense burden that extends beyond physical care and into deep emotional, spiritual, and existential dimensions. Recognizing this load is the first step toward providing the comprehensive support that these families deserve. As society tries to better understand and address these difficulties, it is critical to recognize and encourage the resilience of these mothers. It is recommended that information and counseling services be provided not only to mothers, but also to other family members to facilitate their contribution to the care and support of mothers and expansion of mothers' social support networks. Fathers were not included in the study because they could not be interviewed even though they did not stay in the hospital. In the future, similar studies including fathers could be conducted to investigate the caregiving burden and resilience more in-depth.

The burden of care was higher in the present study's mothers with low levels of psychological resilience, as compared to those with high levels of resilience. It is recommended to provide information and counseling services not only to mothers but also to other family members to enhance the psychological resilience of mothers. This aims to involve other family members in caregiving and to support the expansion of mothers' social support networks.

ETHICAL DECLARATIONS

Ethics Committee Approval: Ethical approval for the research was obtained from the Ethics Committee of the university (Date: 01.03.2021, Decision No: 496). ,

Informed Consent: The hospital where the study was conducted received institutional permission, and the participants gave written and verbal consent.

Referee Evaluation Process: Externally peer-reviewed.

Conflict of Interest Statement: The authors have no conflicts of interest to declare.

