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THE ASSOCIATION BETWEEN FUNCTIONAL INDEPENDENCE IN CHILDREN WITH CEREBRAL PALSY AND PARENTAL PERCEPTIONS OF FAMILY-RELATED PROBLEMS AND PESSIMISM

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Abstract

Objective: This study aims to investigate the perceived stress levels of families with children diagnosed with cerebral palsy (CP), with a particular focus on family-related problems and levels of pessimism across various demographic and contextual variables.

Methods: The study was conducted with the families of 67 children diagnosed with cerebral palsy who were receiving treatment at the Department of Physical Medicine and Rehabilitation, Kocaeli University Hospital. Participants' socio-demographic characteristics were obtained through a structured socio-demographic information form. Functional independence was assessed using the Functional Independence Measure for Children (WeeFIM), and family stress was measured using the Family Stress Questionnaire (QRS-F).

Results: The analysis revealed no statistically significant correlation between the WeeFIM scores and the 'Parent–Family Problems' subscale of the QRS-F. A statistically significant correlation was observed between the 'Pessimism' subscale and the following WeeFIM scores: Self-care (p=0.028, r=-0.268), Mobility (p=0.037, r=-0.255), Communication (p=0.033, r=-0.261), Social situation (p=0.036, r=-0.257), Motor subscore (p=0.033, r=-0.261), Cognitive subscore (p=0.030, r=-0.266), and Total score (p=0.020, r=-0.285).

Conclusion: This study emphasizes the psychological impact of caring for a child with CP. Functional independence levels of children do not make a difference in terms of parental-family problems; less parental-family problems are perceived when both mother and father work in the family.

Keywords: *Cerebral palsy, family problems, functional independence, pessimism.*

Introduction

Cerebral palsy (CP) represents one of the leading causes of physical disability during childhood. It is a heterogeneous neurodevelopmental disorder characterized by permanent, non-progressive impairments in motor control and posture, resulting from damage to the developing brain during the prenatal, perinatal, or early postnatal periods.[1] The clinical presentation of CP varies significantly between individuals, and it is frequently accompanied by a range of comorbid conditions. These may include intellectual disabilities, epileptic seizures, urinary incontinence, visual and auditory perceptual impairments, sleep disturbances, feeding difficulties related to oral-motor dysfunction, respiratory problems, and secondary musculoskeletal deformities.[2,3]

These multifaceted health challenges not only hinder the physical development and functional autonomy of the child but also place a substantial burden on primary caregivers—particularly mothers. For families of children with CP, the continuous demands of physical care, need for ongoing supervision, financial burden, emotional distress, and experiences of social isolation substantially impair the caregivers' biopsychosocial well-being.[4] Moreover, the birth of a child with developmental conditions, as opposed to the expected healthy newborn during pregnancy, may elicit a range of psychosocial stressors and emotional responses within the family. When the gap between the idealized child envisioned before birth and the actual experience post-birth widens, parents may experience heightened levels of disappointment, grief, and psychological distress.[5] This emotional dissonance contributes significantly to the overall caregiving burden and highlights the need for comprehensive family-centered support interventions.

Irrespective of the specific type or degree of the child's disability, its persistent and typically non-reversible nature frequently gives rise to multifaceted emotional and psychosocial stressors within the family unit. These challenges are influenced by a variety of factors, including the psychological resilience of family members, socioeconomic status, educational background, lifestyle, level of social support from close networks, and prevailing societal attitudes toward disability.[6]

Parents—especially mothers—often face complex emotional responses such as depression, anxiety, guilt, and helplessness as they attempt to adjust to their child's disability. Among caregivers of children with cerebral palsy, the extent to which stressors impact family life is closely associated with the severity of the child's functional limitations and the caregivers' psychological responses, such as increased perceived challenges and heightened pessimism.[7] In addition, these experiences are not limited to individual psychological struggles, but are also shaped by social and structural dynamics that impact family functioning and parental roles.[8,9]

