Investigation of awareness of parents of children with cerebral palsy about illness, physiotherapy and rehabilitation

Serebral palsili çocukların ebeveynlerinin hastalık, fizyoterapi ve rehabilitasyon hakkındaki farkındalık durumlarının incelenmesi

Abstract

Aim: This study aimed to examine the awareness levels of parents who provide primary care to children with Cerebral Palsy (CP) about the disease, physiotherapy, and rehabilitation. **Methods:** Parents (n=78) of children with aged 4-18 years diagnosed CP, were included in

the study. Cerebral Palsy Disease, Physiotherapy, and Rehabilitation Awareness Evaluation Questionnaire was used to determine the level of awareness.

Results: The majority of the survey participants were mothers (85.9%). It was determined that the general awareness levels of the parents were low (5.17%), medium (56.41%), and high (38.46%). Awareness levels were found to be similar according to the education level and economic status of the parents (p>0.05). In addition, although parental awareness levels of children with CP increased according to their surgery history, age distribution, and gross motor function levels (GMFCS), there was no significant difference between them (p>0.05).

Conclusion: It was determined that the awareness levels of parents with children with CP about the disease, physiotherapy, and rehabilitation were generally medium and high. It was observed that the awareness levels were not affected by the education levels of the parents, the GMFCS levels of their children, the age of the children, and the economic status of the family.

Keywords: Awareness; cerebral palsy; parents; rehabilitation

Öz

Amaç: Bu çalışmanın amacı Serebral Palsi'li (SP) çocuklara primer bakım veren ebeveynlerin hastalık, fizyoterapi ve rehabilitasyon hakkındaki farkındalık düzeylerini incelemektir.

Yöntemler: Çalışmaya 4-18 yaş arası SP'li çocuğu olan 78 ebeveyn dâhil edildi. Farkındalık düzeyleri yarı yapılandırılmış görüşmelerle araştırmacıların hazırladığı Serebral Palsi Hastalık, Fizyoterapi ve Rehabilitasyon Farkındalık Değerlendirme Anketi ile belirlendi.

Bulgular: Anket katılımcılarının büyük oranda annelerden oluşuyordu (%85,9). Ebeveynlerin genel farkındalık düzeylerinin düşük (%5,17), orta (%56,41) ve yüksek (%38,46) düzeyde olduğu belirlendi. Ebeveynlerin eğitim düzeyi ve ekonomik durumuna göre farkındalık düzeyleri benzer bulundu (p>0,05). Ayrıca SP'li çocukların ameliyat öyküsü, yaş dağılımı ve kaba motor fonksiyon düzeylerine (GMFCS) göre ebeveyn farkındalık düzeyleri artmış olsa da, farkındalık seviyeleri arasında anlamlı fark bulunmadı (p>0,05).

Sonuç: SP'li çocukları olan ebeveynlerin hastalık, sosyal ve günlük yaşam aktiviteleri ile fizyoterapi ve rehabilitasyon hakkındaki farkındalık düzeylerinin genel olarak orta ve yüksek olduğu saptandı. Farkındalık düzeylerinin, ebeveyn eğitim düzeylerinden, çocuklarının kaba motor fonksiyon seviyelerinden, çocukların yaşlarından ve ailenin ekonomik durumlarından etkilenmediği gözlendi.

Anahtar Sözcükler: Ebeveyn; farkındalık; rehabilitasyon; serebral palsi

Hatice Secinti¹, Hatice Adiguzel², Nevin Ergun³

- ¹ Department of Physiotherapy and Rehabilitation, Instute of Health Sciences, SANKO University
- ² Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, Kahramanmaras Sutcu Imam University
- ³ Department of Physiotherapy and Rehabilitation, Faculty of Health Sciences, SANKO University

Received/*Geliş* : 25.08.2023 Accepted/*Kabul*: 04.12.2023

DOI: 10.21673/anadoluklin.1349686

Corresponding author/Yazışma yazarı Hatice Adiguzel

Kahramanmaraş Sütçü İmam Üniversitesi, Sağlık Bilimleri Fakültesi, Fizyoterapi ve Rehabilitasyon Bölümü, Kahramanmaraş, Türkiye.

E-mail: fzthatis@gmail.com

ORCID

Hatice Seçinti: 0000-0003-2026-1470 Hatice Adiguzel: 0000-0001-9323-839X Nevin Ergun: 0000-0001-6575-7205

INTRODUCTION

Cerebral palsy (CP) is a non-progressive but age-related loss of motor function, posture, and movement disorder that develops due to damage in the perinatal period in the immature brain (1). Abnormal muscle tone, insufficiency of postural control, weakness of muscle strength, abnormal behaviors, and sensory disorders are common symptoms of motor impairments (1). Although CP presents symptoms in early infancy, the diagnosis age may be delayed. CP is a condition characterized by multiple problems that require longterm and complex care. The process of parents getting acquainted with the disease and increasing awareness about it takes time. The diagnosis of CP can be traumatic for parents (2).

