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The mediating role of social support in the relationship between care burden and sleep status of parents of children with cerebral palsy

Serebral palsili çocukların ebeveynlerinin bakım yükü ile uyku durumları arasındaki ilişkide sosyal desteğin aracı rolü

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ABSTRACT

***Aim*:** This study was conducted to examine the mediating role of social support in the relationship between the care burden of parents of children with cerebral palsy (CP) and their sleep states.
Methods: This descriptive correlational study was conducted with the parents of children with CP who were hospitalized in the pediatric clinics of a university hospital and followed up in the pediatric outpatient clinics. The data were collected using the parent information form, Zarit Caregiver Burden Interview, Multidimensional Scale of Perceived Social Support, and Richards Campbell Sleep Scale.
Results*:* According to the results of the analysis, the care burden scores of the parents negatively predicted their sleep quality scores ($\beta=-0.932$; $p<0.050$). Parents' burden of care scores explained 86.8% of the sleep quality scores ($R^2=0.868$). Parents' care burden scores negatively affect their perceived social support scores ($\beta=-0.914$; $p<0.050$). Parents' care burden scores explained 85.8% of their perceived social support scores ($R^2=0.858$). Parents perceived social support scores positively affect sleep quality scores ($\beta=0.130$; $p<0.050$). As a result of the analysis conducted with the bootstrap technique, it was determined that the social support perceived by parents played a mediating role in the relationship between care burden and sleep quality ($\beta=-0.127$; 95% CI [-0.223; -0.023]).
Conclusion: The high care burden experienced by parents of children with CP affects their sleep quality and perceived social support. As the social support perceived by parents from the environment increases, their care burden decreases and their sleep quality increases.

Keywords*:* caregiver burden; cerebral palsy; child; parents; social support

ÖZ

Amaç: Bu araştırmada Serebral Palsi (SP) çocukların ebeveynlerinin bakım yükü ile uyku durumları arasındaki ilişkide sosyal desteğin aracı rolünü incelemek amacıyla yapılmıştır.
Yöntem: Tanımlayıcı ilişkisel tipte bir araştırma olarak yapılan araştırma bir üniversite hastanesinin çocuk sağlığı kliniklerinde yatan ve çocuk polikliniklerinde takip edilen SP çocukların ebeveynleriyle yürütülmüştür. Verilerin toplanmasında Ebeveyn Bilgi Formu, Zarit Bakım Yükü Ölçeği, Çok Boyutlu Sosyal Destek Ölçeği ve Richards Campbell Uyku Ölçeği kullanarak toplanılmıştır.
Bulgular: Analiz sonuçlarına göre, ebeveynlerin bakım yükü puanları uyku kalitesi puanlarını negatif yönde etkilemektedir ($\beta=-0.932$; $p<0.050$). Ebeveynlerin bakım yükü puanları uyku kalitesi puanlarının %86.8'ini açıklamaktadır ($R^2=0.868$). Ebeveynlerin bakım yükü puanları algılanan sosyal destek puanlarını olumsuz etkilemektedir ($\beta=-0.914$; $p<0.050$). Ebeveynlerin bakım yükü puanları, algıladıkları sosyal destek puanlarının %85.8'ini açıklamaktadır ($R^2=0.858$). Ebeveynlerin algıladıkları sosyal destek puanları uyku kalitesi puanlarını pozitif yönde etkilemektedir ($\beta=0.130$; $p<0.050$). Bootstrap tekniği ile yapılan analiz sonucunda ebeveynlerin algıladıkları sosyal desteğin bakım yükü ile uyku kalitesi arasındaki ilişkide aracı rol oynadığı tespit edilmiştir ($\beta=-0.127$; %95 CI [-0.223; -0.023]).
Sonuçlar: SP'li çocukların ebeveynlerinin yaşadığı yüksek bakım yükü uyku kalitelerini ve algıladıkları sosyal destek durumları etkilemektedir. Ebeveynlerin çevreden algıladıkları sosyal destekleri artıkça bakım yükleri azalmakta ve uyku kaliteleri artmaktadır.

Anahtar kelimeler*:* bakıcı yükü; çocuk; ebeveynler; serebral palsi; sosyal destek

Introduction

Cerebral palsy (CP) is defined as a neurodevelopmental movement and posture disorder affecting muscle tone and motor activity that can occur before birth, during birth or in early childhood after birth (Novak et al., 2017). The worldwide prevalence of CP is reported to be 9.3%. In developing countries it is reported to vary between 2 and 3 per 1000 live births. This rate has been reported as 4 in every 1000 live births and to be gradually increasing (Garip et al., 2016).

