Türkiye Klinikleri Hemşirelik Bilimleri Dergisi
Turkiye Klinikleri Journal of Nursing Sciences Turkiye Klinikleri J Nurs Sci. 2024;16(4):995-1002

ORIGINAL RESEARCH ORİJİNAL ARAŞTIRMA

DOI: 10.5336/nurses.2023-98916

Assessment of the Difficulties and Care Burdens of Caregivers of Children with Complex Health Care Needs at Home: Descriptive Study

Evde Karmaşık Sağlık Bakım İhtiyacı Olan Çocuklara Bakım Verenlerin Yaşadıkları Güçlükler ve Bakım Yüklerinin Değerlendirilmesi: Tanımlayıcı Çalışma

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This study was prepared based on the findings of Merve Yetimoğlu's thesis study titled "Evaluation of the difficulties and care burdens of caregivers of children with complex health care needs at home" (Trabzon: Karadeniz Technical University; 2021).
This study was presented as a summary orally in 3rd International Mediterranean Pediatric Nursing Congress, October 12-15, 2022, Ankara, Türkiye.

ABSTRACT Objective: The research was conducted to determine the difficulties experienced by caregivers of children with complex health care needs at home and to evaluate their care burden. **Material and Methods:** The primary caregivers of 55 children who were registered in the home healthcare services unit of a province in the northeast of Türkiye and who met the inclusion criteria for the study were included. In the study, data were collected by face-to-face interview method by making home visits with the information form and Caregiver Burden Scale. Standard deviation, mean value, frequency, and percentage were used in the analysis of descriptive data. Mann-Whitney U test and Kruskal-Wallis test were used to analyse categorical data. **Results:** The mean age of the children in the study was 11.2±5.99 years. The majority of primary caregivers stated that they had difficulties in the care of the child, respectively, in the aspiration procedure (66.6%), the use of home-type mechanical ventilators (66.6%) and tracheostomy care (61.9%). It was found that caregivers who stated that their psychological health and social relations were impacted had a higher caregiver burden and there was a significant difference ($p<0.05$). **Conclusion:** In the study, primary caregivers have difficulties in caring for children with complex health care needs at home and their average care burden is high.

Keywords: Caregivers; caregiver burden; child health; home care; nursing

ÖZET Amaç: Bu araştırma, karmaşık sağlık bakım gereksinimi olan çocuklara bakım verenlerin evde yaşadıkları güçlükleri belirlemek ve bakım yüklerini değerlendirmek amacıyla yapılmıştır. **Gereç ve Yöntemler:** Türkiye'nin kuzeydoğusundaki bir ilin evde sağlık hizmetleri birimine kayıtlı ve araştırmaya dâhil edilme kriterlerini karşılayan 55 çocuğun birincil bakım verenleri araştırmaya dâhil edilmiştir. Çalışmada veriler, bilgi formu ve Bakım Verme Yükü Ölçeği ile ev ziyaretleri yapılarak yüz yüze görüşme yöntemi ile toplanmıştır. Tanımlayıcı verilerin analizinde standart sapma, ortalama değer, frekans ve yüzde kullanılmıştır. Kategorik verileri analiz etmek için Mann-Whitney U testi ve Kruskal-Wallis testi kullanılmıştır. **Bulgular:** Çalışmaya alınan çocukların yaş ortalaması 11,2±5,99 yıldır. Birincil bakım verenlerin çoğunluğu çocuğun bakımında sırasıyla aspirasyon işlemi (%66,6), ev tipi mekanik ventilatör kullanımı (%66,6) ve trakeostomi bakımı (%61,9) konusunda zorluk yaşadıklarını belirtmişlerdir. Psikolojik sağlıklarının ve sosyal ilişkilerinin etkilendiğini belirten bakım verenlerin bakım verme yükünün daha fazla olduğu ve aradaki farkın anlamlı olduğu saptanmıştır ($p<0,05$). **Sonuç:** Araştırmada, evde karmaşık sağlık bakımı ihtiyacı olan çocukların birincil bakım vericilerinin çocukların bakımında zorluk yaşadıkları ve ortalama bakım yüklerinin yüksek olduğu görülmüştür.

