

The Impact of Pain in Individuals with Cerebral Palsy on Parents

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ABSTRACT

Aim: The aim of this study is to evaluate the pain seen in individuals with Cerebral Palsy (CP) and to investigate its impacts on the parents.

Material and Methods: The study included 66 individuals with Cerebral Palsy aged between 6-16, with a mean age of 8.83±3.17. The levels of the individuals included in the study were determined using the Gross Motor Function Classification System and the Manual Ability Classification System. The pain intensity of the individuals with Cerebral Palsy was assessed through a visual analog scale reported by the parents. The Impact on Family Scale was used to determine the state of the parents' impact.

Results: A significant positive correlation was found between the visual analog scale and sub-parameters of the Impact on Family Scale, excluding the coping parameter ($p<0.05$). A statistically significant result was found when comparing the Impact on Family Scale total scores according to the Gross Motor Function Classification System levels ($p=0.026$). Parents stated that their children with CP most frequently experienced leg pain, at a rate of 34.8%.

Conclusion: Our results showed that the prevalence of pain in children with Cerebral Palsy is high. The pain problems observed in individuals with Cerebral Palsy negatively impact their parents in many financial, social and familial aspects. The assessment and prevention of pain in children with CP is an important issue for both children and parents.

Keywords: Cerebral palsy; disabilities; pain; parents.

Serebral Palsili Bireylerde Görülen Ağrının Ebeveynler Üzerindeki Etkisi

ÖZ

Amaç: Bu çalışmanın amacı, Serebral Palsili (SP) bireylerde görülen ağrının değerlendirilmesi ve ebeveyne olan etkisini araştırmaktır.

Gereç ve Yöntemler: Çalışmaya yaş ortalaması 8,83±3,17 olan 6-16 yaş arası 66 SP'li birey dahil edildi. Çalışmaya dahil edilen bireylerin Kaba Motor Fonksiyon Sınıflama Sistemi ve El Becerileri Sınıflama Sistemi ile seviyeleri belirlendi. SP'li bireyin ağrı şiddeti görsel analog skalası ile ebeveyn raporu şeklinde değerlendirildi. Ebeveynlerin etkilenim durumunun belirlenmesi için Aile Etki Ölçeği kullanıldı.

Bulgular: Görsel analog skalası ile Aile Etki Ölçeği'nin başa çıkma parametresi hariç diğer alt parametreler arasında pozitif yönde anlamlı bir ilişki bulundu ($p<0,05$). Kaba Motor Fonksiyon Sınıflama Sistemi seviyelerine göre Aile Etki Ölçeği toplam puanları karşılaştırıldığında istatistiksel olarak anlamlı bir sonuç bulundu ($p=0,026$). Ebeveynler Serebral Palsili çocuklarının en sık %34,8 bacak ağrısı yaşadığını belirtti.

Sonuç: Sonuçlarımız Serebral Palsili çocuklarda ağrı prevalansının yüksek olduğunu gösterdi. Serebral Palsili bireylerde görülen ağrı problemleri ebeveynlerini finansal, sosyal ve ailesel yönden birçok boyutta olumsuz etkilemektedir. SP'li çocuklarda ağrının değerlendirilmesi ve önlenmesine yönelik yaklaşımlar hem çocuklar hem de ebeveynler açısından önemli bir konudur.

Anahtar Kelimeler: Ağrı; ebeveynler; engelliler; serebral palsi.

