



# The Caregiver Burden of Mothers of Patients Who Received Tracheostomy in a University Hospital Pediatric Intensive Care Unit

Bir Üniversite Hastanesi Çocuk Yoğun Bakım Servisinde Trakeostomi Açılan Hastaların Annelerinin Bakım Verme Yükü

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## Abstract

**Introduction:** The aim of this study was to determine the caregiver burden of mothers of patients who were treated in a university hospital pediatric intensive care unit and had tracheostomy.

**Methods:** The mothers of 41 patients who were hospitalized and received tracheostomy at Çukurova University Medical Faculty Pediatric Intensive Care Unit between 10.06.2020-31.12.2020 were included in the study. A data collection form consisting of three parts was used to collect the data. With the "caregiver and socio-demographic information form" in the first section, the data belonging to the mother and family were obtained. With the "care given information form" in the second section, the data belonging to the child with tracheostomy were obtained. With the "caregiver burden inventory" in the third section, the caregiver burden of mothers was determined.

**Results:** The mean caregiver burden total score of the mothers was 40.2±14.3 (16.0-81.75). The caregiver burden sub-scores were detected from the highest to the lowest in the form of time-dependence burden, developmental burden, physical burden, social burden and emotional burden. The caregiver burden total score was found significantly higher in mothers whose families receive economic support, who have health problems after their child's tracheostomy care has started, who have difficulties in caring for their children, who have difficulties in meeting the needs of other members of their family.

**Conclusion:** It is of great importance to reduce the caregiver burden of mothers who care for children with tracheostomy to provide effective care and to protect and improve the health status of both the mother and the child with tracheostomy.

**Keywords:** Mothers, caregiver burden, tracheostomy, child with tracheostomy

## Öz

**Giriş:** Bu araştırmanın amacı bir üniversite hastanesi çocuk yoğun bakım servisinde tedavi görmüş ve trakeostomi açılmış hastaların annelerinin bakım verme yükünün saptanmasıdır.

**Yöntemler:** Çukurova Üniversitesi Tıp Fakültesi Çocuk Yoğun Bakım Servisi'nde 10.06.2020-31.12.2020 tarihleri arasında yatarak tedavi görmüş ve trakeostomi açılarak izlenmiş 41 hastanın annesi araştırmaya dahil edilmiştir. Verilerin toplanmasında üç bölümden oluşan bir veri toplama formu kullanılmıştır. Birinci bölümde yer alan "bakım veren ve sosyo-demografik bilgi formu" ile anne ve aileye ait veriler elde edilmiştir. İkinci bölümde yer alan "bakım verilen bilgi formu" ile trakeostomili çocuğa ait veriler elde edilmiştir. Üçüncü bölümde yer alan "Bakım verenlerin yükü envanteri" ile annelerin bakım verme yükü belirlenmiştir.

**Bulgular:** Annelerin bakım verme yükü toplam puanı ortalaması 40,2±14,3 (16,0-81,75) olarak saptanmıştır. Bakım verme yükü alt puanlarının en yüksekte en düşüğe doğru zaman-bağımlılık yükü, gelişimsel yük, fiziksel yük, sosyal yük ve duygusal yük şeklinde olduğu saptanmıştır. Ailesi ekonomik destek alan, çocuğunun trakeostomi bakımı başladıktan sonra rahatsızlık yaşayan, çocuğunun bakımında zorlanan ve ailesinin diğer bireylerinin ihtiyaçlarını karşılamakta zorlanan annelerde, bakım verme yükü toplam puanı anlamlı olarak yüksek bulunmuştur.

**Sonuç:** Trakeostomili çocuklara bakım veren annelerin etkili bir şekilde bakım verebilmesi, hem annenin hem de hasta çocuğun sağlığının korunması ve iyileştirilmesi için annelerin bakım verme yükünün azaltılması büyük önem taşımaktadır.