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REFERENCES

1. WHO. 2023. Noncommunicable diseases. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases
2. Koch KD, Jones BL. Supporting parent caregivers of children with a life-limiting illness. Children 2018;5:85.
3. Shore CP, Austin JK, Dunn DW. Maternal adaptation to a child's epilepsy. Epilepsy Behav 2004;5:557-68.
4. Lee MH, Matthews AK, Park C. Determinants of health-related quality of life among mothers of children with cerebral palsy. J Pediatr Nurs 2019;44:1–8.
5. Toledano-Toledano F, Moral de la Rubia J. Factors associated with anxiety in family caregivers of children with chronic diseases. BioPsychoSocial Med 2018;12:20
6. Önder A, Gülay H. Examining the relationship between mothers' level of acceptance and their children's empathy skills. PAUEFD 2007;2:23-30.
7. Cipolletta S, Marchesin V, Benini F. Family functioningis a constituent aspect of a child's chronic illness. J Pediatr Nurs. 2015 30:19–28.
8. Sharma N, Sharma P, Mishra TA. Burden of care among mothers having children with congenital heart diseases. JNPS 2020; 40:72-7.
9. Pedrón-Giner C, Calderón C, Martínez-Costa C, Borraz Gracia S, Gómez-López L. Factors predicting distress among parents/caregivers of children with neurological disease and home enteral nutrition. ChİId Care Hlth Dev 2014;40: 389–97.
10. Palacio GC, Krikorian A, Gómez-Romero MJ, Limonero JT. Resilience in Caregivers: A Systematic Review. Am J Hosp Palliat Care 2020; 37:648–58.
11. Luthar SS, Cicchetti D, Becker B. The construct of resilience A critical evaluation and guidelines for future work. Child Dev 2000;71:543-62.
12. Çöp E, Dinç GŞ, Kültür SEÇ. Relationship with Psychiatric Symptoms: A Preliminary Report Coping Styles of Mothers of Children with Chronic Diseases and Their. Türkiye Çocuk Hast Derg. 2016;10(3):170-6.
13. Köse S, Arar AT, Yıldırım G. The relationship between caregiving burden and anxiety levels in parents of children diagnosed with cancer. J Educ Res Nurs 2019;16:282-7.
14. Lee I, Lee EO, Kim HS, Park YS, Song M, Park YH. Concept development of family resilience: A study of Korean families with a chronically ill child. J Clin Nurs 2004;13:636-45.
15. Taşçıoğlu G, Beyazıt U, Ayhan A. Examination of Caregiving Burden in Parents of Children Hospitalized for Treatment. Adnan Menderes University Journal of Health Sciences Faculty 2017;1:10-9.
16. Zan H, Scharff RL. The heterogeneity in financial and time burden of caregiving to children with chronic conditions. Matern Child Health J 2015;19: 615-25.
17. Zarit SH, Reever KE, Bach-Peterson J. Relatives of The Impaired Elderly Correlates of Feelings of Burden. Gerontologist 1980;20:649-55.
18. İnci FH, Erdem M. Adaptation, Validity, and reliability of the caregiving burden scale into Turkish. Atatürk University Journal of Nursing School 2008;11:85-95.
19. Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Jennifer Bernard J. The brief reslience scale: Assessing the ability to bounce back. Int J Behav Med 2008;15:194–200.
20. Doğan T. Adaptation of the Brief Resilience Scale into Turkish: A Validity and Reliability Study. J Happiness Well-Being 2015;3:93-102.
21. Family Caregiver Alliance (FCA). Family Caregiver Alliance Caregiver Statistics: Work and Caregiving. https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/ accessedc Mart 9, 2019.
22. Çalışır H, Karabudak SS, Karataş P, Tosun AF, Meşealan İ. Family burden and hopelessness levels of mothers with children with cerebral palsy. Dokuz Eylül University Faculty of Nursing Electronic J 2018;11:147-56.
23. Turan M, Yayan EH. Examining the Effect of Caregiver Burden of Parents whose Child has a Metabolic Problem on the Perceived Social Support and Life Quality. AUHSJ 2021;12:445-51.
24. Türe E, Yazar A, Akın F, Aydın A. Assessment of Caregiving Burden among Caregivers of Chronically Ill Children. Bozok Med J 2018;8:46.
25. Budak MA, Geçkil E. Determining the caregiving burden of mothers of children with chronic illness and their levels of anxiety and depression. AUHSJ. 2020;3:391-9.
26. Werner H, Latal B, Buechel EV, Beck I, Landolt MA. The impact of an infant's severe congenital heart disease on the family: a prospective cohort study. Congenit Heart Dis 2014;9:203–10.
27. Alahan NA, Aylaz R, Yetiş G. The caregiving burden of parents with children having chronic illness. Ann Health Sci Res 2015;4:1-5.
28. Kobos E, Imiela J. Factors affecting the level of burden of caregivers of children with type 1 diabetes. Appl Nurs Res 2015;28:142-9.
29. Gharaibeh HF, Gharaibeh MK. Quality of life of working and non-working Jordanian mothers caring for chronically ill child and its associated factors. Heliyon 2021;7-3: e06320.
30. Olagunju AT, Bioku A, Ohaeri JU, et al. A comparative study of perceived burden in parent caregivers of adolescents with epilepsy in a resource-restricted setting: Investigating the explanatory factors of perceived burden. E&B 2021;120:107992.
31. Russell BS, Tomkunas AJ, Hutchison M, Tambling RR, Horton AL. The protective role of parent resilience on mental health and the parent–child relationship during COVID-19. Child Psychiatry Hum Dev 2022;53:183-96.
32. Fossati M, Negri L, Fianco A, Cocchi MG, Molteni M, Delle Fave A. Resilience as a moderator between Objective and Subjective Burden among parents of children with ADHD. Arch Psychiatr Nurs 2020;34:53–63.
33. Lindsey RA, Barry TD. Protective factors against distress for caregivers of a child with autism spectrum disorder. J Autism Dev Disord 2018;48:1092–107.
34. Wee LX, Tan PST, Chen HC. Experiences and needs of families caring for children and adolescents with chronic kidney disease: A meta-Synthesis. J Pediatr Nurs 2022;63:52–63.
35. Ebrahim MT, Alothman AA. Resilience and social support as predictors of post-traumatic growth in mothers of children with autism spectrum disorder in Saudi Arabia. Res Dev Disabil 2021;113:103943.
36. Yüksel H, Tanrıverdi A. Social Problems and Coping Mechanisms in Families of Children with Special Needs. Ankara University Faculty of Educational Sciences Journal of Special Education 2019;20:535-59.

37. Eccleston C, Fisher E, Law E, Bartlett J, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. Cochrane Database Syst Rev 2015;4:4:CD009660.
38. Kaplan HB. Toward an understanding of resilience. In M. D. Glantz & J. L. Johnson (Eds.), Resilience and development. Springer, Boston, MA. 1999. pp17-83.
39. Keniş-Coşkun Ö, Atabay CE, Şekeroğlu A, et al. The Relationship Between Caregiver Burden and Resilience and Quality of Life in a Turkish Pediatric Rehabilitation Facility. J Pediat Nurs 2020;52:108–13.
40. Mostafavi M, Areshtanab HN, Ebrahimi H, Vahidi M, Amiri S, Norouzi S. Caregiver burden and related factors in Iranian mothers of children with attention-deficit hyperactivity disorder. Nurs Midwifery Stud 2020;9:149-56