Children with CP may experience various problems, such as spastic paralysis, cognitive impairment, chronic pain, and speech and vision problems. They also have various limitations in their daily self-care functions, such as feeding, dressing, bathing and moving. These children may also experience communicative, emotional, social and mental disorders (Nimbalkar et al., 2014). These problems experienced by children cause psychological, social and financial effects on their families (Albayrak et al., 2019). The problems experienced by children with CP necessitate their parents to provide longer-term care compared to the parents of healthy children (Nimbalkar et al., 2014; Parkes et al., 2009). This highlights the concept of care burden for parents of children with CP.

In developing countries like Türkiye, most children with CP are cared for by their mothers who are the primary caregivers (Farajzadeh et al., 2018; Garip et al., 2016). Parents of children with CP provide care in many aspects, such as lifting, lowering, turning the child, helping in bathing, helping with

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toilet, putting the child to sleep, and dressing the child (Terzi & Tan, 2016; Tseng et al., 2016). This can cause an increase in the care burden of individuals and lead to psychological problems such as stress, anxiety and depression (Albayrak et al., 2019; Garip et al., 2016). The increased care burden of parents also negatively affects their physical and emotional health and daily living activities (Garip et al., 2016; Singogo et al., 2015). Parents who care for children with CP have reported that they do not have enough time and energy to socialize with their friends, with increased care burden as the most important reason for this situation. They have also reported a decrease in their friendships due to increased care burden and devoting all their time to their children (Pretorius & Steadman, 2018). Meeting the needs of the child with cerebral palsy other than their own individual care increases the burden of caregiving (Albayrak et al., 2019; Vadivelan et al., 2020). Increased care burdens of parents impair their quality of life, increase their fatigue and pain (hand, arm, foot and back), and lead to poor sleep (Albayrak et al., 2019).

Parents may also experience problems with their sleep pattern due to their physical, psychological, social and emotional problems. The ability of parents to meet their own emotional, personal, social and financial needs decreases during the caregiving process (Singogo et al., 2015).

Parents' daily responsibilities, such as carrying and lifting their children, assisting in their bathing, feeding and toilet care, increase their physical and emotional care burden. Caregivers' personal, emotional, social, physical, and financial needs are usually neglected and compromised (Wang et al., 2020). In this case, the increasing care burden of parents can be an important predictor of sleep quality, duration and efficiency (Bentum et al., 2023; Dlamini et al., 2023).

A growing body of evidence supports the importance of sleep in parent and child health and development (Chaput et al., 2016). CP children are more likely to have sleep problems. Sleep difficulties have been shown to be associated with poorer sleep quality for their parents and caregivers (Lang et al., 2021). However, according to parents of children with CP, clinicians rarely ask about the sleep status of children and parents. They underestimate the impact of parental sleep on the family. Parents reported that this is a cause for concern and a significant source of stress within the family (Hulst et al., 2024; Micsinszki et al., 2018). In studies examining the sleep of parents of children with neurodevelopmental disabilities in the literature, it was reported that parents of children with neurodevelopmental disabilities had worse sleep quality than parents of healthy children (Hulst et al., 2024; Micsinszki et al., 2018).

Considering the relationships of parents with children who have CP, it is noteworthy that social support is a significant need. The fact that parents do not spare enough time for themselves at home, outside, and in the circle of friends and consider themselves primarily responsible for the child shows that they need serious social and emotional support (Pretorius & Steadman, 2018; Singogo et al., 2015; Vadivelan et al., 2020). In the literature, it is stated that parents of children with CP need family, friend and community support (Singogo et al., 2015). Various studies in the literature have examined the care burden of parents who have children with CP (Ahanotu et al., 2018; Albayrak et al., 2019). Parents' ability to care for their children and meet their physical, emotional and social needs increases the care burden and reduces the level of social support they receive from the environment (Bentum et al., 2023; Dlamini et al., 2023). In the study conducted with parents of children with CP, it was determined that mothers had higher care burden and lower perceived social support than fathers (Yıldırım et al., 2022). This shows that care burden is an important independent variable of social support.

Social support may play a role in the adaptation process of the family in the face of the stress associated with the birth of an SP child and may come to the fore as a protective factor against stressful events as well as an important predictor of parental adjustment (Lima et al., 2016). As the social support perceived by the parents increases, it reduces feelings such as abandonment, sadness and anxiety and enables the family to cope with this process (Lima et al., 2016; Polita & Tacla, 2014). At the same time, the social support perceived by individuals refers to the material and psychological resources that they think are offered to them through their interpersonal relationships. The stronger the social support that individuals perceive from their environment and their families, the more likely it is that the social support network they have and the established ties are sufficient for the current demands (Pfeifer et al., 2014; Polita & Tacla, 2014).

As a result of the literature review, increasing care burdens of parents negatively affect their sleep quality. The concept of perceived social support stands out as a triggering factor between care burdens and sleep quality. We think that parents' decreasing care burdens will increase the social support they will receive from friends, family and their environment. We also think that increased social support network will be an important enhancing factor in sleep quality. Therefore, we examine whether perceived social support plays a mediating role between care burden and sleep quality of parents with children with cerebral palsy.