**Anahtar Kelimeler:** Anneler, bakım veren yükü, trakeostomi, trakeostomili çocuk

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## Introduction

Childhood chronic diseases are increasing gradually and appear as an important health problem in our country as well as in many countries of the world.<sup>1,2</sup> As a result of the developments in intensive care units and the increasing use of mechanical ventilators, tracheostomy has become one of the most frequently performed surgical procedures in children today.<sup>3,5</sup> Since the use of long-term ventilation support in children, the concepts of home mechanical ventilation and long-term care have begun to develop.<sup>4</sup> With home respiratory support, it is aimed to prolong the life of children, prevent them from getting other diseases, improve their physical and psychological conditions, and improve the quality of life of the child and family. Despite all these positive effects, the care of technology-dependent children with tracheostomy can cause fear, anxiety and panic in families.<sup>6,7</sup>

Responsibility for home care of the child brings a lot of burden to the family due to reasons such as treatment method, course of treatment, daily activity restriction, and long-term effects.<sup>2</sup> The concept of caregiving burden is used to express the physical, psychological, emotional, social and economic reactions that can be experienced while providing care to an individual who is unable to perform the activities of daily living due to a physical or mental illness.<sup>1,3</sup> Studies have shown that mothers generally take on the responsibility of providing care for children with chronic diseases, which is due to the widespread view that mothers are more compassionate, have a stronger emotional relationship with their children, and cope with problems better than men.<sup>2,5</sup> In order for parents, especially mothers, to provide effective care in this difficult process, it is of great importance to determine and reduce the burden of caregiving for mothers. In our country, no study has been found about the caregiving burden of caregivers of technology-dependent pediatric patients with tracheostomy, who need continuous and attentive special care. The aim of this study is to determine the caregiving burden of the mothers of the patients who were treated in the pediatric intensive care unit of a university hospital and performed tracheostomy.<sup>8</sup>

## Materials and Methods

The research was designed in descriptive and cross-sectional type. The universe of the study included the mothers of all patients who were hospitalized for treatment and performed tracheotomy in Çukurova University Medical Faculty Pediatric Intensive Care Unit between 10.06.2020 and 31.12.2020, or those responsible for the primary care of children in the absence of mothers. The primary caregivers of all children with tracheostomy who were hospitalized in the pediatric intensive

care unit between the specified dates were informed about the study and the written consent of 41 mothers who agreed to participate in the study was obtained for the study. The research was conducted in accordance with the principles of the Declaration of Helsinki. Ethics committee approval of the study was obtained from Çukurova University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee with the decision no: 12 on 05.06.2020.

## Data Collection

A data collection form consisting of three parts was used to collect the data. The dependent variable of the study was "caregiving burden of mothers" and it was determined with the "caregiver burden inventory" in the third part of the data collection form. The independent variables of the study were the variables questioned in the "caregiver and socio-demographic information form" and "care receiver information form" in the first and second parts of the data collection form. The data collection form was implemented by the researchers with face-to-face interview technique. Some data such as diagnosis, disease duration, and tracheostomy opening time were obtained from the files of the patients.

**Caregiver and socio-demographic information form:** This section consists of 35 items questioning socio-demographic information such as about mother's age, mother's and father's educational status, their employment status and occupation, marital status of parents, permanent place of residence, number of children in the family, the presence of children with other chronic diseases and in need of care in the family, the presence of other people living with the family and those in need of care, the presence of chronic diseases in the mother and father, the perception of income, the family's getting any financial support, the difficulty in meeting the child's health expenses, and the presence of social security, and some information related to mother and care of child with tracheostomy.

**Care receiver information form:** Data on the age and gender of the child with tracheostomy, the diagnosis of the disease requiring tracheostomy, the duration of the disease, the time spent with tracheostomy, the presence of additional disease, whether the child was ventilator-dependent and bedridden were evaluated with 8 questions. Age, duration of disease, and time spent with tracheostomy were calculated based on the day the data were collected.

