

Original Article

Examining Care Burden, Social Support, and Loneliness in Parents of Children with Cerebral Palsy

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Abstract

Background: In studies examining parents' burden of care, social support and loneliness, either mothers were studied only, or mothers that made up the majority of the sample were studied. It is thought that fathers as well as mothers are involved in the care of their children and are affected by the negative consequences of this process.

Objective: This study was conducted to investigate care burden, social support, and loneliness in parents of children with cerebral palsy (CP).

Methodology: This study was carried out as a descriptive study with parents of 178 children with CP for whom both parents could be reached. The Descriptive Information Form, Burden Interview, Multidimensional Scale of Perceived Social Support (MSPSS), and UCLA Loneliness Scale were used as data collection tools.

Results: It was determined that the care burden for mothers was higher than the care burden for fathers and that mothers' perceived social support and loneliness levels were lower. In addition, it was determined that there was no significant correlation between the care burden, social support, and loneliness levels of mothers and fathers. As a result of the structural equation model, it was determined that the social support of the parents had a significant effect on the care burden ($\beta = -0.105$; $p < 0.05$) and their loneliness ($\beta = 0.40$; $p < 0.05$).

Conclusions: Healthcare professionals should encourage parents to share the care burden and cope with loneliness by shouldering equal responsibilities within the scope of family-centred care.

Keywords: Cerebral palsy, care burden, social support, loneliness, parent

Introduction

Cerebral palsy (CP) is the most common motor disorder in childhood (Stavsky et al., 2017), and its prevalence is reported to be 1–5 per 1,000 live births, although this varies across societies (Sucuoglu, 2018). In a study conducted with children aged between 2 and 16 years in the society in which this study was conducted, the prevalence of CP was determined to be 4.4 per

1000 live births (Serdaroglu et al., 2006). Parents are primarily responsible for the care of their children and meeting the needs of the child. The responsibilities of parents of children with special needs are even greater (Demircioglu et al., 2018). These parents must make changes in their private lives, social environments, life expectancies, plans, work lives, and family functions (Kirbas & Ozkan, 2013). In one study, parents of special

needs children reported that their social lifestyles were different from those of parents who have no children with special needs and that they spent more time on tiring tasks as compared to such parents (Ozkubat et al., 2014). Children with physical developmental disabilities are dependent on their parents, and this causes parents to experience difficulties with care (Girgin Aykanat & Balci, 2015). In a study conducted by Piran et al. (2017) to investigate the care burden of the parents of children with chronic disease, they reported that the care burden of parents of children with CP was higher than the care burden of parents of children with other chronic diseases (Piran et al., 2017). In their study, Marron et al., (2013) stated that the care burden of parents increased as the degree of disability of the child with CP increased (Marron et al., 2013). It was reported that the social support levels of mothers increased as the burden on families increased (Sivrikaya & Cifci Tekinarslan, 2013).

Social support plays an important role in parents coping with their care burden, but it has been stated that parents with disabled children have inadequate social support and family members, especially mothers, isolate themselves from the social environment (Cigerli et al., 2014). There are also studies reporting that social support for parents affects their levels of life satisfaction (Cattik & Aksoy, 2018; Ekas et al., 2010) and psychological well-being (Ekas et al., 2010) in a positive way. In a study conducted by Karadag (2009) concerning mothers with disabled children, it was found that mothers who were concerned about the futures of their children had feelings of disappointment and guilt, difficulty dueing the treatment process, and low social support levels (Karadag, 2009).

Insufficient social relationships and low levels of satisfaction with these relationships form the basis of loneliness (Yildiz Bicakci & Yasar, 2019). Another study found a negative correlation between social support and loneliness levels (Yilmaz et al., 2008). In a study conducted with mothers of children with mental disorders, it was found that as the disability level of the children increased, the loneliness levels of their mothers also increased (Yildiz Bicakci & Yasar, 2019).