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INTRODUCTION

Cerebral Palsy (CP) is characterized by motor function limitations, postural development problems, and disorders in body structure and functions, constituting a motor dysfunction (1). There are high rates of pain problems reported by parents in children with CP, stemming from physical disabilities (2-4). According to studies on comorbidities, diseases and functional limitations associated with CP, the majority of children experienced pain (5). It is reported that 30-80% of pain have moderate to severe activity limitations caused by pain of individuals with CP. Pain has been defined as acute, recurrent or chronic forms, depending on various reasons (6). Researchers have reported that recurrent musculoskeletal pain is common and associated with higher levels of health problems and worse health-related quality of life (5). The most common causes of pain associated with CP include dystonia, hip dislocation, and constipation (3). Pain can be caused by spasticity, weakness, contracture, or musculoskeletal deformity, or it may lead to an increase in these problems (5). Older age and female gender are seen as risk factors for pain. It is reported that the most common pain occurs in the lower extremities, along with frequent occurrences of abdominal pain and headaches (3,7). Pain is a common health problem and has serious consequences for both the quality of life of children with CP and their families (8). The presence of pain in children with CP negatively affects quality of life and participation, leading to anxiety, behavioral problems, and fatigue, and creates a source of stress within the family (3,4,8-11). In addition to pain, pain anxiety problems also accompany. Pain intensity problems related to pain anxiety are reported to be associated with behavioral and emotional problems in children (10). Pain also adversely affects the parent's personal time and causes limitations in family activities (12).

Despite the common occurrence of pain problems in CP, it is stated that they are not sufficiently understood, therefore not adequately diagnosed, and treated (3). However, it has been determined that the literature does not review the impacts of pain problems in individuals with CP on the parents. Based on this information, the aim of this study was to evaluate the pain seen in individuals with CP and to investigate its impact on their parents. It is thought that determining the impacts of pain on the parents will be guiding in terms of solution approaches to be made towards these factors.

MATERIAL AND METHODS

Participants

A cross-sectional prospective study was approved by Gaziantep Islam Science and Technology University clinical research ethics committee (Protocol Number: 2022/122). Data were collected between July 2022 and June 2023. The study included parents of 66 children diagnosed with CP, aged between 6 and 16. Children whose families agreed to participate in the study were included. Children who could not be reached by their parents and whose parents could not read or write in Turkish, diagnosed with a psychiatric disorder, and have a chronic disease (liver, kidney disease, hematologic, etc.) that can cause pain were excluded from the study.

In the socio-demographic information form created for the study, information such as the children's age, gender, height, weight, and the socio-demographic information of the children's parents was questioned. The Gross Motor Function Classification System (GMFCS) was used to classify the gross motor function levels of the children with CP included in the study, and the Manual Ability Classification System (MACS) was used to classify manual ability (13). The Impact on Family Scale was used to assess the impact on the individual's parents. The presence of pain problems in the children with CP included in the study was questioned within the last week and 3 months. If pain problems were experienced, pain intensity was evaluated with a visual analog scale (VAS). The VAS consists of a 10 cm line drawn on paper (0 = no pain, 10 = severe pain). Pain severity was graded as follows: 1-2 was considered mild, 3-4 was considered moderate, 5-6 was considered severe, 7-8 was considered very severe, and 9-10 was considered unbearable (14). In addition, the painful area and the cause of the pain were also questioned. Evaluations related to pain were obtained from the parents. The assessments of the individuals included in the study were taken using face-to-face interviews. Written informed consent forms were obtained from all individuals participating in the study. This study was conducted in accordance by the Principles of the Declaration of Helsinki.

Impact on Family Scale (IFS); Impact on Family Scale is a 24-item scale that evaluates the extent to which the families of children with chronic disabilities are affected (15). Its Turkish validity was conducted by Beydemir et al. (16). The scale assesses the family's level of impact under 4 headings: financial burden, familial/social impact, personal strain, and coping. The 4-point Likert type options are 'strongly agree (1)', 'agree (2)', 'disagree (3)', and 'strongly disagree (4)'. The minimum score that can be obtained from the scale is 24, and the maximum score is 96 (15,16). Cronbach's alpha was 0.88 for the total scale in development research (15). Cronbach's alpha was seen to be 0.81 in Turkish validity study (16).

Statistical Analyses

Statistical analyses were conducted using IBM SPSS v.25 (Chicago, USA) software package. The normality of the data was analytically examined using the Kolmogorov-Smirnov Test.