Treatment is carried out through a specialized multidisciplinary team working in accordance with the child's needs and with the active involvement of parents in CP. The family is one of the most crucial members in the treatment and rehabilitation process, which is based on a multidisciplinary approach (3,4). Under the umbrella of physiotherapy and rehabilitation, the goals include improving motor skills and functions, lowering postural abnormalities, regulating muscle tone, and correcting musculoskeletal deformities. However, these goals can only be met through positive parent-physiotherapist interactions and by making sure that kids participate in society and everyday activities.

The view that families play a significant role in the lives of disabled children has gained increasing validity over time. The socio-economic status of the family, the psychological state of the parents, and their level of education are important factors in the development of children with CP (4). Providing care for their children and accessing government services can be challenging for families. In rehabilitation, a family-centered approach should be adopted, taking into account the needs and priorities of the families (5). There is not enough data about the variables that affect the needs of families with children with CP in the literature (6-8). However, these parents are indispensable in the decision-making process of the healthcare team. According to research, collaborating with parents is crucial to enhancing parental satisfaction with their children's rehabilitation (6-8).

Motor activity loss and movement disorders in children with CP result in increased dependency and the need for more external support in their daily lives (9). Parents are the ones who know their child's functional abilities and needs best. They have various responsibilities, such as managing treatments, educational services, general medical check-ups, medications, devices, and educational materials. Therefore, involving parents in the rehabilitation process provides stronger rehabilitation services for children (10,11). In recent years, with the increasing importance of family-centered practices, all family members have started to actively participate in rehabilitation by continuing rehabilitation goals at home and in the community (10,12).

The family is the most crucial element in the transformation of treatment into a lifestyle due to the lifelong nature of the illness. Therefore, it is essential to assess the awareness of CP in parents of children with CP before planning the education or interventions they need. Because parents can handle this trip more professionally in terms of social, economic, and personal obligations and anxiety levels when they are informed about their children's illnesses and processes. It can improve their involvement in life by enabling parents to see their children's potential and by encouraging them to be more engaged. The research question in this study was whether awareness levels change depending on the parents' socioeconomic level, education level, and the child's functional level. This study aims to determine the awareness level of parents providing primary care to children with CP regarding the disease, physiotherapy, and rehabilitation.

MATERIAL AND METHODS Study Design

This study is a descriptive cross-sectional study.

Participants

The research was conducted with parents (n=78) providing primary care to children with CP having therapy at private education and rehabilitation centers in Gaziantep between June 2020 and June 2021. Consent was obtained from all parents who met the inclusion criteria for participation in the study. According to the power analysis, the sample size was calculated to be a minimum of 49 individuals, considering the effect size as 0.2, α (significance level) as 0.05, and γ - β (power) as 0.80. However, it was decided to reach a minimum of 70 parents to increase the power of the study.

Parents who volunteered to take part in the study and provided main care for a child with CP between the ages of 4 and 18 and who could communicate to respond to the questions on the personal information form and evaluation form were included in the study. Parents with any type of psychiatric condition were disqualified.

Ethical approval was obtained from the SANKO University Non-Interventional Clinical Studies Ethics Committee (date: 05.05.2020, decision no: 2020/07-7). The clinical trial number is NCT05213663.

Measurements

All parents' and children's sociodemographic information was recorded. The data were collected using questionnaires prepared by the researchers by reviewing the literature, which examined personal information about the children and parents, and a 40-item survey prepared to assess parents' awareness of CP disease, physiotherapy, and rehabilitation. Detailed information about the purpose of the research was provided to the parents of children with CP. Each questionnaire form was completed in a quiet environment in the rehabilitation center through a face-to-face meeting between the primary caregiver of the child with CP and the physiotherapist, taking approximately 20-30 minutes.

Cerebral Palsy Disease, Physiotherapy, and Rehabilitation Awareness Assessment Questionnaire: The questionnaire prepared by the researchers consisted of 40 multiple-choice questions with one correct answer, aiming to assess the knowledge level of parents of children with CP regarding the disease, physiotherapy, and rehabilitation. Before the study, the form was administered to ten parents of children with CP who met the inclusion criteria to identify any unclear points and make revisions, resulting in the final version of the questionnaire. Each assessment was completed through face-to-face meetings with the parents of the child with CP in a quiet environment. Based on the applied form, if the number of correct answers is between 0 and 15, the parent's awareness of the disease, physiotherapy, and rehabilitation was considered low; if the number of correct answers is between 16 and 30, it was considered moderate; and if the number of correct answers is between 31 and 40, it was considered high.

