Psychological Problems in Children with Cerebral Palsy and Its Relationship with Health-Related Quality of Life

Hasan BİNGÖL[*], Dilan DEMİRTAŞ KARAOBA[**]

Abstracts

Aim: To investigate the association between psychological problems and health-related quality of life (HRQOL) parameters in children with cerebral palsy (CP).

Method: A convenience sample size of 68 children with CP (mean age: 6.82 years and standard deviation: 1.8; 31 males and 37 females) were recruited in the study. Parent-reported versions of the Strengths and Difficulties Questionnaire (SDQ) and Cerebral Palsy Quality of Life were used to detect the presence of psychological symptoms and HRQOL outcomes in children with CP. Psychological symptoms included emotional symptoms, conduct problems, hyperactivity/inattention, peer problems, and prosocial behavior.

Results: Children with hemiplegic, diplegic, and ataxic CP were mostly found to be in scoring band of close to average on SDQ-Total difficulties Scale (TDS) (SDQ-TDS<14), whereas those with quadriplegic and dyskinetic CP were in very high scoring band (SDQ-TDS >20) on the SDQ-TDS. In terms of association, there were moderate to strong associations between scores for psychological symptoms and HRQOL (r=-0.45 to 0.860).

Conclusion: The results suggest that the nature and extent of mental health problems vary among CP subtypes, with children with tetraplegic and dyskinetic CP more likely to experience mental health symptoms. Given the potential benefits of physical activity on both HRQOL outcomes and psychological mental symptoms, it is essential to encourage children with CP to participate in more physical activities.

Keywords: Cerebral palsy, mental health, psychological symptom, health-related quality of life.

Serebral Palsi'li Çocuklarda Psikolojik Problemler ve Bunun Sağlıkla İlişkili Yaşam Kalitesiyle ile İlişkisi

Öz

Amaç: Serebral palsili (SP) çocuklarda psikolojik sorunlar ile sağlıkla ilişkili yaşam kalitesi (HRQOL) parametreleri arasındaki ilişkiyi araştırmak.

Yöntem: 68 SP'li çocuktan oluşan uygun büyüklükte bir örneklem çalışmaya dahil edildi (ortalama yaş: 6,82 yıl ve standart sapma: 1,8; 31 erkek ve 37 kız). Aile bildirimli Güçler ve Güçlükler Anketi (GGA) ve Serebal Palsi Yaşam Kalitesi (SPYK) SP'li çocuklarda sırasıyla psikolojik semptomların varlığını ve SİYK sonuçlarını belirlemek için kullanıldı. Psikolojik semptomlar, duygusal semptomları, davranışsal problemleri, hiperaktivite/dikkatsizlik, akran sorunları ve sosyal davranışsal sorunları içermekteydi.

Bulgular: Hemiplejik, diplejik ve ataksik SP' li çocuklar çoğunlukla GGA-Toplam Zorluklar Skala (TZS)'da ortalamaya yakın skorlama bandında yer alırken (GGA-TZS<14), kuadriplejik ve diskinetik SP'li çocuklar GGA-TZS'de çok yüksek skorlama bandında yer almışlardır (GGA-TZS>20). Karşılaştırma açısından, psikolojik semptomlar ve SİYK skorları arasında orta-güçlü ilişkiler bulunmuştur (r=-0.45 ila 0.860).

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ETHICAL STATEMENT: The Ethical Board for Non-Interventional Scientific Research at Bingöl University approved the study protocol (date: 18/07/2024 No: 24/06).

Sonuç: Sonuçlar, ruh sağlığı sorunları türlerinin ve ciddiyet düzeylerinin SP alt tipleri arasında farklılık sergilediğini ve kuadriplejik ve diskinetik SP'li çocukların ruh sağlığı semptomları yaşama olasılığının daha yüksek olduğunu göstermektedir. Fiziksel aktivitenin hem SİYK sonuçları hem de ruh sağlığı semptomları üzerindeki potansiyel faydaları göz önüne alındığında, SP'li çocukları daha fazla fiziksel aktiviteye katılmaya teşvik etmek önemlidir.

Anahtar Sözcükler: Serebral Palsi, ruh sağlığı, psikolojik semptom, sağlıkla ilişkili yaşam kalitesi.