Anahtar Kelimeler: Bakım vericiler; bakım yükü; çocuk sağlığı; evde bakım; hemşirelik

TO CITE THIS ARTICLE:
Yetimoğlu M, Kobya Bulut H. Assessment of the difficulties and care burdens of caregivers of children with complex health care needs at home: Descriptive study. Turkiye Klinikleri J Nurs Sci. 2024;16(4):995-1002.

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Peer review under responsibility of Turkiye Klinikleri Journal of Nursing Sciences.

Received: 21 Jul 2023 ***Received in revised form:*** 08 Jun 2024 ***Accepted:*** 24 Aug 2024 ***Available online***: 29 Aug 2024

The number of children needing -complex health care needs (CHCN) is increasing day by day.[1,2] Preterm babies, congenital, genetic, and chronic diseases play key roles in the increasing number of these children.[3] A child with CHCN is defined as a child with special health care needs, who has one or more chronic diseases and a significant dysfunction associated with it.[4] These children are at chronic, physical, behavioral, developmental, or emotional risk and require additional care.[5] It has been documented that the rate of children under the age of 18 with chronic diseases ranges between 10% and 15% across the world. When children with sensory, mental, behavioral, and learning problems are added, this rate rises to 30-40%.[6] In our country, 1-2% of the child population has a chronic disease that affects activities of daily living or requires treatment. In addition, 10% of these children have a serious chronic disease and are in the CHCN category.[7]

Thanks to advances in medical technology, the survival rate of children with chronic diseases has increased, which has led to the need to continue to meet their health care needs at home.[8,9] Across Europe, 6.6 out of every 100,000 children, 9.9 in Australia and 12 in New Zealand require CHNC at home. The number of children in need of CHCN at home in Türkiye is unknown.[10] Mothers are primarily responsible for the primary care of these children at home.[1] They experience some difficulties in fulfilling their role of caring for children with CHCN at home.[11] When the literature is reviewed, it is noticed that the caregivers of these children have difficulties in percutaneous endoscopic gastrostomy (PEG) care, tracheostomy care, positioning, feeding, and aspiration.[12-16] These difficulties experienced in care reveal the concept of care burden in primary caregivers.[12] Caregiver burden is defined as the difficulty and feeling of pressure of the caregiver during the caregiver's service for the individual with a chronic illness or disability.[17] In a study, it was reported that the burden of caring for children with more than one chronic disease increased even more.[18]

Nurses are at an important point among health professionals in reducing the difficulties experienced in care. Nurses are responsible for ensuring the safe and successful transition of these children from the hospital to the home environment, ensuring effective continuity of care, and providing necessary support to primary caregivers and families.[13,18] It is thought that attempts to reduce the difficulties experienced in the care of these children will reduce the care burden of primary caregivers. In line with this information, this study was conducted to determine the difficulties experienced by caregivers of children with CHCN at home and to evaluate the care burden.

MATERIAL AND METHODS

STUDY DESIGN AND SAMPLE

This research is descriptive cross-sectional research. It was carried out in the home care unit of a province located in the northeastern part of Türkiye. There are a total of 11 home health units in the province. The population of the study consisted of 65 children. Calculator.net was used to calculate the sample. The incidence was 9%, the margin of error was 0.05%, the power was 0.80, and the minimum count of samples to be involved in the study was found to be n=54.[19] Its incidence is based on the figure stated in the study in the literature.[10] Pre-application was made with 4 people and 6 people did not want to participate in the study. The study was conducted with 55 people who agreed to participate in the research. The inclusion criteria are as follows;

- Having a child between the ages of 0-18 years,
- The child has at least one complex health care [such as tracheostomy care, PEG care, oral care, decubitus care, port care, nasogastric (NG) tube insertion and NG tube feeding, urinary catheterization and oxygen administration],
- The caregiver does not have a mental illness or communication problem,
- The caregiver can speak Turkish.