Research questions:

1) Is there a relationship between the care burden of parents of children with CP and their sleep status?
2) Does the social support received by the parents of children with CP have a mediating role between care burden and their sleep status?

Methods

Study design and setting

This is a descriptive correlational study, which was conducted between 20.11.2022 and 31.06.2023 The parents of children with CP followed in the pediatric clinics of the hospital located in a province in southeastern Türkiye comprised the study sample. In this study, data were collected from the parents of children who applied to the pediatric clinics of a specific hospital for treatment or control purposes between the specified dates. Easily Accessible Sampling method was used in the study. This sampling method was preferred because the parents who would participate in the study were easily accessible.

The study included 511 mothers who met the inclusion criteria and who agreed to participate. Fathers did not participate in the research. There are three important reasons for this. In the cultural factor where the research was conducted, the person who actively cares for the child and spends constant time with him/her is the mother. Furthermore, the active care, education, clothing, bathing and physical exercises of children with CP are carried out by their mothers. In addition, when children come to the hospital for follow-up or treatment purposes, only their mothers accompany them. Consequently, fathers were not included in the study.

Inclusion criteria

The study included mothers;

- who had a child diagnosed with CP,
- who did not have a physical disability to participate in the study,
- who came to the hospital for treatment and follow-up,
- who did not have a mental problem answering the questions,
- who did not have a medically psychiatric diagnosis,
- who agreed to participate in the study.

Exclusion criteria

The study excluded;

- parents who held Syrian refugee status,
- parents who had a barrier to communicate,
- fathers of CP children,
- do not reside in the area where the research was conducted,
- mothers with chronic diseases such as diabetes, hypertension, COPD and asthma,
- children with cystic fibrosis, asthma, diabetes, etc. apart from the diagnosis of CP,
- parents of children with comorbidities.

Data collection

The data for the study were collected from the parents of children diagnosed with CP who met the inclusion criteria and volunteered to participate. Data collection included a face-to-face interview with each parent, when applicable. The interviews were conducted with parents whose children were hospitalized in Child Health and Diseases Clinic 1, Child Health and Diseases Clinic-2, and Child Neurology Clinic. Data were further collected from the parents of pediatric patients with CP who were admitted to the pediatric outpatient clinic for follow-up through face-to-face interview in a suitable room. Each interview lasted approximately 20-25 minutes. The Parent Information Form, Zarit Caregiver Burden Interview, Multidimensional Scale of Perceived Social Support, and Richards Campbell Sleep Scale were used to collect data.

Data collection instruments

Parent information form

The demographic questions in the parent information form were prepared through literature review. CP was prepared with questions such as the child's CP type, age, sex, mother's education level, father's education level, number of individuals the parent cared for, the number of siblings, and the number of people in the house.

Zarit Caregiver Burden Interview

The Zarit Caregiver Burden Interview was developed by Zarit et al. in 1980. The scale consists of 22 items, with each item having a five-point Likert type scale and it is evaluated as a single dimension. The scale uses a Likert-type rating system ranging from 0 to 4: never, rarely, sometimes, often, or almost always, respectively. The scale is used to evaluate the difficulties experienced by those who care for individuals in need of care or those who care for elderly individuals. It is preferred to determine the effect of care given by the caregiver on the patient's life. The total score on the scale ranges between 0 and 88 points. A higher score from the scale shows that the caregiver's burden of care increases (Zarit et al., 1980).The validity and reliability study of the scale was conducted by İnci and Erdem (İnci & Erdem, 2008). In the present study, the internal consistency coefficient was 0.90.

Multidimensional Scale of Perceived Social Support

The scale was developed by Zimet et al. in 1988 to determine the social support perceived by individuals from their environment (Zimet et al., 1988). The Multidimensional Scale of Perceived Social Support consists of three subdimensions, which consist of subjective evaluation of the support received from family, friends, and significant others. The scale consists of 12 items and each subdimension consists of four items. Each item is rated on a Likert-type scale: definitely no=1 and definitely yes=7. The minimum obtainable score of the scale is 12, while the maximum obtainable score is 84. Increased scores from the scale show increased social support from family, friends, and significant others (Zimet et al., 1988). Turkish validity and reliability of the scale was assessed by Eker and Arkar and revised in 2001 (Eker et al., 2001). In the present study, the internal consistency coefficient of the scale was found to be 0.86.

Richards–Campbell Sleep Questionnaire

The scale was developed by Richards et al. in 2000 to measure the sleep quality of individuals. It is used to evaluate the depth of sleep, the duration of falling asleep, the frequency of waking up, the time to stay awake when awakened, and the quality of sleep. It also evaluates the noise level in the environment where individuals sleep. It consists of six items, with each item being scored between 0 and 100 points. While the first five items evaluate sleep quality, the sixth item determine the noise level in the environment. The score is obtained by adding the first five items and dividing them by five. A score of 0-25 is considered poor sleep quality, while a score of 76-100 indicates good sleep quality (Richards et al., 2000). The validity and reliability study of the scale was conducted by Özlü et al. The Cronbach's alpha value of the scale was found to be 0.94 (Özlü & Özer, 2015). In the present study, the internal consistency coefficient of the scale was found to be 0.85.