**Caregiver burden inventory:** It was developed by Novak and Guest<sup>9</sup> and its Turkish validity and reliability study was performed by Küçüköçlü et al.<sup>8</sup> The caregiver burden inventory is a Likert-type (0-4) scale consisting of 24 questions. Scoring is as follows: (0) Point for "never defined", (1) point for "less defined", (2) points for "moderately defined", (3)

points for “highly defined”, and (4) points for “very much defined”. The total score for burden of caregiving total burden (TB) varies between 0 and 100. In addition, sub-scores of time-dependence burden (TDB), developmental burden (DB), physical burden (PB), social burden (SB) and emotional burden (EB) can also be calculated, each scored between 0 and 20 points. In the PB subscale, which consists of four items, the score obtained from each item (0-4) is multiplied by 1.25 and a maximum of 20 points is yielded from this section. The caregiver burden inventory is evaluated as the score increases, the burden of care also increases.<sup>8,9</sup>

### Statistical Analysis

The data obtained from the research were analyzed using the SPSS 22.0 software. The conformity of the data to the normal distribution was evaluated with the Shapiro-Wilk test and histogram, and it was determined that the data other than “mothers’ age” and “caregiver burden inventory TB score” did not comply with the normal distribution. The descriptive data of the study group were evaluated with number and percentage for categorical variables, with mean and standard deviation for continuous variables with normal distribution, and with median, minimum and maximum values for continuous variables without normal distribution. The Mann-Whitney U test was used because parametric conditions could not be met in the pairwise group comparison of the scores obtained from the “caregiver burden inventory”. The relationship between continuous variables and scale scores was evaluated with correlation analyses. The significance level for all analyses was accepted as  $p < 0.05$ .

### Results

In our study, all primary caregivers of children with tracheostomy were mothers (Table 1). More than half of the mothers stated that they had difficulty in meeting the health expenses of their sick children and they received financial support. Of them, 17 received state aid, 3 of them only received financial aid from their family, and 1 of them received both state aid and aid from their family (Table 2).

Of the 4 mothers who stated that they had a chronic disease, 2 stated that they had chronic asthma, 1 had hypertension and thalassemia carrier, and 1 had lumbar hernia. Out of 10 fathers with chronic disease, 2 had chronic heart disease, 2 had hypertension, 1 had diabetes and hypertension, 1 had chronic heart disease and hypertension, 1 had cancer, 1 had epilepsy, 1 had hormonal disorder, and 1 had ankylosing spondylitis. Although none of the families had another children in need of care due to their illness, only one family had a person in need of care other than the child because the father had cancer.

**Table 1. Socio-demographic data of mothers and families**

Characteristic (n=41)	n	%
<b>Primary caregiver</b>		
Mother	41	100.0
<b>Educational status of mother</b>		
Illiterate	2	4.9
Primary school	16	39.0
Middle school	6	14.6
High school	9	22.0
University and above	8	19.5
<b>Working status of mother</b>		
Yes	6	14.6
No	35	85.4
<b>Occupation of mother</b>		
Housewife	35	85.4
Civil servant (5 teachers, 1 health technician)	5	14.6
<b>Educational status of father</b>		
Primary school	11	26.8
Middle school	4	9.8
High school	17	41.5
University and above	9	22.0
<b>Working status of father</b>		
Yes	34	82.9
No	7	17.1
<b>Occupation of father</b>		
Without a specific occupation	4	9.8
Tradesman	9	22.0
Worker	21	51.2
Civil servant	7	17.1
<b>Marital status of parents</b>		
Parents are married and live together	39	95.2
Parents divorced	2	4.8
<b>Permanent residence</b>		
City center	31	75.6
District/town/village	10	24.4
<b>Income perception of family</b>		
My income is less than my expenses	20	48.8
My income covers my expenses	19	46.3
My income is more than my expenses	2	4.9
<b>Family's difficulty in meeting the health expenses of the sick child</b>		
Yes	25	61.0
No	16	39.0
<b>Family's getting financial support</b>		
Yes	21	51.2
No	20	48.8
<b>Family's having social insurance</b>		
Yes	35	85.4
No	6	14.6

Table 1. Continued		
Characteristic (n=41)	n	%
<b>Presence of any chronic disease in mother</b>		
Yes	4	9.8
No	37	90.2
<b>Presence of any chronic disease in father</b>		
Yes	10	24.4
No	31	75.6
<b>Presence of other people living in the home with the family</b>		
Yes	4	9.8
No	37	90.2
<b>Presence of other people in need of care in the family</b>		
Yes (father)	1	2.4
No	40	97.6
Characteristic (n=41)	Minimum-maximum	
Age of mothers (median $\pm$ SD)	35.1 $\pm$ 7.5	(24.0-55.0)
Number of children in the family (median)	2.0	(1.0-5.0)
SD: Standard deviation		