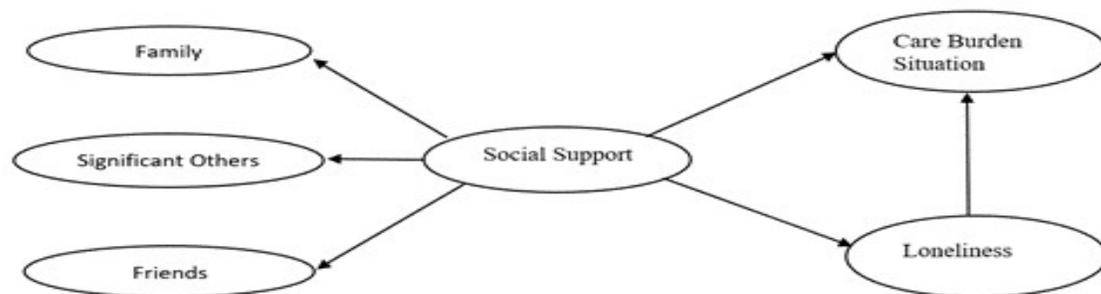
Having a child with CP can cause parents to experience problems related to care burden, social support and loneliness. According to literature reviews, the majority of the studies conducted with parents of children with CP or special needs have been conducted with mothers because they are accepted as the primary caregivers (Albayrak et al., 2019; Calisir et al., 2018). No study was found investigating care burden, social support, and loneliness among fathers, who are members of the family and have as much of a responsibility to provide care as the mother. The aim of this study was to examine mothers and fathers together.

Methodology

Study design : This descriptive study was conducted to investigate care burden, social support, and loneliness among parents of children with CP.

Sample and setting: The study was conducted with parents of children with CP who were followed up on in the paediatric clinics of a University Hospital located in the Southeastern Anatolia Region. Here, the Child-1 clinic has 18 beds, the Child-2 clinic has 18 beds, Paediatric Neurology has 16 beds and two nurses were working on each shift.

Figure 1. Theoretical model proposed in the study



Recruitment and study procedures: The researcher attempted to reach the entire population, without using any sampling method. The study was completed with the parents of 178 children with CP who could be reached and met the inclusion criteria. The inclusion criteria for parents were as follows: being over the age of 18, having a child with CP in the age group of 1–18 years, reaching both parents, and both parents agreeing to participate in the study.

Data collection: The Descriptive Information Form, Burden Interview, Multidimensional Scale of Perceived Social Support (MSPSS), and UCLA Loneliness Scale were used as data collection tools.

Descriptive Information Form: This form consists of 18 questions on the sociodemographic characteristics of the parents and children.

Burden Interview: The Burden Interview was developed in 1980 by Zarit, Reever and BachPeterson to evaluate the stress experienced by people providing care to an individual or an elderly person with care needs. An adaptation, validity and reliability study of the scale for the Turkish culture was conducted by Inci in 2006. The Burden Interview is a 22-point Likert-type scale ranging from 0 to 4 (0=never, 1=rarely, 2=sometimes, 3=often, 4=almost always). It can be filled out with the caregivers themselves or by the researcher after asking the caregivers the questions. The lowest possible score is 0 points, and the highest possible score is 88 points. A high scale score signifies that the distress experienced is high. If the score taken from the scale is between 0 and 20, this indicates “no care burden”. A score between 21 and 40 refers to a “mild care burden”. A score between 41 and 60 refers to a “moderate care burden”, and a score between 61 and 88 refers to a “severe care burden”. It was reported in the validity and reliability study that the internal consistency coefficient of the scale varied between 0.87 and 0.94, test-retest reliability was 0.71 and internal consistency coefficient was 0.95 (Inci, 2006; Inci & Erdem, 2008). In the present study, the Cronbach’s Alpha value was calculated to be 0.97.

Multidimensional Scale of Perceived Social Support (MSPSS): This scale was developed by Zimet et al. (1988). Eker et al. conducted a Turkish validity and reliability study in 2001. The MSPSS is a scale consisting of twelve items.

It has a total of three subscales, each of which has four items. These three subscales are family, friends, and significant others. Each item is rated using a seven-interval scale. By collecting the scores of the four items in each subscale, the subscale score is obtained, and the total score of the scale is obtained by collecting all the subscale scores. A high score indicates that the perceived social support level is high (Eker et al., 2001). In the present study, the Cronbach’s alpha value was calculated to be 0.99.

UCLA Loneliness Scale: This scale was developed in 1978 by Russell, Peplau and Ferguson, and its psychometric properties were then reviewed in 1980 by Russell, Peplau and Cutrona. Finally, a new version was prepared by Russell in 1996. A Turkish adaptation of the scale was first conducted by Yaparel in 1984, and a more updated adaptation of the scale was made by Demir in 1989. In his study, conducted with the Turkish version of the scale, a high internal consistency coefficient of 0.96 was obtained, as in the study conducted with the original version. The scale is a four-point Likert-type scale with 20 items (1=inappropriate, 2=rarely appropriate, 3=sometimes appropriate, 4=often appropriate). While scoring, positive statements are scored in reverse fashion, unlike negative statements (1=4, 2=3, 3=2, 4=1). These positive items are represented with the item numbers 1, 4, 5, 6, 9, 10, 15, 16, 19 and 20 in the scale. While the lowest possible score for the scale is 20, the highest is 80. As the score obtained from the scale increases, the sense of loneliness also increases (Demir, 1989). In the present study, the Cronbach’s Alpha value of the study was calculated to be 0.86.