Data analysis

In this study, skewness and kurtosis values were examined to evaluate whether the data were normally distributed using the SPSS 22 (Statistical Program in Social Sciences) software. Reliability analysis and multicollinearity analysis were used along with the SPSS software. PATH analysis was conducted with structural equation modeling. The mediating role of social support in the relationship between parental care burden and the sleep status of parents of children with CP was examined by using the Process Macro software in AMOS. The level of significance was accepted as 0.05.

To test whether the Multidimensional Scale of Perceived Social Support variable had a mediating role in the relationship between the Richards–Campbell Sleep Questionnaire and the Zarit Caregiver Burden Interview, an analysis was conducted based on the bootstrap method. In the bootstrap analysis, 5000 resamples were used. The 95% confidence interval (CI) obtained from the analysis made with the bootstrap technique should not cover the zero (0) value. The mediator model used in the research is shown in Figure 1.

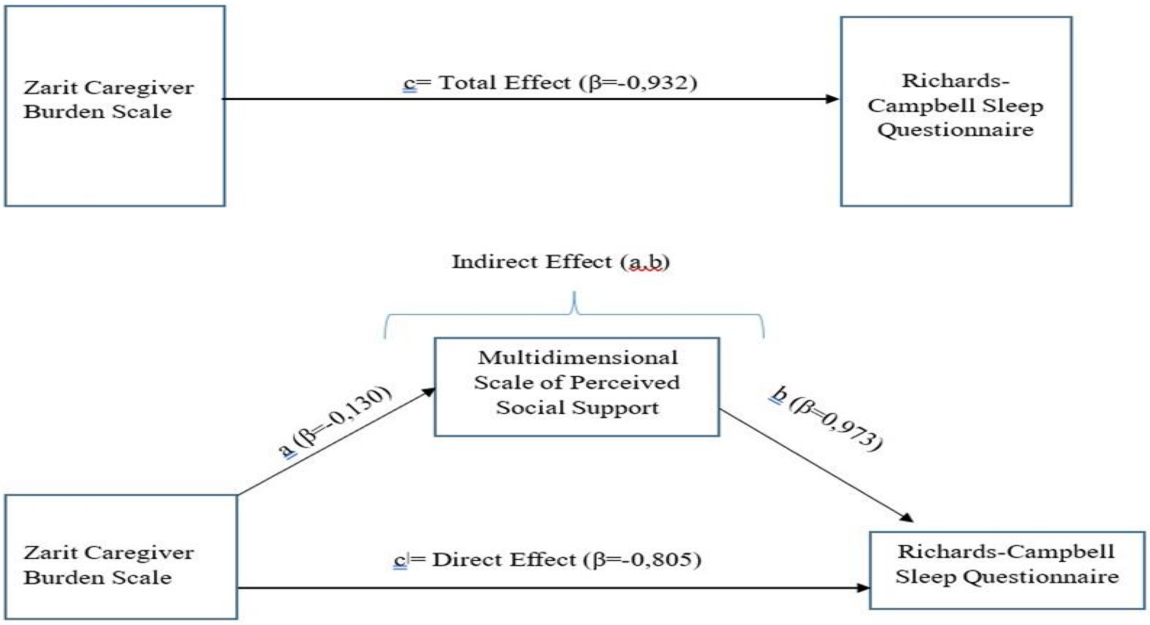

Figure 1. Simple effect model

Path analysis with observed variables

Path analysis and a mediator model were used by using the total scores of the Zarit Caregiver Burden Interview consisting of 22 items, the Richards–Campbell Sleep Questionnaire consisting of six items, and the Multidimensional Scale of Perceived Social Support consisting of 12 items.

Ethical considerations

In this study, institutional permission was obtained from Harran University. The research was approved by the Harran University Humanities and Humanitarian Sciences Ethics Committee with the decision number (E-76244175-050.01.01.01.01-186815) at the session dated 18.11.2022. After the parents were informed about the study, they were informed that participation was voluntary and their written consent was obtained.

Results

The mean age of the mothers who participated in the study was 38.45±2.36 years, the mean age of their children with CP was 3.75±1.46 years. Each child had been diagnosed with CP for 4.89±1.55 years. In the households where mothers lived, the average number of people was 6.63±2.07, the average number of children in the households was 3.78±1.48, and each mother cared for 1.52±0.53 people on average. Of the children with CP, 52% were male. Of the participating mothers, 27% were illiterate and 23% were primary school graduates. While 30% of the fathers of CP children were primary school graduates, 23% were secondary school graduates (Table 1).