Statistical Analysis

The data were analyzed using the Statistical Package for the Social Sciences package program version 24.0 (SPSS Inc., Chicago, IL, USA) After entering the data obtained from the questionnaires into SPSS, the responses to the 40 questions were scored. In scoring, correct answers were considered as 1, and incorrect answers as 0, resulting in the creation of 40 variables. The total awareness score was obtained by summing all these variables. The total awareness score was then transformed into awareness groups based on predefined low, moderate, and high values. As a result, a three-stage dataset was created, including demographic data of parents, demographic data of children, and the scored awareness levels of parents. Descriptive and inferential statistical analyses were performed on these data. Continuous variables mean ± standard deviation, median (minimum-maximum values), and categorical variables are given as number (n) and percentage (%). Additionally, cross-tabulation and graphical representations were used to examine the relationships between awareness levels and certain demographic groups (such as education level, income status, number of surgical operations the child underwent, etc.). Chi-square analysis was conducted to determine the levels of association and statistical significance. All data were considered statistically significant at the p<0.05 level.

RESULTS

Based on the demographic information of the families in the study, the population consisted of 67 mothers (85.9%) and 11 fathers (14.1%). Out of the total parents, 13 (16.7%) were employed, while 65 (83.3%) were not employed. Among the parents, 3.8% had received no formal education, 30.8% had completed primary

Table 1. Sociodemographic characteristics	s of the participants
---	-----------------------

Sociodemographic characteristics		n/%
Caregivers (n=78)	Mother	67 (85.9)
Caregivers (II=78)	Father	11 (14.10)
	20-30	11 (14.1)
Age	30-40	31 (39.7)
	40-50	29 (37.2)
	50-70	7 (8)
Working status	Working	13 (16.7)
	Not working	65 (83.3)
	None	3 (3.8)
	primary school	24 (30.8)
Education level	Secondary school	13 (16.7)
	High school	23 (29.5)
	University/Higher education	14 (18.2)
Marital status	Married	74 (94.9)
	Widowed, divorced	4 (5.1)
	1	11 (14.1)
	2	12 (15.4)
	3	27 (34.6)
Number of children	4	15 (19.2)
	5	7 (9)
	6	6 (7.7)
	Income less than expenses	20 (25.6)
Socioeconomic status	Income and expense equal	41 (52.6)
	Income more than expenses	17 (21.8)
Age of CP children	4-8	36 (46.2)
	9-13	26 (33.3)
	14-18	16 (20.5)
Sex of children	Male	57 (73.1)
	Female	21 (29.9)
Number of children with CP	1	74 (94.9)
	2	4 (5.1)

*CP: Cerebral Palsy, n: number, %: percent

school, 16.7% had completed middle school, 29.5% had completed high school, and 18.2% had completed undergraduate or graduate studies. All sociodemographic information of the parents is presented in **Table 1.**

When the level of awareness of parents about CP disease, physiotherapy, and rehabilitation was evaluated according to the surgical history of children with CP, it was found that 3.8% of those who underwent surgery were low, 65.4% were moderate, and 30.8% were at high awareness levels. The awareness levels of the parents according to their surgical history are shown in **Table 2.** According to the surgical history of their children with CP, there was no difference between the awareness levels of the parents (p>0.05).

When the awareness levels of the parents whose financial income is less than the expense are examined according to the economic status; It was found that 70% of the group with less income and expenses were at the medium level of awareness. 53.7% of parents whose financial income equaled their expenses were found to be at a medium level of awareness. It was found that 47.1% of the parents whose financial income was more than their expenses were moderate and 52.9% were at

Table 2. Awareness levels according to children's surgical history, parents' socioeconomic status,	children's age distribution, and children's
GMFCS level	

Suggical history	Low awareness	Medium awareness	Higher awareness	p
Surgical history	n/%	n/%	n/%	
Yes	1 (3.8)	17 (65.4)	8 (30.8)	0.527
No	3 (5.8)	27 (51.9)	22 (42.3)	
Socioeconomic status				
Income less than expense	1 (5)	14 (70)	5 (25)	
Income and expense equal	3 (7.3)	22 (53.7)	16 (39)	0.392
Income more than expenses	0 (0)	8 (47.1)	9 (52.9)	
Children's age (year)	n/%	n/%	n/%	
4-8	3 (8.3)	14 (38.9)	19 (52.8)	
9-13	1 (3.8)	18 (69.2)	7 (26.9)	0.064
14-18	0 (0)	12 (75)	4 (25)	
Education				
None	0 (0)	2 (66.7)	1 (33.3)	
Primary	1 (4.2)	5 (62.5)	8 (33.3)	
Secondary	2 (15.4)	9 (69.2)	2 (15.4)	0.148
High bachelor	0 (0)	14 (60.8)	9 (39.2)	
GMFCS level	n/%	n/%	n/%	
Ι	0 (0)	7 (46.7)	8 (53.3)	
I	1 (4.5)	15 (68.2)	6 (27.3)	
III	1 (6.3)	9 (56.3)	6 (37.5)	0.562
IV	0 (0)	7 (58.3)	5 (41.7)	
V	2 (15.4)	6 (46.2)	5 (38.5)	

*Fisher's exact test, p<0.05, GMFCS: Gross Motor Function Classification System, n: number, %: percent

high awareness levels. The awareness of the parents according to their socioeconomic status was shown in table and figure (**Table 2** and **Figure 1**). There was no difference between the awareness states according to the economic level of the parents (p>0.05).