Among these influencing factors, the child's level of functional independence plays a particularly significant role in shaping the psychological health of the caregivers. As functional competence decreases, the need for intensive caregiving increases, often leading to heightened levels of stress, anxiety, and depressive symptoms among parents. A review of the literature shows that Dilek et al.[10] found a positive relationship between the degree of dependency in children with CP and the level of stress experienced by their families. Specifically, the greater the assistance required for daily living activities, the higher the maternal stress levels were reported to be. Similarly, Brehaut et al.[11] reported increased psychological stress and depression among parents of children with limited mobility and greater caregiving demands. Recent evidence indicates that the level of a child's functional independence is a key determinant of parental stress and psychological outcomes. Studies consistently demonstrate that as children's dependency in daily life activities increases, parents—especially mothers—report higher levels of psychological distress, pessimism, and reduced quality of life[12,13,14] In this context, the present study aims to examine the levels of perceived family problems, and pessimism among families of children with CP in relation to various factors such as the child's level of functional independence, parental education and employment status, socioeconomic status and the availability of economic and social supports.

Methods

The present study employed with the families of 67 children aged 1 to 18 years who were receiving treatment for cerebral palsy at the Physical Therapy Clinic of Kocaeli University Hospital. Children with severe intellectual disabilities, visual or hearing impairments, uncontrolled seizures, other neuromuscular disorders, spinocerebellar ataxia, or autism spectrum disorder were excluded from the study. Prior to participation, all parents were thoroughly informed about the study, and written informed consent was obtained in accordance with ethical standards.

Sociodemographic information was recorded for the children with CP included in the study. The form included details such as the child's gender, age, family structure (nuclear/extended), parental education and employment status, perceived income level, and the availability of economic and social support. The assessment tools used were the Functional Independence Measure for Children (WeeFIM) and the short form of Questionnaire on Resources and Stress (QRS-F).

Sample Size Calculation

Sample size estimation was performed using the G*Power software. Within the t-test family, the 'Correlation: Point biserial model' was selected with an effect size of 0.3, an alpha (α) level of 0.05, and a power ($1-\beta$) of 0.80, yielding a required sample size of 64 participants. To account for potential attrition, 67 patients were ultimately recruited.

Assessment Tools

The Functional Independence Measure for Children (WeeFIM)

The Functional Independence Measure for Children (WeeFIM) is a standardized, observational assessment tool designed to evaluate functional independence in children during activities of daily living. It is the pediatric adaptation of the Functional Independence Measure (FIM), which was originally developed for adults.[15]

The WeeFIM includes 18 items distributed across three primary domains:

1. Self-Care (6 items)
2. Mobility / Motor Functions (5 items)
3. Cognitive Functions (7 items)

Each item is rated on a 7-point scale, where:

- 1 indicates complete dependence (requiring 100% assistance), and
- 7 indicates complete independence (no assistance or supervision needed).

The total score ranges from 18 to 126, with higher scores reflecting greater functional independence.

The Questionnaire On Resource And Stress

The Turkish validity and reliability studies of the original form, short form of the Questionnaire on Resources and Stress (QRS-F), and the psychometric properties of the scale were conducted by Kaner using data obtained from parents of children across a wide age range and various disability groups. The items of the scale are answered as "true" or "false," with a score of 1 for correct answers and 0 for incorrect answers. The test consists of 52 items. Its 3 subscales are as follows: 1. Functional disability, 2. Pessimism, 3. Parent-family Problems.[16]

Statistical Analysis

Statistical analyses were performed using IBM SPSS Statistics for Windows, version 25.0 (IBM Corp., Armonk, NY, USA). The normality of the data distribution was assessed using the Kolmogorov–Smirnov test. Categorical variables were presented as frequency (%). Differences between groups were evaluated using the Mann–Whitney U test. Relationships between categorical variables were determined using the chi-square test. Correlations between numerical variables were calculated using Spearman’s correlation coefficient. A *p*-value of <0.05 was considered statistically significant in hypothesis testing.