Data management and analysis: In the evaluation of the study data, the IBM SPSS Statistics 25.0 software package was used. Percentage, mean, standard deviation, multiple linear regression, and correlation analyses were used to assess the data. The statistical significance level was accepted as $p < 0.05$. The AMOS 24 program was used for structural equation model analysis to assess the role of parents' social support on care burden and quality of life. The role of parents' social support on care burden and loneliness was evaluated by looking at the standardized regression coefficients (β). "CMIN/DF, GFI, CFI, and RMSEA" values were checked to evaluate the validity of the model. The fact that the CMIN/DF value is 0-3, the GFI

and CFI values are above 0.95, and the RMSEA value is below 0.08 indicates that the model is acceptable (Ilhan & Cetin, 2014).

Ethical Dimension of the Study: Before starting the study, the necessary ethics committee permission (Ethics Committee No: 2019/363) was obtained from the Scientific Research and Publication Ethics Committee (Health Sciences Non-Interventional Clinical Trials Ethics Committee). The aim of the study was explained to the parents, and their verbal consent was obtained.

Results

When the sociodemographic characteristics of the parents were examined, it was determined that the majority of the parents were illiterate (52.5%), that most of them were employed (71.5%) and that many had a moderate care burden (41.4%) (Table 1). When the mean care burden, social support and loneliness scale scores of the parents were examined, it was found that they were 48.41 ± 15.39 , 52.45 ± 19.59 and 53.49 ± 6.26 , respectively (Table 2).

It was determined that there was a statistically significant correlation between the gender, education and working status of parents; the care burden levels of parents; and the care loads of parents. The parents who were illiterate, were unemployed and had a severe care burden were determined to have higher mean care burden scores (Table 3). There was a statistically significant correlation between the parents' gender, education and working status; care burden levels and perceived social support. The parents who had primary completed school, were employed and had a significant care burden had higher mean scores for social support (Table 3). When the factors affecting the loneliness of the parents were examined, there was a statistically significant correlation between the parents'

gender, education and working status; care burden levels and loneliness. Mothers who had at least a primary school education, were employed, had no or mild care burdens and had higher mean loneliness scores (Table 3).

According to the results of the correlation analysis, a negative and weak correlation was found between the care burden of mothers and perceived social support. There was a negative and weak correlation between the care burden of the father and perceived social support and a negative and low correlation between the care burden of the father and loneliness. A positive and weak correlation was found between the loneliness of father and perceived social support (Table 4).

The structural equation model was established and tested to determine the effects of care burden, social support and loneliness of parents on each other. In the model, social support was determined as an independent variable and care burden and loneliness were determined as dependent variables. Standardized estimation results of the model are shown in Figure 2. It was determined that the "CMIN/DF=1.198, GFI=0.994, CFI=1.000 and RMSEA=0.025" fit indices related to the established model have acceptable fit values. When the standardized regression (Beta) coefficients were examined, it was seen that parents' perceptions of social support had a positive effect ($\beta=0.40$; $p<0.05$) on their loneliness. It was determined that parents' perceptions of social support had a negative effect ($\beta = -0.105$; $p < 0.05$) on care burden. In the model, the effect of the loneliness on the care burden of the parents was also examined and it was found that the loneliness had a negative effect ($\beta=-0.110$; $p < 0.05$) on the care burden. It was determined that the compliance rate of the established model was 43.32%. (Figure 2, Table 5)

Table 1. Sociodemographic characteristics of the parents.

	Number (n)	Percentage (%)
Mean age	31.30±9.77	
Education level of the parents		
Illiterate	171	52.5
Primary school	99	30.4
Secondary school and higher	56	17.1
Working status of the parents		

Unemployed	93	28.5
Employed	233	71.5
Care burden levels of the parents *		
No care burden	11	3.4
Mild care burden	97	29.7
Moderate care burden	135	41.4
Severe care burden	83	25.5

*Determined according to the score range of the burden interview.