According to the results of the analysis, the care burden scores of the parents negatively predicted their sleep quality scores (β=-0.932; p<0.050). A one-unit increase in the care burden scores of parents causes a 0.932-unit decrease in their sleep quality scores. Parents' burden of care scores explained 86.8% of the sleep quality scores (R^2=0.868) (Table 2).

A mediator model analysis was established in which the social support perceived by parents from the environment was included. In the first pathway of the mediator model; parents' care burden is considered as an independent variable and perceived social support as a dependent variable. In the second pathway of the mediator model; the relationship between parents perceived social support and sleep quality was examined. Parents perceived social support is considered as the independent variable and sleep quality as the dependent variable.

Table 1. Mean and distribution of some demographic characteristics of parents who have children with CP

Characteristics	Mean±SD	Median (Min-Max)
Child's age	3.75 ± 1.46	3 (1 - 9)
Mother's age	38.45±2.36	39 (18-55)
Years since the diagnosis	4.89 ± 1.55	5 (2 - 10)
Number of people at home	6.63 ± 2.07	6 (1 - 14)
Number of siblings	3.78 ± 1.48	3 (1 - 9)
Number of people cared at home	1.52 ± 0.53	2 (1 - 3)
	n	**%**
Child's gender		
Female	243	48
Male	268	52
Mother's educational status		
Illiterate	138	27
Primary education	118	23
Secondary education	73	14
High school	108	21
University	74	14
Father's educational status		
Illiterate	60	12
Primary education	154	30
Secondary education	120	23
High school	81	16
University	96	19

Parents' care burden scores negatively affect their perceived social support scores (β=-0.914; p<0.050). A one-unit increase in parents' care burden scores leads to a 0.914-unit decrease in their perceived social support scores. Parents' care burden scores explained 85.8% of their perceived social support scores (R^2=0.858) (Table 2). In the second path of the mediation model, parents perceived social support scores positively affect sleep quality scores (β=0.130; p<0.050). A one-unit increase in parents perceived social support scores leads to a 0.130-unit increase in sleep quality scores (Table 2).

Table 2. Structural equation model results

Predictive variables	Outcome variables			
	Multidimensional Scale of Perceived Social Support		Richards-Campbell Sleep Questionnaire	
	β (95% CI)	**SE**	**β (95% CI)**	**SE**
Zarit Caregiver Burden Scale (total effect)	-		-0.932 (-0.941; 0.922)*	0.005
R^2			0.868	
Zarit Caregiver Burden Scale	-0.914 (-0.899; -0.927)*	0.002	-	
R^2	0.858			
Zarit Caregiver Burden Scale (direct effect)	-		-0.805 (-0.907;-0.710)*	0.051
Multidimensional Scale of Perceived Social Support	-		0.130 (0.229; 0.023)*	0.053
R^2	-		0.869	
Indirect effect	-		-0.127 (-0.223;-0.023)*	

*p<0.050; Bootstrap indirect effect (95% CI); SE: Standard Error; β: Standardized coefficients; R^2: Determination coefficient

The negative relationship between care burden scores and sleep quality scores continued to be significant with the inclusion of perceived social support between care burden and sleep quality scores (β=-0.805; p<0.050). In this case, parents perceived social support partially mediated the relationship between burden of care and sleep quality. It was determined that parents' care burden scores and perceived social support scores explained 86.9% of the sleep quality scores (R^2=0.869) (Table 2).

As a result of the analysis conducted with the bootstrap technique, it was determined that the social support perceived by parents played a mediating role in the relationship between care burden and sleep quality (β=-0.127; 95% CI [-0.223; -0.023]) (Table 2).

Discussion

This study showed that the relationship between sleep problems and caregiving burden in parents of children with CP and the social support they receive depends on various factors. In the study, it was found that care burden scores of parents negatively affected sleep quality scores, and an increase in care burden scores led to a decrease in sleep quality scores. It was concluded that parents' care burden scores negatively affected their perceived social support scores, and an increase in care burden scores led to a decrease in perceived social support scores. In addition, it was found that parents' perceived social support scores positively affected sleep quality scores, and an increase in perceived social support scores led to an increase in sleep quality scores. In addition, it was determined that parents' perceived social support played a mediating role in the relationship between care burden and sleep quality. Our research has shown that reducing parental caregiving and improving social support can improve or be associated with parental sleep quality.

Considering that children with CP have multidimensional care needs and require a high level of care, the difficulties experienced by their parents are important. This study revealed a significant relationship between parental care burden and sleep status and showed that social support factor played a mediating role in the relationship between parental care burden and sleep status. Some studies suggest that providing social support to parents may support the family's care burden (Nimbalkar et al., 2014; Tosun & Temel, 2017) and that this support may contribute to psychological well-being from the initial diagnosis (Al-Gamal & Long, 2013; Albayrak et al., 2019).