Introduction

Children with childhood-onset physical disability, including those with cerebral palsy (CP), are at risk of decreased participation[1], pain[2], low levels of physical activity[3], intellectual disability[4], and a number of comorbidities[5], that can negatively affect mental health and health-related quality of life (HRQOL). Additionally, research has demonstrated that depression and anxiety often occur in children with CP[6] and contribute significantly to behavioral and emotional difficulties[7]. This is in line with epidemiological research reporting that mental health disorders are common in the general population[8,9] and that social and physical risk factors further augment the risk of developing mental health disorders[6]. This also corroborates the fact that even people without mental health issues can experience a variety of emotional problems including feelings of exclusion, sadness, and unhappiness[10]. Notably, environmental factors such as bullying[6], negative environmental attitudes, feeling excluded, and other negative social experiences can markedly increase the risk of developing psychological problems[11,12]. Given these facts, it is not surprising that mental health or psychological problems have been reported as frequent comorbidities in children with CP, with a prevalence rate of 35%[13].

According to the World Health Organization (WHO), mental health implies a person's psychological, emotional, and social well-being[10]. Mental health enables individuals to utilize their abilities in accordance with the core values of society. Furthermore, it is essential to note that mental and physical health are intimately interrelated, and children with chronic conditions, such as CP, are particularly vulnerable to developing mental health problems[6]. Furthermore, mental health disorders have been shown to increase the global disease[8]. When untreated, mental health problems can exacerbate comorbidities, physical impairments, and low physical activity levels in this population[14]. This highlights the critical need to address mental health problems. Therefore, gaining a better understanding of mental health disorders in children with CP could enable interventions at an earlier stage. Over the past three decades, several epidemiological and observational studies have investigated mental health disorders in children with CP[6,9,13,15]. In a study by Whitney et al.'s[15], it was found that mobility restriction, sleep disorders, communication problems, pain, and developmental comorbidities accounted for the association between CP and mental health disorders. In another study by Whitney et al.[6] reported that difficulty with friendships and being bullied accounted for psychiatric conditions and behavior/conduct problems in children with CP. Previous research indicates that depression and anxiety are more common among mothers of children with CP than among mothers of typically developing children[16]. Finally, a recent systematic review revealed a scarcity of studies on the prevalence of mental health

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disorders across various subtypes of CP. Therefore, the main aim of the current study was to explore the presence or severity of mental health disorders according to the CP topography. The second aim of this study was to examine the relationship between aspects of mental health disorders and HRQOL.

Material and Methods

Study Design and Participants

This study employed a cross-sectional design, which entailed data collection at a single point in time. Ethical approval for this study was obtained from the Ethical Board for Non-Interventional Scientific Research at Bingöl University (Date: 18/07/2024; No: 24/14). A convenience sample of 68 participants (31 males and 37 females) with their primary caregivers and parents was included in the study. They were recruited from special education and rehabilitation centers in Türkiye's city of Bingöl and received rehabilitation services twice a week in these centers. The inclusion criteria were children diagnosed with different sub-diagnoses of CP based on primary motor impairment (spastic, dyskinetic, and ataxic), aged 4 years and older, and who volunteered to participate in the assessment procedure. The exclusion criteria were children aged less than 4 years as the optimum use of the Communication Function Classification System (CFCS) and Strength and Difficulties Questionnaire for those aged 4 years and older. Additionally, children whose primary caregivers or parents were non-literate or had problems with understanding questions in the questionnaires were excluded. After providing detailed information regarding the study to primary caregivers and parents, informed consent was obtained from the primary caregivers and parents.

Assessments

Classification

The current gross motor function of children with CP was classified using the Gross Motor Function Classification System-Expanded & Revised (GMFCS-E&R), where level I describes higher-level mobility and level V describes lower-level mobility. GMFCS-E&R was derived from the GMFCS by including an age band for youth aged 12 to 18 years. The Turkish version of the GMFC-E&R, which has been shown to be reliable in Turkish children with CP[17], was employed to describe the gross motor function of children. The communication performance of the children in this study was evaluated using the Communication Function Classification System (CFCS), where level I indicates the highest communication performance and level V signifies the lowest communication performance[18]. The Turkish CFCS was used to describe the communication performance of the children with CP in the current study[19].