Table 2. Mean care burden, social support and loneliness scores of the parents

Scales	Mean ± Sd	Median (Min- Max)
Burden interview	48.41±15.39	52.00 (15.00- 88.00)
Social support scale	52.45±19.59	56.00 (12.00- 84.00)
Loneliness Scale	53.49±6.26	53.00 (40.00- 67.00)

Table 3. Comparison of sociodemographic characteristics of the parents with their care burden, social support and loneliness scale mean scores.

	N	Care interview Total Score	Social Support Scale Total Score	Loneliness Scale Total Score
		Mean±Sd	Mean±Sd	Mean±Sd
Parent's gender				
Mother	163	61.07±7.12	37.16±15.31	48.48±3.66
Father	163	35.74±10.00	67.83±7.87	58.47±3.89
Test		t=26.191	t=-22.691	t=-23.809
		p=0.000	p=0.000	p=0.000
Education status of the parents				
Illiterate	171	51.13±15.65	49.73±20.99	52.64±6.23
Primary school	99	43.44±15.41	56.77±17.68	55.39±6.42
Secondary school and higher	56	48.87±12.33	53.19±17.06	52.70±5.38
Test		KW=14.986	KW=6.154	KW=11.108
		p=0.001	p=0.046	p=0.004
Working status of parents				
Unemployed	93	59.79±7.45	37.17±14.76	48.05±3.64
Employed	233	43.86±15.40	58.58±17.88	55.63±5.77
Test		t=9.530	t=-10.227	t=-11.711
		p=0.000	p=0.000	p=0.000
Care burden levels of parents				
No care burden	11	18.36±1.80	72.00±2.40	59.36±3.90
Mild care burden	97	31.12±4.78	68.40±7.29	59.13±4.13
Moderate care burden	135	52.32±6.15	51.00±17.98	52.16±5.11
Severe care burden	83	66.22±5.39	33.56±14.59	48.21±4.23
Test		KW=288.228	KW=152.035	KW=151.318

		p=0.000	p=0.000	p=0.000
The gender of the child with CP				
Girl	143	49.62±15.66	51.49±20.32	53.38±6.34
Boy	183	47.46±15.16	53.20±19.02	53.57±6.22
Test		t=1.257	t=-0.782	t=0.934
		p=0.210	p=0.435	p=0.791

Table 4. The correlation between parents’ care burden, social support and loneliness levels.

		Social support Mother	Loneliness Mother	Care Burden Father	Social support Father	Loneliness Father
Care burden Mother	r	-0.284**	-0.010	-0.103	0.044	0.098
	p	0.000	0.896	0.192	0.576	0.212
Loneliness Mother	r	0.041		0.120	0.123	-0.027
	p	0.608		0.128	0.121	0.734
Care burden Father	r	0.068	0.120		-0.227**	-0.314**
	p	0.390	0.128		0.004	0.000
Social support Father	r	0.047	0.123	-0.227**		0.175*
	p	0.554	0.121	0.004		0.026

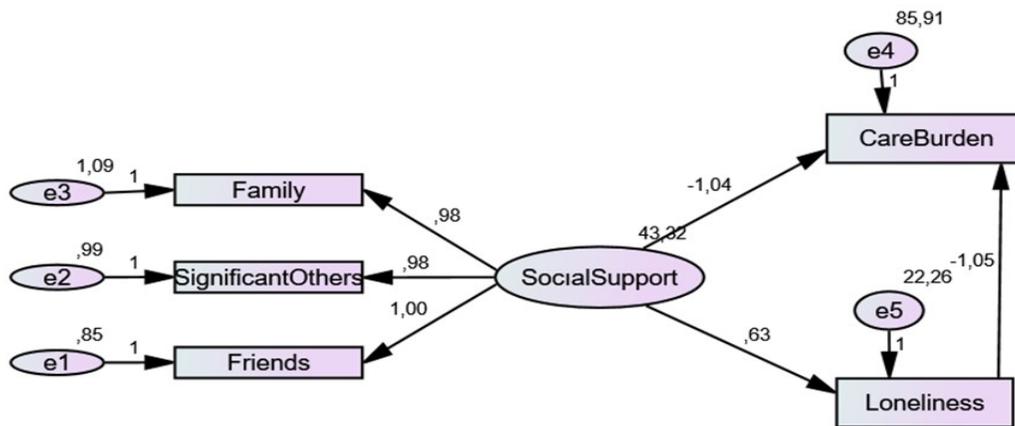


Figure 2. Structural equation modeling

Table 5. Fit indices of the structural equation model

	CMIN	DF	CMIN/DF	RMSEA	GFI	CFI	IFI	RFI	NFI	TLI
Model Fit Indices	4.793	4	1.198	0.025	0.99	1.00	1.00	0.99	0.99	0.99