One of the results of the study was that the care burden score predicted social support and sleep scores. Although not assessed with a sleep questionnaire (Atay et al., 2018), reported that parents of children with CP experienced similar sleep problems and had much higher levels of care burden and anxiety than parents with healthy children. Wayte et al. (2012) found that caring for children with CP created additional care burden in parents, 40% of their mothers had poor sleep quality and this was accompanied by depressive mood (Wayte et al., 2012). In a systematic review, examined the factors associated with care burden for parents of children with CP and mostly discussed studies using the same care burden scale as our study (Liu et al., 2023). According to the results, social support and sleep were among the factors related to the caregiver, and the results of the systematic review conducted by Micsinszki et al. (2018) also showed that social support was among the factors affecting the caregiver's need for sleep. Albayrak et al. (2019) found that the care burden scores of mothers of children with CP were higher than the control group and their sleep status was affected more than the control group. The same study suggested that receiving support from other family members and increasing psychosocial support improved the mother's health status (Albayrak et al., 2019). Similarly, Lang et al. (2021) reported that 71% of caregivers of children with CP had poor sleep. While the functional limitation of children with CP creates care burden on parents, it also causes poor sleep outcomes (Lang et al., 2021). The findings obtained from the studies in the literature overlap with the results of our study.

In this study, the results related to the increase in social support decreasing the dependent variable of care burden are significant. Providing care in a disease with long-term functional limitations such as CP causes fatigue, physical and mental problems in caregivers, especially the mother (Ahanotu et al., 2018; Pfeifer et al., 2014). The majority of informal caregivers of patients with CP reported that they had a significant care burden and perceived social support was moderate. The care burden of a child with CP has a significant impact on social support and quality of life. In the qualitative study conducted by (Pretorius & Steadman, 2018) the low level of social support received by parents in the care of a child with CP constitutes an important obstacle in providing care and parents cannot rest due to care burden. Tosun and Temel (2017) examined the factors that may affect social support and care burden in order to reduce the care burden of family members caring for stroke patients. Social support perceived in the care process affects the burden of care (Tosun & Temel, 2017). It was stated that mothers of children with CP did not receive support from their spouses, families or community members during the caregiving process (Vadivelan et al., 2020). It stated that mothers of children with CP do not receive enough support from family, community or health systems and feel socially isolated (Singogo et al., 2015). Qualitative research examining psychosocial problems among parents of children with CP; It was stated that providing education opportunities for the child in a special education institution or hospital environment, which is a different dimension of social support, can support not only the child but also the whole family and reduce the burden of care (Nimbalkar et al., 2014). Examples in the literature show that families of children with CP do not receive adequate social support and that this support significantly affects the burden of care. These findings support our study findings.

There is no previous study on the mediating role of parents of children with CP having the same or different social support dimensions. However, in a study conducted by Zhao et al. (2021) examining the mediating role of social support, a significant relationship was found between parenting stress, social support and resilience of parents with children with disabilities. Moreover, the analyses showed the mediating effect of social support between parenting stress and parental resilience. The study showed that reducing parental stress and improving social support may increase or be related to parental resilience (Zhao et al., 2021). In the study of Skok et al. (2006), which looked at the mediating role of social support to caregivers on stress and well-being, it was determined that it had a moderate and mild role.

In conclusion, high care burden experienced by parents of children with CP negatively affects sleep quality and social support factors play a mediating role in the relationship between care burden and sleep status. Providing adequate social support to parents may reduce the increased physiological and psychological care burden. It may help to organize interventions for important physiological needs such as sleep and support the caregiver. Conducting studies with such a mediation model may contribute to the understanding of the factors affecting the process, including various care processes, in CP and other diseases requiring care and to make relevant interventions.

Limitations

This study has some limitations, including its cross-sectional design examination of social support from a single perspective without considering different dimensions. In addition, it is noteworthy to remind that social support in different contexts within the population under consideration may be affected by various factors, such as the transfer of care within the family to the mother as well as the cultural, economic, social and psychological status of the caregiver. There is a need for future studies that predict physiological needs, which are affected by many different factors like sleep, by addressing different dimensions of social support. The data obtained in the research should be evaluated within the context of the characteristics of the participants included in the sample.

Conflict of Interest

No conflict of interest.

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Ethics Committee Approval

In this study, institutional permission was obtained from Harran University. The research was approved by the Harran University Humanities and Humanitarian Sciences Ethics Committee with the decision number (E-76244175-050.01.01.01.01-186815) at the session dated 18.11.2022. After the parents were informed about the study, they were informed that participation was voluntary and their written consent was obtained.

Informed Consent

Written informed consent was obtained from the participant(s).

Peer-Review

Externally peer-reviewed.

Author Contributions

M.E.D.: Design, Methodology, Data Collection, Data Collection, Data Analysis, Methodology Writing, Original Draft.

K.Ş.: Design, Methodology, Methodology Writing, Original Draft.

H.K.: Design, Methodology Writing, Original Draft.