Measures

Strengths and Difficulties Questionnaire (SDQ): The SDQ is a brief screening tool that is used to determine the probable presence of mental health disorders. The SDQ was designed to detect mental health problems in children aged 4-17 years. It consists of 25 items based on five symptoms: emotional, conduct, hyperactivity/inattention, peer, and prosocial behavior. Items scored as '*Somewhat True*' signify always signified 1. However, the scores for *'Not True'* and '*Certainly True'* varied with the item (0 or 2).

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Each subscale score ranges from 0 to 10 if all items are answered. Total difficulties score (TDS) is established by summing all subscale scores, except for the prosocial behavior scale[20]. The externalizing score, which varies between 0 and 20, is the sum of the conduct and hyperactivity scales, whereas the internalizing score, which ranges from 0 to 20, is the sum of the emotional and peer problems scales. The validity and reliability of the Turkish version of the SDQ have been previously described[21]. In the current study, the parent-reported version of the SDQ was used to describe the presence of mental health problems in children with CP. The scoring bands (i.e., cut-off points for SDQ scores) for each SDQ subscale and TDS are presented in Table 2.

Quality of Life Questionnaire for Children (CP QOL-Child): The CP QOL-Child has been established by international research and clinical teams in conjunction with parents and children with CP to describe their quality of life. There are two versions of the CP QOL-Child: self-and primary caregiver proxy reports. In this study, the Turkish CP QOL-primary caregiver proxy report was used to describe the HRQOL of children with CP. It consists of 66 items and seven subdomains: social well-being and acceptance, functioning, participation and physical health, emotional well-being, access to services, pain and impact of disability, and family health[22]. The Turkish CP QOL-Turkish CPQOL-primary caregiver proxy report is a reliable and valid tool for assessing HRQOL in children with CP[23].

Statistical Analysis

Descriptive and correlation statistics were performed using IBM SPSS version 25.0 (SPSS Statistics for Windows, Version 25.0. (IBM Corporation, Armonk, New York, United States) software package program. Descriptive data were summarized using means along with standard deviations and medians with interquartile ranges (IQR) for numerical data, while percentages or rates were used for categorical data. Given that the SDQ score is categorical data, Spearman's correlation, a non-parametric test, was employed to examine the correlations between the SDQ and the CP QOL subdomain scores. Correlation coefficients were interpreted as weak when $r<0.50$, moderate when r was between 0.50 and 0.70, and strong if $r>0.70$. Statistical significance was defined as $p < 0.05$. Stacked bar charts and box-and-whisker plots were generated using Microsoft Excel.

Results

Demographic and clinical features of the participating children were summarized in Table 1. The mean age of the 68 children was 6.82 years (range 4-10 years), with a standard deviation of 1.8, of which 31 (45.6%) were boys and 37 (54.4) were girls. Of the 68 participants, 26 (38.2%) had a diagnosis hemiplegia, 18 (26.5%) with diplegia, 18 (26.5%) with quadriplegia, 2 (2.9%) with dyskinesia, and 4 (5.9%) with ataxia. Regarding gross motor and communication functions, children had GMFCS-E&R and CFCS levels I-V, with the majority classified as levels I-III.

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Table 1. Demographic and clinical characteristics of the study participants

Participants with CP (N=68)		
Age (M± SD)	6.82±1.8	
Gender	**n**	**%**
Male	31	45.6
Female	37	54.4
CP Subtype		
Spastic Hemiplegic	26	38.2
Spastic Diplegic	18	26.5
Spastic Quadriplegic	18	26.5
Dyskinetic	2	2.9
Ataxic	4	5.9
Comorbidity (Yes/no)		
Speaking/Communicating	18/50	26.5/73.5
Emotion/Behavioral	20/48	29.4/70.6
Seizure/Epilepsy	9/59	13.2/86.8
Digestion	18/50	26.5/73.5
Sleeping	19/49	27.9/72.1
Repeated Infection	15/53	22.1/77.9
Breathing Problems	9/59	13.2/86.8
Pain	18/58	26.5/73.5
GMFCS-E&R		
Level I	22	32.4
Level II	18	26.5
Level III	10	14.7
Level IV	12	17.6
Level V	6	8.8
CFCS		
Level I	36	52.9
Level II	11	16.2
Level III	14	20.6
Level IV	7	10.3

M, Mean; SD, Standard Deviation; CP, Cerebral Palsy; GMFCS-E&R, Gross Motor Function Classification System-Expanded &Revised; CFCS, Communication Function Classification System.