52.8% of parents of children with CP in the 4-8 age group were high, and 69.2% of parents in the 9-13 age group were intermediate; parents in the 14-18 age group were found to have a moderate level of awareness. The awareness levels of parents according to the age distribution of the children were shown in the table and figure (**Table 2** and **Figure 2**). There was no difference between the awareness levels of the parents according to the age distribution of the children (p>0.05).

It was found that 66.7% of parents with no education were at an intermediate level, 62.5% of parents with primary school graduation were at an intermediate level, 69.2% of secondary school graduates were at an intermediate level, 60.8% of parents with high school graduation were at an intermediate level, and 71.4% of parents with undergraduate and graduate degrees were at a high level of awareness. The awareness of parents according to their level of education is shown in in table and figure (**Table 2** and **Figure 3**). There was no difference between the awareness levels of the parents according to their education level (p>0.05).

Parents of children with CP at GMFCS I levels reported 46.7% had moderate and 53.3% had high levels; 68.2% of parents of children with CP at GMFCS Table 3. Parents' awareness levels of disease knowledge

	Low	Medium	Higher
	awareness	awareness	awareness
Questions	n/%	n/%	n/%
q1) What is cerebral palsy?	2 (50)	31 (70.4)	30 (100)
q2) Which of the following is not accompanied by cerebral palsy?	0 (0)	41 (93.1)	30 (100)
q3) Could siblings of children with cerebral palsy have the same disease?	0 (0)	16 (36.3)	12 (40)
q4) Which of the following are not causes of cerebral palsy?	1 (25)	36 (81.8)	28 (93.3)
q5) Which of the following is not an abnormal condition that can be seen in the first 6 months?	1 (25)	18 (40.9)	18 (60)
q10) Which of the following are the types of cerebral palsy?	1 (25)	34 (77.2)	29 (96.6)
q13) Which of the following true for cerebral palsy?	1 (25)	34 (77.2)	29 (96.6)
q14) Which of the following are not types of cerebral palsy?	2 (50)	28 (63.6)	28 (93.3)
q18) Which of the following is not accompanied by cerebral palsy?	2 (50)	32 (72.7)	29 (96.6)
q24) Which of the following is right for the treatment of cerebral palsy?	1 (25)	25 (56.8)	23 (76.6)
q28) When is surgery performed on a child with cerebral palsy?	3 (75)	35 (79.5)	29 (96.6)
q32) Which of the following is not the cause of surgery in cerebral palsy?	1 (25)	15 (34)	7 (23.3)
q35) Which of the following is true for cerebral palsy?	1 (25)	8 (18.1)	20 (66.6)
q36) Which of the following does not pose a risk for cerebral palsy?	1 (25)	25 (56.8)	27 (90)
q37) Which of the following is not accompanied by cerebral palsy?	2 (50)	42 (95.4)	29 (96.6)
q38) Which of the following is wrong for the treatment of the child with cerebral palsy?	1 (25)	29 (65.9)	29 (96.6)
Parents' awareness levels of social and daily living	activities		

	Low awareness	Medium awareness	Higher awareness
Questions	n/%	n/%	n/%
q7) Which one can a child with Cerebral Palsy do?	1 (25)	35 (79.5)	29 (96.6)
q9) Can cerebral palsy children participate in sports activities?	0 (0)	23 (52.2)	24 (80)
q17) Are there any sports activities in your region or province for children with cerebral palsy?	2 (50)	15 (34)	10 (33.3)
q20) What sport can children with cerebral palsy participate in?	0 (0)	19 (43.1)	22 (73.3)
q29) Which of the following is not one of the benefits of sports for a child with cerebral palsy?	2 (50)	9 (50.4)	11 (36.6)
q39) What is wrong with what sport has brought to children with cerebral palsy?	2 (50)	33 (75)	29 (96.6)

n: number, %: percent

II level had moderate to moderate; 56.3% of parents of children with CP at GMFCS III level were found to be moderate; 58.3% of parents of children with CP at GMFCS IV level had moderate levels and 41.7% had high levels; Parents of children with CP at GMFCS V levels were found to have a moderate level of awareness. The awareness status of the parents according to the GMFCS level was shown in in table and figure (**Table 2** and **Figure 4**). There was no difference between their children's GMFCS levels and their parents' awareness levels (p>0.05).

The survey's questions, which assessed the parents of children with CP's degree of knowledge regarding the condition, physiotherapy, and rehabilitation, were divided into three categories: disease knowledge, physiotherapy and rehabilitation, and social and daily living activities. The degrees of awareness based on the questions are shown in tables (**Tables 3 and 4**).

When the general awareness levels of the parents of children with CP were examined, it was determined that 5.13% of the parents were at a low level, 56.41% were at a medium level and 38.46% were at a high awareness level (Figure 5).