Results

The study was conducted between March and December 2019 at the Pediatric Rehabilitation Unit of the Department of Physical Medicine and Rehabilitation, Faculty of Medicine, Kocaeli University. Initially, 75 children with spastic cerebral palsy were screened and assessed for age, gender, type of CP, inclusion, and exclusion criteria. Eight children diagnosed with CP were not included in the final analysis due to not fulfilling the inclusion criteria. Consequently, the study sample comprised 67 children, with a mean age of 8.0±4.6 years. Of the children included in the study, 28 (41.8%) were girls and 39 (58.2%) were boys. Among the 67 children with CP included in the study, 13 (19.4%) were hemiplegic, 23 (34.3%) were diplegic, and 31 (46.3%) were quadriplegic. According to the GMFCS classification, 9 (13.4%) were level I, 7 (10.4%) level II, 8 (11.9%) level III, 20 (29.9%) level IV, and 23 (34.3%) level V. Forty-nine families (73.1%) had nuclear families, while 18 (26.9%) had extended families. The mean education level was 8.5 years for mothers and 10.4 years for fathers. Demographic information about the patients is provided in Table 1. Information regarding parents' employment status, perceived income level, and economic-social support is presented in Table 2. The WeeFIM scores of the children with CP included in the study are shown in Table 3. According to this, the children scored 33.4±23.4 points on the “Motor” subscale (norm value: 91) and 22.2±11 points on the “Cognitive” subscale (norm value: 35). In the total score, they scored 55.7±31.3 points out of a total of 126 points. While there was no significant correlation between the subparameters of WeeFIM and the “Parent-Family Problems” subparameter of the QRS-F, a significant correlation was found with the “Pessimism” subparameter, as follows: Self-care (*p*=0.028/r=-0.268), Mobility (*p*=0.037/r=-0.255), Communication (*p*=0.033/r=-0.261), Social situation (*p*=0.036/r=-0.257), Motor subscore (*p*=0.033/r=-0.261), Cognitive subscore (*p*=0.030/r=-0.266), Total score (*p*=0.020/r=-0.285). The correlation values for the data are provided in Table 4. From the socio-demographic data, it was determined that the "Mother's Education Level" had a significant correlation with the “Pessimism” subparameter of QRS-F (*p*=0.032/r=-.263), and the “Employment Status of Spouses” had a significant correlation with the “Parent-Family Problems” subparameter (*p*=0.019). The correlation values of the socio-demographic data with the subparameters of QRS-F are shown in Table 5.

Table 1: Demographic characteristics of the children with CP

	(Mean±S)	(n /%)
Age	8.6±4.6	
CP type		
Hemiplegic		13/19.4
Diplegic		23/34.3
Quadriplegic		31/46.3
GMFCS		
I		9/13.4
II		7/10.4
III		8/11.9
IV		20/29.9
V		23/34.3
Familiy Education Status (year)	Mother 8.5± 4.1 Father 10.4±4.2	
Gender		
Female		28 / 41.8
Male		39 / 58.2
Family type		
Nuclear family		49 / 73.1
Extended family		18 / 26.9

Table 2: Demographic information of the families

	n/%
Perceived Socioeconomic Status	
Low	37/55
Moderate	28/42
High	2/3
Total	67/100
Parental Employment status	
Father	58/86.6
Father&Mother	9/13.4
Total	67/100
Economic Support	
Yes	36/53.7
No	31/46.3
Total	67/100
Social Support	
Yes	19/28.4
No	48/71.6
Total	67/100

Table 3. The WeeFIM scores of the children with CP

Indicators	Mean±SD	Sub-Scores	Normal Value
Motor			
Self-care	13.9±9.8	33.4±23.4	42
Sphincter use	6.7±5.2		14
Transfer	7.8±6.3		21
Mobility	5.4±3.9		14
Cognitive			
Communication	9.3±4.6	22.2±11	14
Social situation	12.9±6.5		21
	Total	55.7±31.3	126

Table 4. The relationship between the subscales of the WeeFIM and the subscales of the QRS-F

WeeFIM	**Parent-Family Problems** ***p***	**Pessimism** ***p*/r**
Self-care	.765	**.028 /-.268**
Sphincter use	.655	.081
Transfer	.725	.077
Mobility	.875	**.037/-.255**
Communication	.213	**.033/-.261**
Social situation	.572	**.036/-.257**
Motor subscore	.558	**.033/-.261**
Cognitive subscore	.351	**.030/-.266**
Total score	.688	**.020/-.285**