Psychological Difficulty Domains in Children with CP

Table 2 and Figure 1 show the extent and types of mental health problems experienced by children with different types of CP. According to the current scoring band established for the five psychological dimensions of the SDQ, children with hemiplegic and diplegic CP, as well as those with ataxic CP, were close to the average band with respect to

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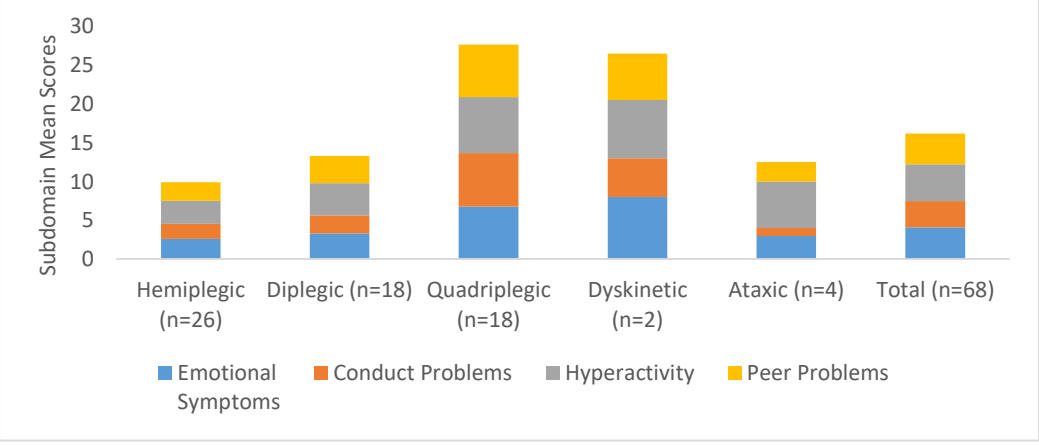
emotional symptoms and conduct problems, whereas children with quadriplegic and dyskinetic CP were in high and very high bands, respectively. Children with hemiplegic and diplegic CP were found to be within the close to average band for hyperactivity/inattention, while those with quadriplegic, ataxic, and dyskinetic CP were observed to fall within the slightly raised to very high bands. In terms of peer problems, children with hemiplegic and ataxic CP were close to the average band, whereas those with diplegic, quadriplegic, and dyskinetic CP were slightly raised to the very high bands. With regard to prosocial behavior, children with hemiplegic and diplegic CP tended to score in the close to average band, whereas children with quadriplegic and dyskinetic CP tended to score in the very high band.

Table 2. Extent and type of psychological problems experienced by cp subtypes

SDQ Domains	Hemiplegic (n=26) Median (IQR)	Diplegic (n=18) Median (IQR)	Quadriplegic (n=18) Median (IQR)	Ataxic (n=4) Median (IQR)	Dyskinetic (n=2) Median (IQR)
Emotional Symptoms	3 (0-8)	4 (0-9)	7 (1-10)	2,5 (0-7)	8 (7-9)
Conduct Problems	2 (0-5)	2 (0-6)	8 (0-10)	1 (0-2)	5 (4-6)
Hyperactivity /Inattention	3 (0-6)	3.5 (0-10)	8 (1-10)	6 (3-9)	7.5 (6-9)
Peer Problems	2 (0-5)	3.5 (0-7)	8 (0-10)	2 (0-6)	6 (4-8)
Prosocial Behavior	9 (3-10)	7 (1-10)	2 (0-10)	5 (3-10)	2.5 (2-3)