DF: Degree of freedom; RMSEA: Root mean square error of approximation; GFI: Goodness of fit index; CFI: Comparative fit index; IFI: Incremental fit index; RFI: Relative fit index; NFI: Normed fit index; TLI: TLI (NNFI): Tucker–Lewis Index

Discussion

Having a child with special needs affects parents in physical, psychological, and social ways (Girgin Aykanat & Balci, 2015). It is known that the care burden (Marron et al., 2013) and loneliness (Yildiz Bicakci & Yasar, 2019) of these parents increases with the degree of disability of the child, but parents' care burden decreased as their social support increased (Sivrikaya & Cifci Tekinarslan, 2013). When studies conducted with parents in general were examined, it was reported that these parents had low care burden levels or no perceived care burden (Al Qadire et al., 2019; Albayrak et al., 2019); on the other hand, their social support (Altay et al., 2014; Malagelada et al., 2016) and loneliness (Yildiz Bicakci & Yasar, 2019) levels were moderate. In this study, it was determined that the care burdens of the parents were mild and that their social support and loneliness were moderate. The low care burden perceptions of the parents were likely because they did not perceive the care of their children as a burden.

When some studies on the care burdens of parents were examined, gender statistically significantly affected the care burden of parents, and the care burden levels of the mothers were higher than those of the fathers (Okcu, 2017; Yayan & Duken, 2019). In contrast, there were also studies reporting that parents' gender does not affect the care burden but that the mean care burdens cores of the mothers were higher than those of the fathers (Agkaya Alahan et al., 2015; Bozkurt et al., 2019; Park & Nam, 2019; Piran et al., 2017). In their study, Al Qadire et al., (2019) determined that the parents' gender did not affect the care burden, but the mean care burden scores of the fathers were found to be higher (Al Qadire et al., 2019). The present study showed that the care burden of the mothers was higher than that of the fathers (Table 3), and there was no significant correlation between the care burdens of the mothers and fathers (Table 4). In general, because women have assumed the primary caregiving responsibility since the existence of humanity (Turan et al., 2011), high care burdens for mothers make sense. In addition, the present study also showed that the education and working statuses of the parents affected the care burdens and that the parents who were illiterate and unemployed had higher care burdens (Table 3). In their study, Agkaya Alahan et al. (2015) reported that the education status of parents affected their care burden and that parents with

primary school education levels had higher care burdens (Agkaya Alahan et al., 2015). Yayan and Duken (2019) also reported similar results in their studies. In studies comparing the care burdens and working statuses of parents, it was determined that the working statuses of the parents did not affect their care burdens (Al Qadire et al., 2019; Bozkurt et al., 2019; Park & Nam, 2019; Piran et al., 2017). This difference may be associated with the increasing rates of employment with the increasing education levels. In the analysis conducted to determine if the care burdens of parents are affected by the gender of the child, it was found that the children's gender did not affect the care burden (Table 3).

However, there are studies supporting the results of the present study (Al Qadire et al., 2019; Okcu, 2017; Piran et al., 2017) and confirming the results of the present study in the literature (Bozkurt et al., 2019; Yayan & Duken, 2019). The cause of these different results in the literature may be the effect of social variables on the care burden perceptions of the individuals. In fact, the care burden of the parents can be affected by the characteristics of societies and the diagnosis of children. Another striking point is that the majority of the sample consists of mothers, and only a small part of the sample is composed of fathers in the studies investigating the care burdens of parents (Agkaya Alahan et al., 2015; Al Qadire et al., 2019; Bozkurt et al., 2019; Okcu, 2017; Park & Nam, 2019; Piran et al., 2017; Yayan & Duken, 2019). What makes the current study different is that the care loads of both parents were evaluated by reaching both the fathers and mothers of children with CP. Considering parents together as a family could explain the results regarding care burden, and this could be used as important speculative information in the evaluation of the family.