References

Ahanotu, C. J., Ibikunle, P. O., & Hammed, A. İ. (2018). Burden of caregiving, social support and quality of life of informal caregivers of patients with cerebral palsy. *Turkish Journal of Kinesiology*, *4*(2), 58–64. https://doi.org/10.31459/turkjkin.418491

Al-Gamal, E., & Long, T. (2013). Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: a cross-sectional study. *Scandinavian Journal of Caring Sciences*, *27*(3), 624–631. https://doi.org/10.1111/j.1471-6712.2012.01071.x

Albayrak, I., Biber, A., Çalışkan, A., & Levendoglu, F. (2019). Assessment of pain, care burden, depression level, sleep quality, fatigue and quality of life in the mothers of children with cerebral palsy. *Journal of Child Health Care*, *23*(3), 483–494. https://doi.org/10.1177/1367493519864751

Atay, C., Uzun, N., & Tarakcı, E. (2018). Serebral palsi'li çocuğa bakım verenlerin uyku süreleri, bakım verme yükleri ve fiziksel aktivite düzeylerinin sağlıklı çocuğa sahip ebeveynler ile karşılaştırılması. *Journal of Exercise Therapy & Rehabilitation*, *10*, 10.

Bentum, L. S., Ohene, L. A., Agyare, V. A., Laari, L., & Ampomah, M. O. (2023). Fathers' experiences of caring for children living with cerebral palsy: a qualitative study in a low resourced socioeconomic context, ghana. *Journal of Pediatric Nursing*, *73*, 100–106. https://doi.org/10.1016/j.pedn.2023.07.019

Chaput, J.-P., Gray, C. E., Poitras, V. J., Carson, V., Gruber, R., Olds, T., Weiss, S. K., Connor Gorber, S., Kho, M. E., Sampson, M., Belanger, K., Eryuzlu, S., Callender, L., & Tremblay, M. S. (2016). Systematic review of the relationships between sleep duration and health indicators in school-aged children and youth. *Applied Physiology, Nutrition, and Metabolism*, *41*(6 (Suppl. 3)), S266–S282. https://doi.org/10.1139/apnm-2015-0627

Dlamini, M. D., Chang, Y.-J., & Nguyen, T. T. B. (2023). Caregivers' experiences of having a child with cerebral palsy. a meta-synthesis. *Journal of Pediatric Nursing*, *73*, 157–168. https://doi.org/10.1016/j.pedn.2023.08.026

Eker, D., Arkar, H., & Yaldız, H. (2001). Çok Boyutlu Algılanan Sosyal Destek Ölçeği'nin gözden geçirilmiş formunun faktör yapısı, geçerlik ve güvenirliği. *Türk Psikiyatri Dergisi*, *12*(1), 17–25.

Farajzadeh, A., Amini, M., Maroufizadeh, S., & Wijesinghe, C. J. (2018). Caregiver Difficulties Scale (CDS): Translation and psychometric evaluation among Iranian mothers of cerebral palsy children. *Occupational Therapy in Health Care*, *32*(1), 28–43. https://doi.org/10.1080/07380577.2017.1422607

Garip, Y., Ozel, S., Tuncer, O. B., Kilinc, G., Seckin, F., & Arasil, T. (2016). Fatigue in the mothers of children with cerebral palsy. *Disability and Rehabilitation*, *39*(8), 757–762. https://doi.org/10.3109/09638288.2016.1161837

Hulst, R. Y., Gorter, J. W., Voorman, J. M., Kolk, E., Vossen, S. Van Der, Visser-Meily, J. M., Ketelaar, M., Pillen, S., & Verschuren, O. (2024). Sleep problems in children with cerebral palsy and their parents. *Developmental Medicine & Child Neurology*, *66*(1). https://doi.org/10.1111/dmcn.15810

İnci, F. H., & Erdem, M. (2008). Bakım Verme Yükü Ölçeğinin Türkçe 'ye uyarlanması geçerlilik ve güvenilirliği. *Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi*, *11*(4), 85–95.

Lang, C. P., Boucaut, A., Guppy, M., & Johnston, L. M. (2021). Children with cerebral palsy: A cross-sectional study of their sleep and their caregiver's sleep quality, psychological health and well-being. *Child: Care, Health and Development*, *47*(6), 859–868. https://doi.org/10.1111/cch.12897

Lima, M. B. S., Cardoso, V. dos S., & Silva, S. S. da C. (2016). Parental stress and social support of caregivers of children with cerebral palsy. *Paidéia (Ribeirão Preto)*, *26*(64), 207–214. https://doi.org/10.1590/1982-43272664201608

Liu, F., Shen, Q., Huang, M., & Zhou, H. (2023). Factors associated with caregiver burden among family caregivers of children with cerebral palsy: a systematic review. *BMJ Open*, *13*(4), e065215. https://doi.org/10.1136/bmjopen-2022-065215