Banding of SDQ-Subscale Scores: **Emotional Symptoms;** 0-4 close to average, 5 slightly raised, 6 high, and 7-10 very high; **Conduct problems**; 0-3 close to average, 4 slightly raised, 5 high, and 6-10 very high; **Hyperactivity /Inattention;** 0-5 close to average, 6 slightly raised, 7 high, and 8-10 very high; **Peer problems**; 0-2 close to average, 3 slightly raised, 4 high, and 5-10 very high; **Prosocial Behavior;** 7-10 close to average, 6 slightly raised, 5 high, and 0-4 very high; IQR: Interquartile Range

Figure 1. Stacked bar charts showing extent and type of psychological problems experienced by cerebral palsy subtypes



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Total Difficulties, Externalizing, and Internalizing Scores

As summarized in Table 3 and illustrated in Figures 2 and 3, children with hemiplegic, diplegic, and ataxic CP were classified within the close to average difficulty band, whereas those with quadriplegic and dyskinetic CP were categorized within the very high difficulty band. We were unable to classify the mental health status of children based on internalizing and externalizing scores since there are no established cut-off points for these categories. However, the internalizing and externalizing scores of children with quadriplegic and dyskinetic CP were significantly higher than those of children with hemiplegic, diplegic, and ataxic CP.

Table 3. SDQ- Total difficulties, internalizing, and externalizing scores of children with different subtypes of cerebral palsy

SDQ Scores	**Hemiplegic (n=26) Median (IQR)**	**Diplegic (n=18) Median (IQR)**	**Quadriplegic (n=18) Median (IQR)**	**Ataxic (n=4) Median (IQR)**	**Dyskinetic (n=2) Median (IQR)**
Total Difficulties Score	10.5 (0-21)	12.5 (5-27)	31 (3-36)	13.5 (7-16)	26.5 (26-27)
Internalizing Score	5 (0-12)	7 (1-16)	15.5 (2-19)	6.5 (2-7)	14 (13-15)
Externalizing Score	5 (0-9)	5 (3-13)	15,5 (1-20)	7 (5-9)	12.5 (12-13)

SDQ: Strengths and Difficulties Questionnaire; IQR: Interquartile Range; Banding of SDQ-Total Difficulties Score: 0-14 close to average, 15-17 slightly raised, 18-19 high, and 20-40 very high

Figure 2. Stacked bar charts showing the severity of psychological problems among children with different CP subtypes based on SDQ Total Difficulties, Externalizing and Internalizing scores

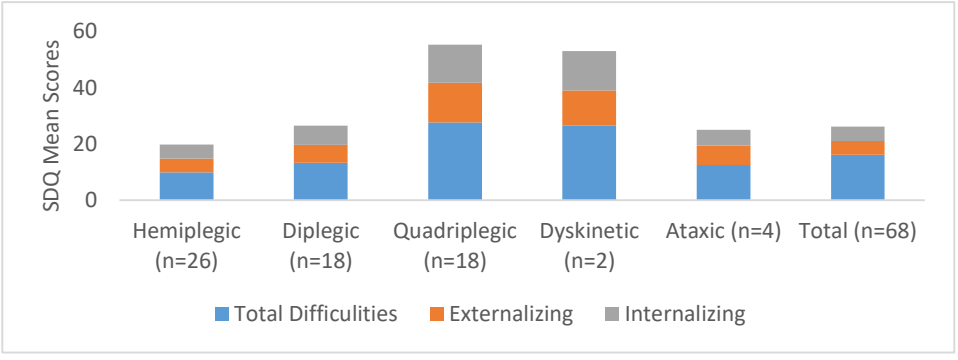

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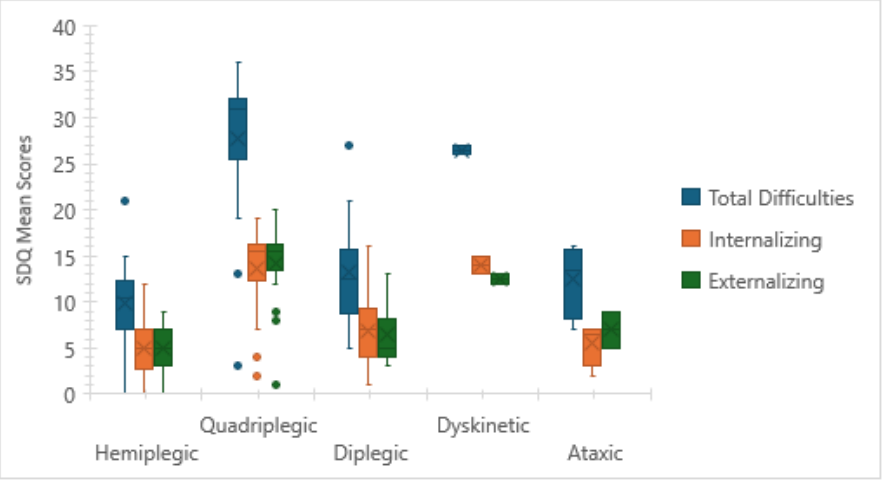
Figure 3. Box and whisker plots of SDQ- Total Difficulties, Internalizing, and Externalizing scores