Descriptive statistics of the data were expressed as n (%) and mean±standard deviation (Mean ± SD) if the variable was normally distributed, and median (minimum-maximum) otherwise. The relationship between IFS, VAS, income, and age of the children with CP was examined using Pearson correlation coefficient. Kruskal Wallis test was used to compare IFS total scores between groups according to GMFCS levels. The required sample size for the research was determined using the G-Power 3.1 program. Based on this, with the hypothesis that there would be a large effect size of $d=1.70$ between groups and using the independent groups' t-test, it was determined to be a minimum of 63 individuals with 90% power and a 5% margin of error.

The statistical significance level was determined as $p<0.05$. The correlation between the two variables was

analyzed with Pearson’s correlation test. Pearson correlation coefficients were classified as low (0.26 – 0.49), moderate (0.5– 0.69), high (0.7– 0.89), or very high (0.9 –1.0) (17).

RESULT

A total of 66 with CP with a mean age of 8.83±3.17 were included in this study (Table 1). 36 (54.5%) of the individuals participating in the study were male and 30 (45.5%) were female. The large majority of the participants (81.8%) were in the middle income level (Table 1). The distribution of VAS scores according to GMFCS levels is given in the Table 2.

Table 1. The physical and sociodemographic characteristics

		Mean ± S.D
Age		8.83 ± 3.17
Height(cm)		124.10 ± 17.82
		Median (min-max)
Weight(kg)		25.50 (13-75)
		n (%)
Gender	Male	36 (54.5)
	Female	30 (45.5)
GMFCS Level	Level I	12 (18.2)
	Level II	15 (22.7)
	Level III	13 (19.7)
	Level IV	12 (18.2)
	Level V	14 (21.2)
MACS Level	Level I	11 (16.7)
	Level II	23 (34.8)
	Level III	9 (13.6)
	Level IV	12 (18.2)
	Level V	11 (16.7)
Educational Level of the Respondents	Primary/ Secondary School	42 (63.6)
	High School	19 (28.8)
	University	5 (7.6)
Income	Low	2 (3.0)
	Medium	54 (81.8)
	High	10 (15.2)
Presence of pain in the last week	Yes	27 (40.9)
	No	39 (59.1)
Presence of pain in the last 3 months	Yes	39 (59.1)
	No	27(40.9)

S.D: Standard Deviation, GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System

Table 2. Distribution of VAS scores according to GMFCS levels

	VAS	
	n (%)	Mean ± S.D
GMFCS Level I	3 (7.3)	4.33 ± 1.52
GMFCS Level II	8 (19.5)	6 ± 1.77
GMFCS Level III	11 (26.8)	4.18 ± 1.66
GMFCS Level IV	8 (19.5)	4.62 ± 1.18
GMFCS Level V	11 (26.8)	4.18 ± 1.16

S.D: Standard deviation, GMFCS: Gross Motor Function Classification System, VAS: Visual Analog Scale

The parents included in the study, 41 (62.1%) reported that their children had pain problems. Additionally, the parents reported that 23 (34.8%) of the children had leg pain, 5 (7.6%) had headaches, 4 (6%) had back and waist pain, and 3 (4.5%) had widespread pain. When parents were asked about the causes of pain in their children with CP, it was found that 32 (48.8%) were due to spasticity, 6 (9.8%) from continuous sitting or lying down (due to immobility), and 5 (7.3%) equally from trauma and psychological sources.

As the monthly income level in Turkish lira increased, IFS total score values decreased. The distribution of individuals' IFS total scores according to income is given in Figure 1.