ETHICS OF RESEARCH

Ethics committee approval (date: May 5, 2021; number: 2021/127) was obtained from Karadeniz Technical University Faculty of Medicine Scientific Research Ethics Committee and institutional permission was obtained from the relevant institution. The research adhered to the Declaration of Helsinki.

DATA COLLECTION TOOLS

In this study, an “Introductory Form and a Caregiver Burden Scale” were used.

Introductory Form

This section was prepared by the researcher using the relevant literature.[1,2,10,12,14,15] This section includes socio-demographic questions for the child and family and questions about the difficulties experienced by the caregiver in care.

Caregiver Burden Scale

The Caregiver Burden Scale was developed by “Zarit et al.” in 1980.[20] This scale evaluates the stress experienced by caregivers. The Turkish validity and reliability study of the scale was conducted by “İnci and Erdem”.[21] The scale consists of 22 statements. The scale is 0 for “never”, 1 for “rarely”, 2 for “sometimes”, 3 for “quite often”, and 4 for “almost always”. A minimum of 0 and a maximum of 88 points can be obtained from the scale. The score is directly proportional to the problems experienced, a higher score indicates more problems.[21] The Cronbach alpha value of the scale was 0.94, and in this study, the Cronbach alpha value was found to be 0.83.[21]

DATA COLLECTION

To assess the comprehensiveness and comprehensibility of the introductory form, preliminary administration was conducted with 4 primary caregivers. After the pre-application, adjustments were made to the data collection form. Primary caregivers to whom preliminary administration was conducted were not included in the study. The surveys were collected at the child’s home by the researchers, by making an appointment with the child’s primary caregiver and visiting the home. Participants were informed about the study and their verbal and written consent was obtained. Data collection was conducted by the researcher in around 40-60 minutes by face-to-face interviews with the primary caregivers.

DATA ANALYSIS

Data were analyzed using the SPSS 24.0 (IBM SPSS, Türkiye) program. Standard deviation, mean value, frequency and percentage were used in the analysis of descriptive data. Mann-Whitney U and Kruskal-Wallis tests were used to analyze categorical data. Results were considered significant at $p<0.05$ with 95% confidence interval.

RESULTS

The mean total caregiving burden score was 67.82±12.48. There were no primary caregivers with mild and moderate caregiving burden in the study. It was determined that 18 (32.7%) of the primary caregivers had advanced caregiver burden (52.5±6.90) and 37 (67.3%) of them had extreme caregiver burden scale mean score (75.27±6.06).

The mean age of the children was 11.2±5.99 years and the mean diagnosis time was 9.4±6.23 years. It was found that 69.0% of the children were between 6-18 years of age, 67.7% were male, 52.7% had two or less siblings, 76.3% were fed with NG/PEG and 38.1% were given oxygen with mechanical ventilation at home. Mothers were responsible for 90.9 % of children’s primary care (Table 1).

The caregiving burden score (67.00±16.27) of the caregivers of paralyzed children was higher than that caregivers of non-paralyzed children (67.84±12.57), but there was no statistically significant difference ($p>0.05$). Although no statistically significant relationship was found, caregivers caring for 6 paralyzed children had a higher caregiving burden score than 49 primary caregivers. There was a statistically significant difference between primary caregivers with a child diagnosed with epidermolysis bullosa (80.67±2.88) and those without (67.00±12.81; $p=0.04$) (Table 2).

No significant relationship was found between burden of care and difficulties experienced in home care of children with Complex Health Care Need (CHCN) ($p>0.05$) (Table 3).