It was detected that one third of the fathers helped the housework and half of them supported the care of the sick child. Mothers who received help with housework and taking care of sick children stated that they mostly got support from family members such as grandmother and aunt, and from paid helpers. Out of 12 mothers who stated that they developed discomfort after their children's having started tracheostomy care, 5 developed lumbar and neck hernia, 2 psychological problems, 1 psychological problems and lumbar hernia, 1 hypertension, 1 urticaria, and 2 insomnia (Table 2).

The mothers specified that the first 3 situations in which they had difficulty in the care of their children were bathing, carrying, and tracheostomy cannula care/nasogastric tube change, respectively. Mothers stated that they called 112 after providing aspiration and respiratory support when they encountered an emergency.

The age and disease duration of children with tracheostomy ranged from 3 months to 17 years, and the time spent with tracheostomy displayed a wide range between 1 month and 12 years. Eleven of 17 children with comorbidities had epilepsy and/or hydrocephalia (Table 3).

In comparisons with the Mann-Whitney U test, the total score of caregiving burden was found to be significantly higher in mothers whose families received financial support, who had discomfort after the start of their child's tracheostomy care, who had difficulty in caring for their child, and who had difficulties in meeting the needs of other members of their family ( $p=0.030$ ,  $p=0.014$ ,  $p=0.011$ , and  $p=0.016$ , respectively) (Tables 4, 5).

Table 2. Some information about the mother and care of the child with a tracheostomy		
Characteristic (n=41)	n	%
<b>Mother's getting support in housework</b>		
Yes	17	41.5
No	24	58.5
<b>Mother's getting support in care of the child with tracheostomy</b>		
Yes	26	63.4
No	15	36.6
<b>Mother's having difficulty in meeting the needs of other members of the family</b>		
Yes	19	46.3
No	22	53.7
<b>Mother's ability to spare time for her husband and, if any, other children</b>		
Yes	21	51.2
No	20	48.8
<b>Development of any discomfort in the mother after the child's tracheostomy care has started</b>		
Yes	12	29.3
No	29	70.7
<b>Mother's receiving psychological support due to her child's illness</b>		
Yes	4	9.8
No	37	90.2
<b>Mother's seeing her own level of knowledge adequate about her child's illness</b>		
Yes	32	78.0
No	9	22.0
<b>Mother's having difficulty in care of the child</b>		
Yes	30	73.2
No	11	26.8
<b>Mother's knowing what to do in case of an emergency</b>		
Yes	41	100.0
<b>Availability of access to a doctor or nurse when needed</b>		
Yes	34	82.9
No	7	17.1
<b>Difficulty in reaching the hospital</b>		
Yes	4	9.8
No	37	90.2
<b>Taking the child for regular controls</b>		
Yes	35	85.4
No	6	14.6
<b>Having difficulty related to ventilator and equipment</b>		
Yes	10	24.4
No	31	75.6
<b>Having problems with the supply of materials</b>		
Yes	14	34.1
No	27	65.9

Table 3. Trak information on the children with tracheostomy		
Characteristic (n=41)	n	%
<b>Gender</b>		
Girl	22	53.7
Boy	19	46.3
<b>Diagnosis of the child's disease requiring tracheostomy</b>		
Spinal muscular atrophy	15	36.6
Neurological/syndromic diseases	14	34.2
Metabolic diseases	6	14.6
Trauma	3	7.3
Chronic lung disease	2	4.9
Arrhythmia	1	2.4
<b>Presence of any comorbidities</b>		
Yes	17	41.5
No	24	58.5
<b>The condition of the child being connected to the ventilator</b>		
Yes	39	95.1
No	2	4.9
<b>The condition of the child being bedridden</b>		
Yes	36	87.8
No	5	12.2
Characteristic (n=41)	Median	Minimum -maximum
Age (year)	5.0	0.25-17.0
Duration of the child's disease (year)	3.0	0.25-17.0
Time spent with tracheostomy (year)	2.0	0.08-12.0