DISCUSSION AND CONCLUSION

In our study, the awareness levels of parents who gave primary care to children with CP about the disease,

Table 4. Parents	' awareness	levels of	physiothe	rapy and	d rehabilitation
------------------	-------------	-----------	-----------	----------	------------------

	Low awareness	Medium awareness	Higher awareness
Questions	n/%	n/%	n/%
q6) Which of the following is included in the cerebral palsy physiotherapy program?	3 (75)	40 (90.9)	30 (100)
18) When should physical therapy and rehabilitation begin in individuals with cerebral palsy?	4 (100)	38 (86.3)	26 (86.6)
11) Which of the following is true for the role of the family in physiotherapy in hildren with cerebral palsy?	0 (0)	26 (59)	29 (96.6)
12) Which of the following is wrong for physiotherapy program?	0 (0)	16 (36.3)	25 (83.3)
(15) How to determine the physiotherapy program of the child with cerebral palsy?	2 (50)	26 (59)	23 (76.6)
16) Who should be in the physiotherapy and rehabilitation program of the child /ith cerebral palsy?	1 (25)	18 (40.9)	26 (86.6)
19) Which one is wrong for the standing frame used in physiotherapy?	2 (50)	27 (61.3)	27 (90)
21) Which of the following is wrong for orthotics (an assistive device worn on any art of the body, such as hands, feet, legs)?	0 (0)	26 (59)	29 (96.6)
22) Which of the following is wrong for botox (intervention with a needle by octors into the muscle)?	3 (75)	26 (59)	29 (96.6)
23) Which of the following is not one of the goals of physiotherapy?	2 (50)	36 (81.8)	30 (100)
25) Which of the following is true for physiotherapy in children with cerebral alsy?	1 (25)	29 (65.9)	28 (93.3)
26) Which of the following cannot be asserted regarding the family of the cerebral alsy patient being included in the rehabilitation program?	0 (0)	33 (75)	29 (96.6)
27) Which of the following are the assistive devices used in physiotherapy?	2 (50)	36 (81.8)	29 (96.6)
30) Which of the following is not included in the physiotherapy program?	2 (50)	38 (86.3)	29 (96.6)
31) Which of the following should be considered when positioning a child with erebral palsy?	0 (0)	35 (79.5)	25 (83.3)

n: number, %: percent

physiotherapy, and rehabilitation were examined. According to the parameters classified in the questionnaire, parents' awareness levels of disease knowledge, social and daily living activities, physiotherapy, and rehabilitation were generally found at medium and high awareness levels. In addition, it was observed that the awareness levels of the parents were not affected by the level of parental education, the GMFCS levels of their children, the ages of the children, and the economic status of the family.

In the study in which Chen et al. investigated the factors affecting the quality of life of caregivers of children with CP, the vast majority of caregivers were mothers (13). In another study that examined the wellbeing and health of caregivers of children with CP, it was found that the vast majority of caregivers were mothers (14). In our society, it has been observed that the care of children with CP who need care is largely composed of mothers (15,16). In our study, in parallel with these studies in the literature, it was observed that mothers were the primary caregivers. Therefore, it is still thought that the burden of mothers is too much as the primary caregiver.

When the marriage process in families with CP children was assessed in the study by Sipal et al., it was discovered that the vast majority of them continued their marriages (17). The majority of the parents were found to be married in the study by Dambi et al., which looked at how the training workshop they held for parents of children with CP affected the parents' level of knowledge (18). Similar to this, a large percentage of parents in our study were married. These findings suggested that the illness might boost parental connection and attachment.

In the study in which Basaran et al. examined the effect of the quality of life of parents with children with CP, it is stated that the parent who cares for the child with CP does not work at a high rate (19). In our study,

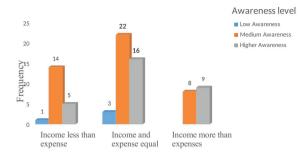


Figure 1. Awareness levels of parents according to socioeconomic status

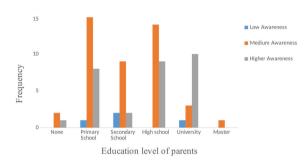


Figure 3. Awareness levels of parents according to parents's education level

the vast majority of primary caregivers did not work, too. This situation shows that caregivers in our country do not prefer to work.

Marron et al. investigate the factors affecting the burden on caregivers of children with CP, examining the educational status of parents, stating that the majority of them have completed post-primary education (20). Wijesinghe et al. reported that the majority of caregivers were at primary school level (21). In our study, the majority of parents were at the primary and high school levels. This has shown that even in studies conducted in different countries, the level of education of parents is similar.