The mean caregiver burden score of primary caregivers who stated that their physical health was not affected (60.40±17.15) was higher than those who stated that it was affected (68.48±12.32). However, there was no significant difference between the groups ($p>0.05$) (Table 4). The total mean score of caregiver burden of primary caregivers who stated that mental health was affected (69.39±11.62) was higher than the group that stated that mental health was not affected (46.75±9.32), and there was a sig-

TABLE 1: Comparison of the characteristics of the children with CHCN at home and the total mean score of the caregiver burden (n=55).

Characteristics		n	%	Caregiver Burden Scale $\bar{X}$±SD	Test/p value
Age group	0-1	5	9.1	69.00±9.79	KW=1.097
	1-6	12	21.9	65.25±11.10	p=0.578
	6-18	38	69.0	68.29±13.71	
Gender	Girl	18	32.7	68.28±13.42	MU=309.500
	Boy	37	67.3	67.49±12.74	p=0.673
Number of siblings	2 and below	29	52.7	69.59±11.50	MU=326.500
	3 or more	26	47.3	65.58±13.95	p=0.394
Child nutrition	NG/PEG	42	76.3	67.10±12.60	MU=120.000
	Oral	13	23.7	69.62±13.59	p=0.432
Home-type mechanical ventilation	Using	21	38.1	64.00±12.40	MU=250.000
	Not using	34	61.9	70.17±12.10	p=0.063
Primary caregiver	Mother	50	90.9	68.10±12.12	MU=106.500
	Others*	5	9.1	63.60±19.30	p=0.588

MU: Mann-Whitney U test; KW: Kruskal-Wallis test; *Older sister (2), auntie (1), father (2); CHCN: Complex Health Care Need; SD: Standard deviation; NG: Nasogastric; PEG: Percutaneous endoscopic gastrostomy.

TABLE 2: Comparison of children's disease diagnoses and the total mean score of caregiver burden (n=55).

Children's disease diagnoses*		n	%	Caregiver Burden Scale $\bar{X}$±SD	Test/p value
Diseases of the neurological system (n=55)					
Epilepsy	Yes	31	33.3	69.97±11.08	MU=305.500
	No	24	66.7	64.88±14.57	p=0.258
Paralysis	Yes	6	6.4	67.00±16.27	MU=145.000
	No	49	93.6	67.84±12.57	p=0.957
Cerebral hemorrhage	Yes	5	5.3	62.60±19.42	MU=107.000
	No	50	94.7	68.26±12.17	p=0.598
Mental retardation	Yes	5	5.3	68.00±11.15	MU=121.000
	No	50	94.7	67.72±13.11	p=0.907
Microcephaly	Yes	5	5.3	62.40±17.64	MU=101.000
	No	50	94.7	68.28±12.38	p=0.482
Hypoxic brain	Yes	4	4.3	68.00±14.35	MU=99.500
	No	51	95.7	67.73±12.88	p=0.935
Respiratory system diseases (n=21)					
Respiratory failure	Yes	21	22.5	70.95±8.14	MU=300.000
	No	34	77.5	65.76±14.81	p=0.323
Muscle diseases (n=13)					
Cerebral palsy	Yes	8	8.6	68.00±11.69	MU=186.500
	No	47	91.4	67.70±13.15	p=0.971
Spinal muscular atrophy	Yes	3	3.2	68.12±12.51	MU=53.500
	No	52	96.8	60.33±17.78	p=0.363
Congenital muscular distribution	Yes	2	2.1	70.00±2.82	MU=47.000
	No	53	97.9	67.64±12.89	p=0.886
Dermatological disease (n=1)					
Epidermolysis bullosa	Yes	3	3.2	80.67±2.88	MU=25.000
	No	52	96.8	67.00±12.81	p=0.049

*More than one option ticked; MU: Mann-Whitney U test; SD: Standard deviation.

nificant difference between the groups (p<0.01) (Table 4). The total mean score of primary caregivers who stated that their social relationships were affected by caring for their child (69.66±13.32) was significantly higher than those who stated that they were not affected (48.00±96.00; p<0.01) (Table 4).

TABLE 3: Comparison of the difficulties experienced by the primary caregivers in the care of a child with CHCN at home and the mean total score of the caregiver burden (n=55).