Micsinszki, S. K., Ballantyne, M., Cleverley, K., Green, P., & Stremler, R. (2018). Sleep outcomes for parents of children with neurodevelopmental disabilities: A systematic review. *Journal of Family Nursing*, *24*(2), 217–249. https://doi.org/10.1177/1074840718773381

Nimbalkar, S., Raithatha, S., Shah, R., & Panchal, D. A. (2014). A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in Western India. *ISRN Family Medicine, 20,* 769619 https://doi.org/10.1155/2014/769619

Novak, I., Morgan, C., Adde, L., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J., Cioni, G., Damiano, D., Darrah, J., Eliasson, A. C., De Vries, L. S., Einspieler, C., Fahey, M., Fehlings, D., Ferriero, D. M., Fetters, L., Fiori, S., Forssberg, H., Gordon, A. M., … Badawi, N. (2017). Early, accurate diagnosis and early intervention in cerebral palsy: advances in diagnosis and treatment. *JAMA Pediatrics*, *171*(9), 897–907. https://doi.org/10.1001/JAMAPEDIATRICS.2017.1689

Özlü, Z. K., & Özer, N. (2015). Richard-Campbell sleep questionnaire validity and reliability study. *Journal of Turkish Sleep Medicine*, *2*(2), 29–32. https://doi.org/10.4274/jtsm.02.008

Parkes, J., Mccullough, N., Madden, A., Mccahey, E., Parkes Bnurs, J., Phd, B., Fellow, R., Rn, B., Research Assistant, B., & Ar, M. P. (2009). The health of children with cerebral palsy and stress in their parents. *Journal of Advanced Nursing*, *65*(11), 2311–2323. https://doi.org/10.1111/j.1365-2648.2009.05089.x

Pfeifer, L. I., Silva, D. B. R., Lopes, P. B., Matsukura, T. S., Santos, J. L. F., & Pinto, M. P. P. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health and Development*, *40*(3), 363–369. https://doi.org/10.1111/cch.12077

Polita, N. B., & Tacla, M. T. G. M. (2014). Network and social support to families of children with cerebral palsy. *Escola Anna Nery - Revista de Enfermagem*, *18*(1). https://doi.org/10.5935/1414-8145.20140011

Pretorius, C., & Steadman, J. (2018). Barriers and facilitators to caring for a child with cerebral palsy in rural communities of the western cape, south africa. *Child Care in Practice*, *24*(4), 413–430. https://doi.org/10.1080/13575279.2017.1347146

Richards, K. C., O'Sullivan, P. S., & Phillips, R. L. (2000). Measurement of sleep in critically ill patients. *Journal of Nursing Measurement*, *8*(2), 131–144. https://doi.org/10.1891/1061-3749.8.2.131

Singogo, C., Mweshi, M., & Rhoda, A. (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *The South African Journal of Physiotherapy*, *71*(1). https://doi.org/10.4102/SAJP.V71I1.274

Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability*, *31*(1), 53–57. https://doi.org/10.1080/13668250600561929

Terzi, R., & Tan, G. (2016). Musculoskeletal system pain and related factors in mothers of children with cerebral palsy. *Agri*, *28*(1), 18–24. https://doi.org/10.5505/agri.2015.74436

Tosun, Z. K., & Temel, M. (2017). Burden of caregiving for stroke patients and the role of social support among family members: an assessment through home visits. *International Journal of Caring Sciences*, *10*(3), 1696–1704.

Tseng, M.-H., Chen, K.-L., Shieh, J.-Y., Lu, L., Huang, C.-Y., & Simeonsson, R. J. (2016). Child characteristics, caregiver characteristics, and environmental factors affecting the quality of life of caregivers of children with cerebral palsy. *Disability and Rehabilitation*, *38*(24), 2374–2382. https://doi.org/10.3109/09638288.2015.1129451

Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*, *20*(1), 1–8.

Wang, Y., Huang, Z., & Kong, F. (2020). Parenting stress and life satisfaction in mothers of children with cerebral palsy: the mediating effect of social support. *Journal of Health Psychology*, *25*(3), 416–425. https://doi.org/10.1177/1359105317739100

Wayte, S., McCaughey, E., Holley, S., Annaz, D., & Hill, C. M. (2012). Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression. *Acta Paediatrica*, *101*(6), 618–623. https://doi.org/10.1111/j.1651-2227.2012.02603.x

Yıldırım, M., Düken, M. E., Dağ, Y. S., & Yayan, E. H. (2022). Examining care burden, social support, and loneliness in parents of children with cerebral palsy. *International Journal of Caring Sciences*, *15*(3), 1655–1664.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Zhao, M., Fu, W., & Ai, J. (2021). The mediating role of social support in the relationship between parenting stress and resilience among chinese parents of children with disability. *Journal of Autism and Developmental Disorders*, *51*(10), 3412–3422. https://doi.org/10.1007/s10803-020-04806-8

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *52*(1), 30–41. https://doi.org/10.1207/s15327752jpa5201_2