Association Between Psychological Problems and Health-Related Quality of Life

The SDQ-Prosocial Behavior scale and CP QOL subdomains showed moderate to very strong relationships (r=0.482 to 0.860), with exception of CP QOL- "*Pain and Impact of Disability"* subdomain (r=0.107). The associations between SDQ-Total Difficulties and CP QOL subdomain scores ranged from -0.493 to-0.625 (moderate to strong relationships). SDQ-Internalizing Score was significantly correlated with CP QOL subdomains (r=-0.45 to -0.75), except for "*Participation and Physical Health"* and "*Pain and Impact of Disability"* subdomains. That is, the SDQ-Internalizing Score exhibited an insignificant and weak relationship with the CP QOL- "*Participation and Physical Health*" and "*Pain and Impact of Disability"* subdomains (r_1 -0.127 and r_2=-0.192, p>0.05). The SDQ-Externalizing Score was found to be moderately to very strongly correlated with all subdomains of the CP-QOL, with correlation coefficients ranging from -0.416 to -0.810, except for the subdomain "*Feelings About Functioning*" (r=-0.038).

Table 4. Spearman correlation of psychological problems and health related quality of life

SDQ Scores	Cerebral Palsy Quality of Life (CP QOL)				
	Social Wellbeing and Acceptance	**Functioning**	**Participation and Physical Health**	**Emotional Wellbeing**	**Pain and Impact of Disability**
Prosocial Behavior	0.683*	0.482*	0.763*	0.860*	0.107**
Total Difficulties	-0.493*	-0.565*	-0.551*	-0,625*	-0.601*
Internalizing Score	-0.45*	-0.75*	-0.127**	-0.68*	-0.192**
Externalizing Score	-0.538*	-0.038**	-0.810*	-0.416*	-0.734*

SDQ: Strength and Difficulties Questionnaire; *: p<0.05; **: p>0.05; Note that correlation is significant at the 0.05 level

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Discussion

This study found that a substantial proportion of children with CP were at risk of developing mental health disorders, with those with quadriplegic and dyskinetic CP having higher rates of developing mental health disorders. More children with quadriplegic and dyskinetic CP reported emotional symptoms, conduct problems, hyperactivity/inattention, peer problems, and prosocial behavior problems than those with hemiplegic, diplegic, and ataxic CP. Collectively, children with hemiplegic, diplegic, and ataxic CP scored in the close to average band on SDQ-Total Difficulties Scale (SDQ-TDS), whereas those with quadriplegic and dyskinetic CP scored in the very high band on SDQ-TDS, confirming the results for mental health subdomains. However, due to the small number of children with ataxic and dyskinetic CP in this study, the results regarding mental health associated with these subtypes of CP cannot be generalized. With regard to associations, most of the mental health and HRQOL subdomains were found to be significantly correlated with each other.