The awareness levels of the parents did not change according to the surgical history of the children and their economic status in the current study. In the study conducted by Difazio et al. with caregivers, the expectations and satisfaction of caregivers from the surgery in hip and spine surgery applied to children at GMFCS IV and V levels were evaluated. However, it has been reported that their expectations are unrealistic and awareness should be increased (22). Another study evaluated the functional recovery of children

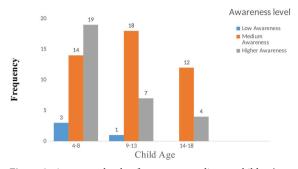


Figure 2. Awareness levels of parents according to children's age distribution

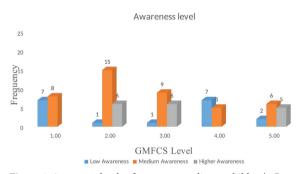
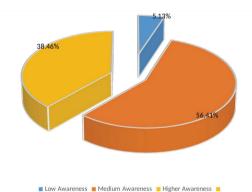


Figure 4. Awareness levels of parents according to children's Gross Motor Function Classification System level



Low Awareness Miedlum Awareness Higher Awarenes

Figure 5. General awareness levels of parents

with CP after spinal arthrodesis for scoliosis. It has been reported that parents do not realize the effects of scoliosis deformity on head control, hand use, and feeding skills (23). These results show that surgical operations do not always increase awareness in parents. A study of families with low socioeconomic status in India found a lack of knowledge and awareness about the options needed for the treatment of their children (24). Bella et al. found that economic status in mothers of children with CP did not affect the burden of caregiving and stress (25). This situation shows that in studies conducted in different populations, the awareness of caregivers and the level of caregiving affected by the economic level may vary.

In another study that examined the burdens and hopelessness levels of the mothers of children with CP, it was determined that the majority of families whose income was equal to their expenses when the income level was evaluated. In this study, it was found that most of the participants had equal income and expenditure levels and that the economic level of the family did not affect the level of awareness about their children's disease (26). Therefore, it was suggested that although the parents of children with CP were not at a good economic level, their level of awareness about the disease and its processes may be good. These results showed that being aware of the disease would not be directly affected by the economic situation.

There was no study that directly examined the age of the child and the level of parental awareness. In Yoruk's study in which mothers of children with CP examined the burden and impact of care, consistent with our study, it was found that parents of children between the ages of 4 and 8 had the highest rate of participation in the study, while those between the ages of 13 and 18 had the lowest rate. It has been observed that the burden of caregiving affects the awareness of the caregiver in relation to the relationship between the patient and the psychological state of the caregiver. In this study, there was no relationship between the age of the child and the mother's burden of caregiving (27). In Mohammed et al.'s study examining the quality of life of CP patients and their caregivers, similar to our study, the parents of children with CP between the ages of 4 and 8 years were found to have the highest rate of participation in the study. In this study, there was no relationship between the burden of caregiving and the age of the child (28). In our study, when the effect of child age on parents' awareness levels was examined, it was observed that awareness levels did not change significantly according to age groups, but as the age increased, parents' awareness levels of disease knowledge, social and daily living activities, physiotherapy and rehabilitation reached medium levels. It was found that the awareness levels of the parents, especially in the 14-18 age range, reached the highest level. Therefore, these results, in parallel with the studies in the literature, in addition to showing that the burden of caregivers does not change in children with CP as the age increases; showed that parents' level of knowledge and awareness of the processes of the disease and their children's performance and activities in daily life increased.

When the age distribution of children with CP was examined, the 4-8 age group had the highest rate and the 14-18 age group had the lowest rate in this study. When the level of awareness of parents of children with CP between the ages of 4 and 8 was examined, half of the parents had a high level of awareness; The vast majority of parents between the ages of 9-13 and 14-18 were found to have a moderate level of awareness. These results show us that as children age, there are no parents with low levels of awareness.

In Asilturk's study examining the care burden of parents of children with CP, the proportion of children at GMFCS I-II-III level is higher than the rate of children at GMFCS IV-V level similar to our study (29). The number of children at the GMFCS I-II-III level was larger than that of children at the IV-V level, according to another study comparing the effects of children with walking and non-walking CP on their carers' mood, health, and daily living experience (26, 30). These findings led us to believe that the children's ambulation levels in studies involving parents of CP children were comparable. No study evaluating the connection between GMFCS level and parental awareness level was found when the literature was reviewed. In our study, there were no parents with poor awareness of the GMFCS I and IV levels of children; the proportion of parents with low awareness of the GMFCS V level of children was found to be at the greatest level. Parents with children with GMFCS II level were found to be aware of the disease, with a high rate of moderate awareness. However, there was no difference in the awareness levels of the parents according to the GM-FCS levels of their children.

Alruwaished et al. examined the level of knowledge about the disease in parents with children with CP and found that education level did not affect the parent's level of knowledge (31). Arora et al. also emphasized that the educational status of parents of children with CP does not affect general knowledge about CP (32). Our study similarly found that education level did not affect parents' awareness levels of knowledge about CP, activities of social and daily living, and physiotherapy and rehabilitation. As a result of our study; Parents with no education and a primary school, middle school, and high school degree were found to have a high rate of moderate awareness. The majority of parents at the undergraduate and graduate levels were found to have a high level of awareness. It was observed that the majority of parents with low levels of awareness were parents at the secondary school level. These results made us think that mindfulness is not affected by the educational level of families.