The sub-scores of TDB, DB, PB, SB and EB, and TB score were found to have no significant relationship with the variables of educational status of the parents, working status of the mother, marital status of the parents, permanent place of residence, perception of income, presence of social security, presence of chronic illness in the father, presence of other people living with the family at home, the mother's getting support in housework and in taking care of the sick child, the mother's getting psychological support, the mother's level of knowledge about her child's disease, being able to reach a doctor or nurse when needed, having difficulty in reaching the hospital, taking the child to the control examinations regularly, having problems with the ventilator and equipment and the supply of materials, the child's being ventilator-dependent and bedridden ( $p>0.05$ ).

In the correlation analyses performed, no significant relationship was detected between the age of the mother, the number of children in the family, the age of the child with tracheostomy, the duration of the disease, and the time spent with tracheostomy, and the sub-scores of TDB, DB, PB, SB and EB, and TB score ( $p>0.05$ ).

Table 4. Caregiving burden scores of the mothers		
Caregiving burden sub-dimensions (n=41)	Median	Minimum-maximum
Time-dependence burden (TDB)	19.0	16.0-20.0
Developmental burden (DB)	8.0	0.0-18.0
Physical burden (PB)	7.5	0.0-20.0
Social burden (SB)	3.0	0.0-17.0
Emotional burden (EB)	0.0	0.0-20.0
<b>Total burden (TB) (mean <math>\pm</math> SD)</b>	<b>40.2<math>\pm</math>14.3</b>	<b>16.0-81.75</b>
While the TB score is in accordance with the normal distribution, the sub-scores of TDB, DB, PB, SB, and EB do not comply with the normal distribution. SD: Standard deviation		

## Discussion

Our research has been an important study in terms of determining the caregiving burden of the mothers of pediatric patients with tracheostomy and examining the factors affecting this situation. In our study, all primary caregivers of children with tracheostomy were mothers. Similarly, in the study conducted by Şişmanlar Eyuboglu et al.<sup>10</sup>, all the caregivers of children with tracheostomy were reported to be mothers. In various studies conducted in our country, it is stated that mothers are mostly responsible for providing care for children with chronic diseases, and this supports the findings of our study.<sup>1-5,11-13</sup>

The TDB sub-score was found to be significantly higher when the father was working than when he was not working. While calculating the TDB sub-score, the level of care receiver's dependency in daily routine activities and in meeting basic needs (eating, drinking, bathing, dressing, etc.) is questioned. Considering that almost all of the pediatric patients with tracheostomy in this study were bedridden, and TDB score constituted the highest part of the total caregiving burden score of the mothers, it is seen that the burden of the mothers in meeting the basic needs of the sick child is quite high. It is thought that this result was reached because most of the fathers worked, they less supported the mother and they could not share the burden of the mother sufficiently.

The EB sub-score was found to be significantly higher in mothers with chronic disease compared to those without. Studies have shown that individuals who care for people with chronic diseases experience depression, fatigue, and burnout as well as feelings of fear, anxiety, anger, helplessness, and anxiety.<sup>1,2,4,13,14</sup> It is an expected result that the process of caring for a child with tracheostomy, which is quite difficult even for healthy individuals, is much more difficult and emotionally more exhausting for mothers with chronic diseases.

The EB sub-score was found to be significantly higher in those who had other family members in need of care compared to those who did not. Similarly, the EB sub-score was detected to be significantly higher in those with three or more children