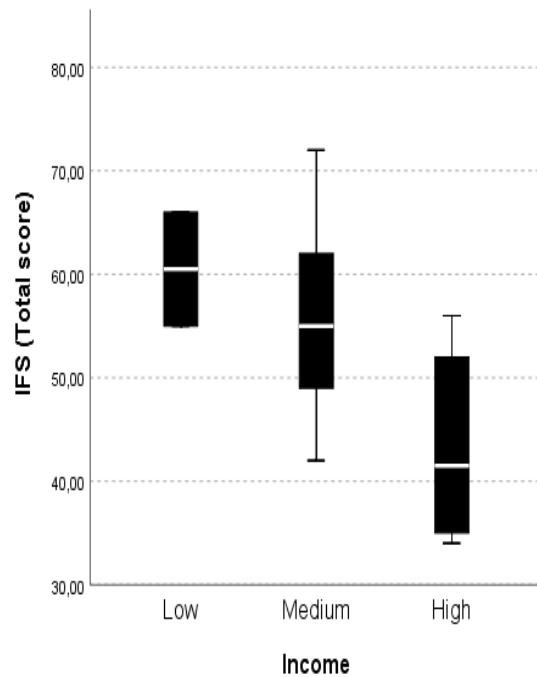


Figure 1. Distribution of individuals' IFS total scores according to income. Income refers to monthly income in Turkish lira. IFS: Impact on Family Scale

A moderately significant positive correlation was found between the VAS and IFS total score, and all other sub-parameters of the IFS (p<0.05), except for the coping (p=0.614) sub-parameter (Table 3). A moderately significant negative correlation was found between the IFS total score and the income level of the parents (p=0.000, Table 3). A moderately significant positive correlation was found between the IFS total score and the age of the children with CP (p=0.000, Table 3). A significant difference was found when IFS total scores were compared according to GMFCS levels (p=0.043, Table 4). The IFS total scores of the parents of GMFCS I level children were significantly lower than the IFS total scores of the parents of GMFCS IV level children (p=0.026).

Table 3. Relationships between the mean scores of IFS, VAS and age of the children

		Financial burden (IFS)	Familial/social impact (IFS)	Personal strain (IFS)	Coping (IFS)	IFS Total score
VAS	r	0.533	0.621	0.507	0.082	0.685
	p	0.000	0.000	0.001	0.614	0.000
Age of the children with CP	r					0.685
	p					0.000
Income	r					0.437
	p					0.000

Pearson correlation test. VAS: Visual Analog Scale, IFS: Impact on Family Scale

Table 4. Comparison of IFS total scores according to GMFCS Levels

	n	IFS Total Score Median (min-max)	χ^2	p
GMFCS Level I	12	46.50 (35-67)		
GMFCS Level II	15	55 (43-72)		
GMFCS Level III	13	55 (34-70)	9.83	0.043
GMFCS Level IV	12	55 (45-66)		
GMFCS Level V	14	54.5 (42-67)		

Kruskal Wallis Test. IFS: Impact on Family Scale, GMFCS: Gross Motor Function Classification System

DISCUSSION

The results of our study examining the pain observed in individuals with CP and its impact on the parents showed that pain problems seen in individuals with CP negatively affect their parents financially, socially, and personally, depending on the intensity of the pain. In addition, it was determined that the incidence of pain in individuals with CP included in the study was high.

It is known that pain in CP negatively affects quality of life, daily living activities, and health status, and limits participation in physical activities (18). Studies have shown that pain is common in children, adolescents, and adults with CP, and that the severity of pain varies depending on factors such as age, gender, level of impairment, mental condition, secondary problems, and functional level (2,11). It was similarly stated that in a study examining the pain in the participation dimension in individuals with CP, they experienced pain at high rates that limited participation. (3). Fairhurst et al. stated that 70% of parents reported pain in the last 3 months, 59% in the previous week, and 50% in the previous day. In addition, it was stated that 56% of children with CP regularly experienced pain (2). It is indicated that the rate of recurring pain problems in adolescents with CP is high, and attention should be paid to the issue of pain, making use of algorithms (19). It was determined that 40.9% of individuals with CP included in our study experienced pain

in the last week, and 59.1% in the last 3 months. This result emphasizes that pain is frequently observed in individuals with CP.