According to the responses to the questionnaire's questions about disease knowledge, social and daily life activities, sports, physiotherapy and rehabilitation, it was found that parents in this study generally had medium to high levels of awareness. Parents' general knowledge and awareness levels of CP were shown to be severely insufficient in research with parents of children with CP conducted in Saudi Arabia (33). The majority of participants had minimal to moderate knowledge of how to professionally care for a child with CP, according to Afzal et al.'s study with carers of children with CP in Iran (34). It was discovered in another study that children with CP participated in physical activities at a low rate, and it was recommended that awareness of sports and recreation be raised and that children with CP be directed (35).

The limitations of this study are the small number of children and parents in the higher age groups, the fact that the study was conducted only in one metropolitan city, the lack of participation of parents in different countries and rural areas, and the failure to achieve equality of women and men in parents. In larger sample studies, different age groups, different countries or regions, research according to the gender of parents will provide more comprehensive information on the subject. Further research in this area will facilitate an understanding of the level of awareness of parents with children with CP in different populations and countries. The determination of this situation is the responsibility of the families; treatment processes, and preventive and preventive rehabilitation methods can increase the effort by providing awareness to increase participation in daily life. It can also provide parents with a vision for enabling their children to

participate in a variety of social, and physical activity, sports skills that they can achieve, as well as play activities or environmental adjustments at school. Children's success rates in physiotherapy and rehabilitation programs may thus rise as parents' knowledge of the condition and its procedures rises. As a result, the primary objectives of treatment programs may be to evaluate parents' knowledge of CP disease, to provide physiotherapy and rehabilitation, and to educate parents about the disease process. In this regard, it is anticipated that our study will serve as a model for future research on the awareness of parents of children with CP.

In this study, it was shown that parents of children with CP generally had medium to high levels of awareness regarding their children's condition, social and daily living activities, physiotherapy, and rehabilitation. It was observed that when the children's ages climbed and they underwent surgery, the parents' degrees of awareness also rose. Additionally, it was shown that the parents' awareness levels were unaffected by their level of education, their children's gross motor function, their ages, or their family's financial situation. According to responses to survey questions about disease information, social and daily life activities, and physiotherapy and rehabilitation, parents generally had a moderate to high degree of awareness.

Acknowledgment

The authors would like to thank all of the parents who participated in to study.

Conflict-of-interest and financial disclosure

The authors declare that they have no conflict of interest to disclose. The authors also declare that they did not receive any financial support for the study.

REFERENCES

- Sadowska M, Sarecka-Hujar B, Kopyta I. Cerebral palsy: Current opinions on definition, epidemiology, risk factors, classification and treatment options. Neuropsychiatr Dis Treat. 2020;16:1505.
- Schuengel C, Rentinck I, Stolk J, et al. Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. Child Care

Health Dev. 2009;35(5):673-80.

- Al-Gamal E, Long T. Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: A cross-sectional study. Scand J Caring Sci. 2013;27(3):624-31.
- Aydin R, Nur H. Family-centered approach in the management of children with cerebral palsy. Turk J Phys Med Rehabil. 2012;58.
- Palisano R, Almarsi N, Chiarello L, Orlin M, Bagley A, Maggs J. Family needs of parents of children and youth with cerebral palsy. Child Care Health Dev. 2010;36(1):85-92.
- Kruijsen-Terpstra AJ, Ketelaar M, Boeije H, et al. Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review. Child Care Health Dev. 2014;40(6):787-96.
- Peplow UC, Carpenter C. Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: a qualitative study. Phys Occup Ther Pediatr. 2013;33(3):285-99.
- Wiart L, Ray L, Darrah J, Magill-Evans J. Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. Disabil Rehabil. 2010;32(3):248-58.
- Hisar F, Abic A. Özel Eğitim Merkezinde Eğitim Gören Engelli Çocukların Evde Bakım Gereksinimlerinin Belirlenmesi. Sağlık ve Toplum. 2016;26(1):46-55.
- Lillo-Navarro C, Medina-Mirapeix F, Escolar-Reina P, Montilla-Herrador J, Gomez-Arnaldos F, Oliveira-Sousa SL. Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study. J Physiother. 2015;61(2):81-6.
- Rosenbaum P, King S, Law M, King G, Evans J. Familycentred service: A conceptual framework and research review. Family-Centred Assessment and Intervention in Pediatric Rehabilitation, 2014; p. 1-20.
- Aydın R, Tedavisinde NHSPÇ. Aile Odaklı Yaklaşım. Turk J Phys Med Rehab. 2012;58:229-35.
- Chen K-L, Tseng M-H, Shieh J-Y, Lu L, Huang C-Y. Determinants of quality of life in children with cerebral palsy: A comprehensive biopsychosocial approach. Res Dev Disabil. 2014;35(2):520-8.
- 14. Raina P, O'Donnell M, Rosenbaum P, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005;115(6):e626-e36.
- 15. Gündede E. Serebral Palsili Çocukların Fonksiyonelliği İle Ebeveynlerinin Bakım Yükü, Aktivite Düzeyi, Yaşam Kalitesi ve Psikolojik Durumu Arasındaki İlişki: Yüksek

lisans tezi, İstanbul: Okan Üniversitesi; 2018.