Difficulty in caring for a child with CHCN at home*		n	%	Caregiver Burden Scale $\bar{X}$±SD	Test/p value
Aspiration procedure (n=21)	I am having difficulties	14	66.6	67.07±10.85	MU=261.500
	I'm not having difficulties	7	33.4	67.90±13.46	p=0.622
Use of a home mechanical ventilator (n=21)	I am having difficulties	14	66.6	69.17±11.63	MU=238.500
	I'm not having difficulties	7	33.4	67.28±13.15	p=0.691
Tracheostomy care (n=21)	I am having difficulties	13	61.9	66.08±12.31	MU=240.000
	I'm not having difficulties	8	38.1	68.26±13.11	p=0.513
Positioning (n=55)	I am having difficulties	28	50.9	70.79±10.25	MU=293.000
	I'm not having difficulties	27	49.1	64.59±14.62	p=0.150
Personal hygiene (n=55)	I am having difficulties	25	45.4	68.52±11.30	MU=367.000
	I'm not having difficulties	30	54.6	67.10±14.17	p=0.890
PEG care (n=22)	I am having difficulties	9	40.9	64.22±12.34	MU=162.500
	I'm not having difficulties	13	59.1	68.37±12.86	p=0.310
Feeding (n=55)	I am having difficulties	21	38.1	71.38±9.11	MU=288.500
	I'm not having difficulties	34	61.9	65.50±14.36	p=0.235
Oral care (n=55)	I am having difficulties	18	32.7	69.83±11.14	MU=297.000
	I'm not having difficulties	37	67.3	66.73±13.63	p=0.518

*More than one option ticked; MU: Mann-Whitney U test; CHCN: Complex health care need; SD: Standard deviation; PEG: Percutaneous endoscopic gastrostomy.

TABLE 4: Comparison of the total mean score of the primary caregiver's health and economic status and the caregiver burden (n=55).

Effects on the life of the primary caregiver		n	%	Caregiver Burden Scale $\bar{X}$±SD	Test/p value
Physical health	Affected	50	90.9	68.48±12.32	MU=90.000
	Not affected	5	9.1	60.40±17.15	p=0.305
Mental health	Affected	51	92.7	69.39±11.62	MU=14.000
	Not affected	4	7.3	46.75±9.32	**p=0.002**
Social relations	Affected	50	90.9	69.66±13.32	MU=20.500
	Not affected	5	9.1	48.00±96.00	**p=0.002**
Economic status	Affected	47	85.4	67.77±13.55	MU=166.000
	Not affected	8	14.6	67.25±6.98	p=0.599

MU: Mann-Whitney U test; SD: Standard deviation.

DISCUSSION

Developments in medical technology increase the survival rate of children with CHCN, and it has emerged that the health care needs of these children should continue in the home environment.[2] With all these developments, the continuation of health care in the home environment is crucial in terms of child health and quality of life; however, it causes huge care responsibilities and difficulties for primary caregivers and families who take care of the child.[22]

In the study, mothers (90.9%) mostly undertake the primary care task of children with CHCN. Similar findings are found in studies on the subject. In the world literature, it has been stated that the primary caregivers of these children are their mothers.[23,24] Likewise, in studies in Türkiye, it has been revealed that the primary caregivers of children are their mothers.[15,16] In studies both in the world and in Türkiye, it is considered that the primary care task of children is on mothers, due to the role attributed to women by society.