Social support, which is seen as a helpful tool (Deveci & Ahmetoglu, 2018), is an important factor in terms of the health of parents of children with special needs, as well as the development of the children (Ersoy & Curuk, 2009). In the present study, the factors affecting the perceived social support of parents were examined, and it was found that the parents' gender affected their perceived social supports, with fathers having higher perceived social support (Table 3). However, there was no significant correlation between the social support levels of the mothers and fathers (Table 4). Yayan and Duken (2019) determined that the perceived social support for

fathers was higher than that for mothers (Yayan & Duken, 2019). Some studies reported that the perceived social support of the parents did not differ according to gender (Cattik & Aksoy, 2018; Deveci & Ahmetoglu, 2018; Olcay-Gul et al., 2015). The high care burden of mothers in the present study can be explained by decreased socialization and support. The analysis showed that the education and working statuses of parents affected their perceived social support. Illiterate and unemployed parents had lower perceived social support (Table 3). The literature shows that parents' education levels (Ben-Zur et al., 2005; Karadag, 2009; Yayan & Duken, 2019; Yersel & Durualp, 2019) and working statuses (Ben-Zur et al., 2005) affect the perceived social support of the parents and that the gender of the child does not affect parents' perceived social support (Altay et al., 2014; Ben-Zur et al., 2005; Cattik & Aksoy, 2018; Deveci & Ahmetoglu, 2018; Yayan & Duken, 2019). In contrast, some studies reported that education status (Altay et al., 2014; Cattik & Aksoy, 2018; Deveci & Ahmetoglu, 2018; Kirbas & Ozkan, 2013; Olcay-Gul et al., 2015) and working status (Kirbas & Ozkan, 2013; Yersel & Durualp, 2019) did not affect the perceived social support of the parents, while the gender of the child (Yersel & Durualp, 2019) affected the perceived social support of the parents. The present study showed that there was a statistically significant correlation between the care burden levels and perceived social support of parents and that parents having severe care burdens have lower perceived social support levels (Table 3). As care burden increases, parents spend more time on the care of their children (Gok Metin & Helvaci, 2019), and this is thought that this increases their benefits from social support networks.

Rather than the number of people one is in contact with, the satisfaction level derived from these communications constitutes the basis of loneliness (Pamuk et al., 2015). In the present study, when the loneliness levels of parents with children with CP were examined, it was determined that there was a statistically significant correlation between the parents' gender, education and working statuses, care burden levels and loneliness and that there was no significant correlation between the parents' loneliness levels and the gender of the child (Table 3). As a result of the reviews, it was determined that the number of studies investigating the loneliness levels of parents with

children with special needs was limited (Bas, 2018; Bozdogan, 2011; Durmus & Yesilyaprak, 2019; Yildiz Bicakci & Yasar, 2019). In these studies, it was determined that the genders and education statuses of parents and the gender of the child did not affect the loneliness of the parents (Bas, 2018; Bozdogan, 2011; Durmus & Yesilyaprak, 2019; Yildiz Bicakci & Yasar, 2019). In this study, both the mothers and fathers of children with CP were reached, and their loneliness levels were investigated. It was found that the loneliness levels of fathers were higher (Table 3) and that there was no significant correlation between the loneliness levels of mothers and fathers (Table 4). Interpersonal relationships are one of the important predictors of loneliness. In the studies, it was reported that the communication skills of women were better than those of men (Asci et al., 2015; Korkut, 2005). Another striking result of the present study is that loneliness and social support were determined to be important predictors of care burden perceptions. The fact that the care burden perceptions of the parents were significantly affected by receiving sufficient social support, which also decreased their loneliness, may pose new questions for the related literature.

Limitations: The concepts of burden of care, social support and loneliness are concepts that can be influenced by cultural factors. It is an important limitation that families' cultural characteristics are not taken into consideration in this study.

Conclusion: In this study, it was determined that the care burdens of the parents were mild and that their social support and loneliness were moderate. The present study showed that the care burden of the mothers was higher than that of the fathers, and there was no significant correlation between the care burdens of the mothers and fathers. In the present study, the factors affecting the perceived social support of parents were examined, and it was found that the parents' gender affected their perceived social supports, with fathers having higher perceived social support. However, there was no significant correlation between the social support levels of the mothers and fathers. In this study, both the mothers and fathers of children with CP were reached, and their loneliness levels were investigated. It was found that the loneliness levels of fathers were higher and that there was no significant correlation between the loneliness levels of mothers and fathers. Another striking

result of the present study is that loneliness and social support were determined to be important predictors of care burden perceptions. The fact that the care burden perceptions of the parents were significantly affected by receiving sufficient social support, which also decreased their loneliness, may pose new questions for the related literature.

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