- 16. Sahin S, Barkın K, Demirok T, Meral H. Hemiparatik serebral palsili çocukların ve bakım verenlerinin çocuklara yönelik aktivite tercihlerinin incelenmesi. Ergoterapi ve Rehabilitasyon Dergisi. 2019;7(1):41-6.
- 17. Sipal R, Schuengel C, Voorman J, Van Eck M, Becher J. Course of behaviour problems of children with cerebral palsy: the role of parental stress and support. Child Care Health Dev. 2010;36(1):74-84.
- Dambi JM, Mandizvidza C, Chiwaridzo M, Nhunzvi C, Tadyanemhandu C. Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers. Malawi Med J. 2016;28(4):167-73.
- Basaran A, Karadavut KI, Uneri S, Balbaloglu O, Atasoy N. The effect of having a children with cerebral palsy on quality of life, burn-out, depression and anxiety scores: a comparative study. Eur J Phys Rehabil Med. 2013;49(6):815-22.
- Marrón EM, Redolar-Ripol D, Boixadós M, et al. Burden on caregivers of children with cerebral palsy: predictors and related factors. Universitas Psychologica. 2013;12(3):767-77.
- Wijesinghe CJ, Cunningham N, Fonseka P, Hewage CG, Østbye T. Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. Asia Pac J Public Health. 2015;27(1):85-95.
- 22. Difazio RL, Vessey JA, Zurakowski D, Snyder BD. Differences in health-related quality of life and caregiver burden after hip and spine surgery in non-ambulatory children with severe cerebral palsy. Dev Med Child Neurol. 2016;58(3):298-305.
- Tsirikos AI, Chang WN, Dabney KW, Miller F. Comparison of parents' and caregivers' satisfaction after spinal fusion in children with cerebral palsy. J Pediatr Orthop. 2004;24(1):54-8.
- 24. Vadivelan K, Sekar P, Sruthi SS, Gopichandran V. Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. BMC public health. 2020;20(1):1-8.
- Bella GP, Garcia MC, Spadari-Bratfisch RC. Salivary cortisol, stress, and health in primary caregivers (mothers) of children with cerebral palsy. Psychoneuroendocrinology. 2011;36(6):834-42.
- 26. Calışır H, Karabudak Ss, Karataş P, Tosun Af, Meşealan I. Serebral palsili çocuğu olan annelerin aile yükü ve umutsuzluk düzeyleri. Dokuz Eylül Üniversitesi Hemşirelik Fakültesi Elektronik Dergisi. 2018;11(2):147-56.

- Yörük BN. Serebral palsili çocukların annelerinin bakım yükü ve etkileyen faktörlerin belirlenmesi: İstanbul Medipol Üniversitesi Sağlık Bilimleri Enstitüsü; 2021.
- Mohammed FM, Ali SM, Mustafa MA. Quality of life of cerebral palsy patients and their caregivers: A cross sectional study in a rehabilitation center Khartoum-Sudan (2014–2015). J Neurosci Rural Pract. 2016;7(03):355-61.
- Asiltürk S. Serebral palsili çocukların yaşam kalitesinin ve ebeveynlerinin bakım verme yüklerinin belirlenmesi: Balıkesir Üniversitesi Sağlık Bilimleri Enstitüsü; 2019.
- 30. Svedberg LE, Englund E, Malker H, Stener-Victorin E. Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support. Eur J Paediatr Neurol. 2010;14(3):239-46.
- Alruwaished A, Ali B, Alhowaimil L, Alhowaimil A, Alhowaimil N, Alessa A. Knowledge and attitude of caregivers of cerebral palsy children in Riyadh city. Int J Med Dev Ctries. 2020;4(1):12-7.

- Arora SK, Aggarwal A, Mittal H. Impact of an educational film on parental knowledge of children with cerebral palsy. Int J Pediatr. 2014;2014.
- 33. Alruwaished A, Ali B, Alhowaimil L, Alhowaimil A, Alhowaimil A, Alessa A. Knowledge and attitude of caregivers of cerebral palsy children in Riyadh city. Int J Med Dev Ctries. 2020;4(1):12-7.
- 34. Razavi Afzal Z, Rassafiani M, Sarfaraz Z, Malekpour M, Salehi M. A Survey on knowledge and application of caregivers regarding special care of children 1-5 years old with cerebral palsy. J Res Rehabil Sci. 2013;9(4):618-28.
- 35. Hanifi E, Sertel M, Alpcan A, Arslan M. The Evaluation of Physical Activity and Physical Fitness Levels in Adolescent Individuals with Cerebral Palsy. Kırıkkale Ünv Tıp Fakültesi Dergisi. 2022;(1):73-82.