It is stated that pain is commonly seen in all age groups and functional levels in CP (20). When comparing pain and GMFCS levels, it is stated that in GMFCS levels II-V, there is higher and more intense pain compared to level I (11). Similarly, it is reported that the likelihood of pain increases in GMFCS levels II and IV (21). In our study, it was found that the mean pain intensity of individuals with CP at GMFCS level II was reported to be higher compared to other levels. It is reported that pain is often located in the lower extremities, back, and abdominal area, and is associated with decreased quality of life (22). In a different study, pain was frequently reported in the foot, hip, knee, and abdomen (4), and in the legs, waist, neck, and arms (21). In our study, congruent with the literature, the most common pain area was reported to be the leg at 34.8%. This was followed by 7.6% reporting head pain, 6% back and waist pain, and 4.5% reporting widespread pain.

The various complex and heterogeneous risk factors are indicated for pain (21). Clinicians working with CP are emphasized to be aware of hip dislocation, dystonia (3), and spasticity, scoliosis (23), which are among the most common causes of pain. The importance of early diagnosis and intervention of pain through routine screenings is highlighted (5). In our study, the causes of pain reported by parents were found to be 48.8% spasticity, 9.8% due to constant sitting or lying down (due to immobility), and 7.3% equally from trauma and psychological sources. We can point out that potential causes of pain should be well understood by clinicians, and the subject of pain should not be overlooked in clinics.

The care burden by parents with CP is multifactorial and complex in nature. It can be affected by many factors such as the child's characteristics, the parents' general and economic structure (24,25). In our study, we found that as parent income decreased and the age of children with CP increased, the total impact scores on the parents increased. This suggests that parents with a child with CP, especially those with older children and lower income levels, are more adversely affected financially, socially, and personally. In addition, when family impacts were examined according to GMFCS levels, it was determined that the impact on families of individuals at level IV was greater compared to level I. In this study, the parents' impact on their children's pain problems was investigated. The impact on parents of children with CP was not examined in a multidimensional way. In this regard, future studies can explore in more detail which factors are related to parents' impact situations.

It is well known that parents of disabled children have to cope with many negative factors such as higher financial burdens, disruption of family routine, decreased social activities, burden of care, increased family and domestic responsibilities, and restricted private life (26,27). Parents of children with CP who experience pain problems report that they believe their children's overall health is poor and will worsen. It is also reported that children with CP who experience pain problems have an impaired quality of life in certain areas compared to those without pain (12). Greater pain intensity has a negative impact on quality of life both physically and psychologically (2). In our study,

we showed that pain problems seen in individuals with CP adversely affect their families financially, socially, and personally, depending on the intensity of the pain, and that the impact on families increases as the intensity of the pain experienced by the children increases. In addition to the negative factors that families with a child with CP are responsible for coping with, their child's pain condition can be identified as an even more challenging factor for them. Therefore, we can emphasize that families with a child with CP who has pain problems are more troubled. Clinicians may be advised to address pain causes in this population to ensure early identification of pain in CP, prevent pain as much as possible, and hasten its treatment. The evaluation of pain in individuals with CP and the investigation of its impacts on the family are strengths of this study. The limitations of this study include the lack of a more comprehensive examination of the effects of pain seen in individuals with CP on the family from a biopsychosocial perspective, and with larger sample sizes. In future studies, the multifactorial levels of pain in individuals with CP and its impact on their parents can be examined more comprehensively.

CONCLUSION

As a result of the present study, it has been revealed that the frequency of pain in addition to the existing motor problems of children with CP was high and it adversely affected the parents in many ways. It is important to investigate the impacts of pain in children with CP on parents. As a result of this study, the importance of emphasizing the importance of pain, which is commonly seen in children with CP, and investigating its effects on the family is an important and strong aspect. We can specify that pain in children with CP is an undetermined factor. In addition, we emphasize the need to increase the number of studies on the pain in children with CP, and examine these in detail in terms of their impacts on parents. It is recommended that clinicians remark to the assessment and prevention of pain in children with CP.

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