**Table 5. The effect of some variables on mothers' caregiving burden scores**

Variables		TDB	p	DB	p	PB	p	SB	p	EB	p	TB	p
Working status of father	Yes	20.00	<b>0.036</b>	6.50	0.986	7.50	0.753	2.00	0.427	0.00	0.352	37.88	0.862
	No	17.00		9.00		7.50		4.00		0.00		41.00	
Presence of any chronic disease in mother	Yes	20.00	0.180	7.50	0.929	20.00	0.066	5.00	0.282	1.00	<b>0.042</b>	55.50	0.147
	No	19.00		8.00		6.25		2.00		0.00		38.00	
Presence of other people in need of care in the family	Yes	19.00	0.786	9.00	0.865	6.25	0.733	5.00	0.379	2.00	<b>0.023</b>	41.25	0.672
	No	19.50		7.50		8.13		2.50		0.00		39.25	
Family's getting financial support	Yes	19.00	0.616	10.00	0.054	10.00	0.134	4.00	0.197	1.00	<b>0.011</b>	41.25	<b>0.030</b>
	No	19.50		4.50		6.25		0.50		0.00		33.13	
Family's difficulty in meeting the health expenses of the sick child	Yes	20.00	0.474	10.00	<b>0.035</b>	8.75	0.427	4.00	<b>0.022</b>	0.00	0.240	41.00	0.059
	No	19.00		4.500		6.25		0.00		0.00		31.38	
Development of any discomfort in the mother after the child's tracheostomy care has started	Yes	20.00	0.915	10.00	0.370	15.00	<b>0.004</b>	4.00	0.101	0.00	0.200	49.5	<b>0.014</b>
	No	19.00		6.00		6.25		2.00		0.00		33.25	
Mother's having difficulty in care of the child	Yes	19.50	0.264	8.50	0.091	9.38	0.054	4.00	<b>0.004</b>	0.00	0.473	41.00	<b>0.011</b>
	No	18.00		2.00		5.00		0.00		0.00		30.00	
Mother's having difficulty in meeting the needs of other members of the family	Yes	20.00	<b>0.024</b>	9.00	0.316	10.00	0.144	4.00	<b>0.003</b>	0.00	0.251	41.25	<b>0.016</b>
	No	18.00		6.00		6.25		0.00		0.00		32.75	
Mother's ability to spare time for her husband and, if any, other children	Yes	19.00	0.181	8.00	0.813	6.25	0.400	0.00	<b>0.008</b>	0.00	0.329	38.00	0.155
	No	20.00		7.50		8.13		4.50		0.00		40.75	
Mother having two or less children		19.00	19.00	0.756	6.00	0.186	6.88	0.769	2.50	0.601	0.00	<b>0.028</b>	36.50
Mother having three or more children		20.00		10.00		8.75		3.00		1.00		41.00	

Mann-Whitney U test was performed, TDB: Time-dependence burden, DB: Developmental burden, PB: Physical burden, SB: Social burden, EB: Emotional burden, TB: Total burden

compared to those with two or fewer children. The burden of caregiving is expected to be high in those who care for more than one person. The results of Erdem et al.'s<sup>2</sup> study also support this expectation. The high EB score in our study was interpreted as mothers who cared for more than one person had difficulty mostly in emotional aspect.

The EB sub-score and TB score were found to be significantly higher in those whose families received financial support compared to those who did not. Although this result suggests that it should be the opposite at first glance, it is an expected result when it is considered that "the people who receive economic support are the ones who need economic support the most and therefore have the most financial difficulties". In the study by Erdem et al.<sup>2</sup>, it was seen that the mothers in the group who stated that they had economic difficulties most were also the mothers in the group that received the higher support. In parallel with this result, in our study, DB and SB sub-scores were found to be significantly higher in those who had difficulty in meeting their child's health expenses compared to those who did not. While calculating the DB sub-score, the caregiver's thoughts about his/her own life, expectations from life and sense of burnout are questioned.

While calculating the SB sub-score, the caregiver's relationship with family members and other individuals and his/her social life are questioned. Considering the continuous care of the sick child, mother usually withdraws from working life and has to deal with the child's care and housework all day, while father may have to work harder to meet the needs of family members and the sick child due to financial difficulties. This situation negatively affects family dynamics, personal relationships and social life, causing a feeling of inadequacy and burnout. In addition, the care of the child with tracheostomy can create an extra financial burden on the family, as he/she is technology dependent and requires special equipment and materials.<sup>2,4,5,15-17</sup> Therefore, in our study, it was thought that the sub-scores of TB and EB, DB, SB were higher in those who had financial difficulties.