As reported by a recent systematic review, nearly one-third of children with CP experienced mental health symptoms as measured by the SDQ[13], with rates varying across studies. More specifically, a study conducted by Parkes et al.[12] reported that children with CP mostly experienced peer problems, followed by hyperactivity and emotional symptoms. A previous epidemiological study by Goodman et al. in 1996[24] have shown that mental health problems are frequent in children with hemiplegic CP. In contrast, the results of the current study showed that children with hemiplegic CP are likely to have fewer mental health problems. The subdomain scores of the mental health of children with hemiplegia were found to be similar to the normative data reported in a study of a national population sample of children and adolescents in the US[25]. This can be explained by the fact that rehabilitation strategies to improve social and physical risk factors in children with CP that are closely related to poorer mental health[15] have advanced over the last three decades[26-28]. Modern rehabilitation strategies for children with CP adopt a comprehensive strategy that integrates physical, occupational, and speech-language therapies alongside psychological and social support. That is, modern rehabilitation strategies prioritize social inclusion and engagement in activities, as these play a vital role in mental well-being. Involvement in social interactions and minimizing experiences of bullying have been found to alleviate mental health problems in children with CP[6]. Studies' findings demonstrated that children with quadriplegic and dyskinetic CP had a greater risk of developing mental health disorders than those with hemiplegic, diplegic, or ataxic CP. This may be attributed to the fact that quadriplegic and dyskinetic CP are closely related lower mobility level[29], pain[30,31], decreased HRQOL[32,33], and severe physical risk factors[32,34]. These variables have been shown to increase the risk of developing mental health disorders in children with CP[12,15]. Despite having lower mobility level[35], it was found that children with ataxic CP in the current study scored mostly close to average or slightly raised bands on both SDQ-TDS and SDQ-subdomains. The reason for this could be the limited number of children with ataxic CP included in the present study. Therefore, findings related to the mental health outcomes of children with ataxic CP are not generalizable.

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The results showed a significant relationship between scores on the SDQ and HRQOL subdomains, except for weak or negligible associations between some dimensions (e.g., between SDQ-*Prosocial Behavior* and CP QOL- *Pain and Impact of Disability*). This was expected, since mental health has been previously reported to be a significant determinant of HRQOL in children with CP[36]. Furthermore, mental health has been demonstrated to be a crucial factor that significantly affects the participation of children with CP[37], which is directly associated with HRQOL[36]. More specifically, it was revealed that the prosocial behavior domain of mental health is an important factor in a child's social well-being, emotional well-being, and participation in different life situations. Surprisingly, although pain in children with CP has been reported to negatively influence their social functioning and participation[6-15], the present study found only weak or negligible associations between SDQ-*Prosocial Behavior* and CP QOL- *Pain and Impact of Disability* subdomains. Since evidence on the direct association between SDQ-Prosocial Behavior and CP QOL-Pain and Impact of Disability is limited, we could not explain this discrepancy. Therefore, future research should explore the direct relationship between these variables. Our findings further showed that the SDQ-externalizing score, sum score of conduct, and hyperactivity scales, were closely related to HRQOL aspects of social well-being and acceptance, participation, emotional well-being, and impact of disability. The results of each relationship between HRQOL and mental health suggest that mental health is a critical factor in improving HRQOL in children with CP. In light of the established benefits of physical therapy[38] and family-centered interventions[39] on mental health, and the well-documented link between mental health and health- HRQOL, addressing mental health concerns in children with cerebral palsy through evidence-based and targeted approaches is of critical importance.

In the present study, only two (2.9%) and four (5.9%) children with CP were diagnosed with dyskinetic and ataxic CP, respectively. This limited the generalizability of the mental health results associated with these CP subtypes. This may be one of the limitations of this study. Second, some participants in the study presented with one or more comorbid conditions, which may have influenced their mental health and HRQOL. However, examining the impact of comorbidities on mental health was beyond the scope of the present study and may warrant investigation in future research. Therefore, future research is needed to investigate mental health status across CP subtypes by including a larger number of individuals with each CP subtype.

Conclusion

The findings of the current study suggest that the presence or severity of mental health problems varies among CP subtypes, with hemiplegic and diplegic CP, the mildest form of CP, being less likely to develop mental health problems. Moreover, mental health and HRQOL subdomains were closely related to each other. Given that mental health is a crucial determinant of participation in children with cerebral palsy (CP), as highlighted in the previous literature, and is closely related to their overall well-being, it is imperative to address mental health in this population. In conclusion, considering the potential benefits of physical activity and family-focused interventions on both HRQOL and psychological mental symptoms, it is essential to encourage children with CP to participate in more physical activities.

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Consent to Participate in the Study: After providing detailed information regarding the study to primary caregivers and parents, informed consent was obtained from the primary caregivers and parents.

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