It was determined that the primary caregivers of children with CHCN did not have any difficulties in caring for the children. Primary caregivers have difficulties in aspirating children (66.6%), using a home mechanical ventilator (66.6%), performing tracheostomy care (61.9%), and positioning (50.9%), respectively. This finding of the study on the care in which primary caregivers have difficulties is similar to the findings of studies conducted in Türkiye and abroad. Flynn et al., it was stated that they had difficulty in tracheostomy care, and Brotherton et al., were found to have difficulty in PEG care.[14,25] In another study conducted in our country, it was reported that primary caregivers had difficulty positioning and feeding their children.[13] It is thought that the burden of primary caregivers will be reduced if health professionals (especially nurses) support families, provide education and counseling about the difficulties experienced by caregivers of children with CHCN at home (aspiration, positioning, feeding, etc.).[1]

Families of children in need of medical care cannot perform their daily routine activities due to the responsibilities of their care.[26] This situation causes primary caregivers to disengage from social life and deterioration of family, friend, and neighbor relationships. This situation adversely affects the social well-being of the caregiver.[27] In a study, it was suggested that primary caregivers could not fulfill their social activities due to the long durations allocated to the care of children.[4] In another study, it was found that 64% of primary caregivers had problems in allocating time for their social activities, 61% did not have enough energy to participate in social activities, and 35% were socially isolated.[2] Similar results were obtained in this study.

In this study, the mental well-being of the primary caregivers was adversely affected, and the caregiver burden of the group whose mental well-being was adversely affected was higher. In the study of Boss et al. it was stated that the mental health of caregivers of children with CHCN at home is under threat.[1] In the study of Nkoy et al. it is stated that caregivers of children with CHCN at home are negatively affected psychologically.[28] Caregivers who stated that they were negatively affected psychologically reported many symptoms such as anxiety, fear, frustration, anger and depression.[29] When we look at the studies on the subject the negative impact on the mental well-being of the primary caregivers of children with CHCN at home is similar to the finding in this study.[1,28]

In this study, it was observed that the primary caregivers had a very high caregiver burden (67.82±12.48) and the majority (37 primary caregivers) had an excessive caregiver burden (75.27±6.06). When the domestic and international literature is reviewed, it is noticed that in some studies, the caregiver burden of primary caregivers is much lower than the average caregiver burden of this study, and in some studies, the burden of care is similar to the finding of this study.[17,28] Adib-Hajbaghery and Ahmadi it is found that primary caregivers have a caregiver burden score of 39.04±15.14 and the majority of them experience a moderate burden.[29] Türe et al. it is found that caregivers have a caregiver burden score of 47.64±15.31 and most of them have an advanced care burden.[17] In this study, it is thought that the caregiver burden of primary caregivers is higher than the studies in the literature because children have more than one chronic disease and CHCN.

CONCLUSION

As a result of this research, almost all of the primary carers of children with CHCN at home are mothers. They fulfil both parenting and health care roles. While fulfilling these roles, primary carers experience some difficulties in caring for the child. The majority of primary caregivers experienced difficulties in aspiration, using home mechanical ventilation, providing tracheostomy care and positioning. Although there was no statistically significant relationship between caregiving difficulty and caregiving burden, caregiving burden scores were high. It has been reported that physical and mental health, social relations and economic status of caregivers are also affected in the process of caregiving.

Practical training and counseling should be provided in line with the needs of primary caregivers. With the training and counseling services to be provided, caregivers can be empowered about the difficulties they experience in care and the burden of caregiving can be reduced. Home care nurses should provide planned multidisciplinary collaboration in assessing the physical, psychological, social and economic needs of caregivers in all dimensions.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct con-

nection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

***Idea/Concept:** Merve Yetimoğlu, Hacer Kobya Bulut; **Design:** Merve Yetimoğlu, Hacer Kobya Bulut; **Control/Supervision:** Hacer Kobya Bulut; **Data Collection and/or Processing:** Merve Yetimoğlu; **Analysis and/or Interpretation:** Hacer Kobya Bulut, Merve Yetimoğlu; **Literature Review:** Merve Yetimoğlu; **Writing the Article:** Merve Yetimoğlu, Hacer Kobya Bulut; **Critical Review:** Hacer Kobya Bulut; **References and Fundings:** Merve Yetimoğlu, Hacer Kobya Bulut; **Materials:** Merve Yetimoğlu, Hacer Kobya Bulut.*

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