In mothers who experienced discomfort after their child's tracheostomy care started, the PB sub-score and TB score were found to be significantly higher, compared to those who did not. While calculating the PB sub-score, mothers' physical health, fatigue level, and sleep quality are questioned. Approximately one-third of the mothers stated that they developed discomfort after their child started tracheostomy

care. Similar to our findings, in the study of Erdem et al.<sup>2</sup>, it was reported that health problems developed in almost half of the mothers following the diagnosis of their child.

Home care of a child with tracheostomy is a complex process that requires knowledge and skills about tracheostomy care and what to do in an emergency. The fact that the child with tracheostomy is mostly dependent on the machine and the bed brings full day responsibility to the caregiver and causes limitations in the daily activities and social lives of the families.<sup>4,17-19</sup> Supporting all these, in our study, the SB sub-score and TB score were found to be significantly higher in mothers who had difficulty in caring for their child with tracheostomy compared to those who did not.

Mothers who had difficulty in meeting the needs of other members of their family had significantly higher TDB and SB sub-scores and TB score than those who did not. Parallel to this finding, the SB sub-score was found to be significantly higher in mothers who could not spare time for their spouse and other children compared to those who could. In our study, it was determined that a significant part of the mothers took on the burden of the care of the sick child alone. In Kiran's study<sup>4</sup>, families having children with tracheostomy stated their most experienced difficulties as that they could not spare enough time for themselves, they made their daily plans according to their sick children, they had difficulties in meeting the needs of other individuals in the house and they could not spare enough time for them, which supports our findings.

Most of the studies in the literature are those on children with chronic diseases and they have been conducted using the zarit caregiver burden scale.<sup>20,21</sup> The reason why we preferred the "caregiver burden inventory" developed by Novak and Guest<sup>9</sup> is that it offers the opportunity to evaluate the care burden in 5 different sub-dimensions in addition to the total score of caregiver burden.<sup>8</sup> The strength of this study is that it is the first study in our country to evaluate the burden of caregiving from five different perspectives on mothers who care for children with tracheostomy.

### Study Limitations

The limitation of the study is that the number of participants was limited to 41 people, as the patients with tracheostomy were not admitted to the intensive care unit unless they were in a very difficult situation due to the pandemic.

### Conclusion

The total score of caregiving burden was found to be significantly higher in mothers who had financial difficulties, had discomfort after their child's tracheostomy care started, had difficulty in caring for their children with tracheostomy,

and had difficulty in meeting the needs of other members of the family. In addition, the caregiving burden sub-scores of mothers who cared for children with tracheostomy were found to be time-dependent burden, developmental burden, physical burden, social burden and emotional burden, from the highest to the lowest. It is of great importance to reduce the caregiving burden of mothers in order to protect and improve the health of both the mother and the sick child, so that mothers could provide effective care for children with tracheostomy. In line with the results obtained from this research, in order to reduce the burden of caregiving, it is recommended to support mothers both in terms of labor force and financially, to meet their physical health and psychosocial needs professionally, to share individuals, institutions and organizations that can provide financial and moral support with the family, and to develop home care and monitoring policies for children in need of home care.

### Ethics

**Ethics Committee Approval:** Ethics committee approval of the study was obtained from Çukurova University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee with the decision no: 12 on 05.06.2020.

**Informed Consent:** The primary caregivers of all children with tracheostomy who were hospitalized in the pediatric intensive care unit between the specified dates were informed about the study and the written consent of 41 mothers who agreed to participate in the study was obtained for the study.

**Peer-review:** Externally peer-reviewed.

### Authorship Contributions

Concept: D.Ö.H., C.H., Ö.Ö.M., D.Y., Design: D.Ö.H., C.H., Ö.Ö.M., D.Y., Data Collection or Processing: D.Ö.H., C.H., Ö.Ö.M., Analysis or Interpretation: D.Ö.H., Literature Search: D.Ö.H., C.H., Ö.Ö.M., D.Y., Writing: D.Ö.H.

**Conflict of Interest:** No conflict of interest was declared by the authors.

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