Table 5. The relationship between the Socio-Demographic data and the subscales of the QRS-F

Variables	**Parent-Family Problems** ***p* (r)**	**Pessimism** ***p* (r)**
Father education	.260 (-.140)	.086 (-.211)
Mother education	.059 (-.231)	**.032 (-.263)**
Family type	.286	.381
Income status	.177	.251
Child gender	.166	.622
Employment status of spouses	**.019**	.443
Additional wage support	.377	.980
Siblings similar situation	.624	.137
Family support	.237	.989
Having your own house	.831	.865

Discussion

In this study, in which the factors affecting the psychological In this study, we aimed to compare the perceived parental-family problems, and pessimism levels of families with children with CP, with the children's functional independence levels, parents' education and employment status, family income levels, and economic and social support parameters. In this context, in addition to the socio-demographic information of families with children with CP, the QRS-F was used to measure the perceived stress and pessimism, and the WeeFIM tests were applied to determine the functional level of the children. During the evaluation, the children with CP and their families showed full compliance, and no issues were encountered. When the WeeFIM scores of the children with CP included in the study were assessed, it was found that they scored significantly below the norm values in both motor and cognitive domains. Specifically, the average Motor subscore was 33.4±23.4, which indicates a severe functional disability compared to the norm value of 91. Similarly, the Cognitive subscore was measured at 22.2±11, significantly below the norm value of 35. These low levels of independence indicate that the children require care to a degree that directly impacts their families' daily lives.

The results indicate statistically significant, but weak to moderate negative correlations between the WeeFIM subparameters and the "Pessimism" subdimension of the QRS-F.

Specifically, as the child's level of independence decreases in areas such as "Self-care", "Mobility", and "Communication" the level of pessimism in parents increases. However, no significant relationship was found in the "Parent-Family Problems" dimension, suggesting that emotional reflections may be more dominant than cognitive assessments. Additionally, a significant relationship was found between the mother's education level and pessimism, as well as between the spouses' employment status and the "Family Issues" subdimension, clearly demonstrating the impact of socio-economic variables on parental mental health and perception.

The findings of this study reveal the impact of functional disabilities in children with cerebral palsy on family psychology. The results are consistent with previous studies. For example, Raina et al.[17] showed that as the child's care needs increase, the parents' stress and pessimism levels also rise. Similarly, Basaran et al.[18] (2013) reported that low levels of functional independence are particularly associated with burnout and depression in mothers. In contrast, Parkes and colleagues,[19] in their study with 818 children with CP aged 8–12 years living in 9 different regions of Europe, examined the relationship between Gross Motor Function Classification System (GMFCS) scores and family stress and anxiety levels. The study found that 26% of parents experienced very high parenting stress. The authors stated that this indicates very high parenting stress is five times more common among families of children with CP than in the general population sample. Nevertheless, in their investigation assessing the potential statistical association between elevated levels of parenting stress and the degree of motor impairment as classified by the GMFCS, no significant correlation was identified. Accordingly, the authors highlighted that healthcare providers should avoid drawing conclusions about parenting stress based solely on the severity of a child's motor limitations. Rather, they recommended taking into account commonly co-occurring conditions—such as impairments in communication and learning—which were shown to have a notable impact in their findings.

The negative correlation found between the motor and cognitive subscores and pessimism in this study suggests that parents experience hopelessness regarding future expectations. Similarly, Telci et al.[20] (2018) reported a significant association between children's functional levels and their mothers' levels of hopelessness, pain, and quality of life. This finding underscores the pivotal role of functional independence in shaping parental mental health. This finding is supported by Gallagher et al.[21] and Trute & Hiebert-Murphy[22], these studies stated that as the child's functional capacity decreases, the parent feels more inadequate and hopelessness increases. In a study by Gallagher and colleagues with 32 children with intellectual disabilities, the assessment criteria were compared with data from 29 healthy children, and it was reported that parents of children with intellectual disabilities recorded high depression and anxiety scores, with the majority meeting the criteria for possible clinical depression and/or anxiety. In a study by Dambi et al.[23] with 46 mothers of children with CP, it was noted that approximately half of the participating mothers experienced clinical-level stress and burden. Additionally, the study highlighted that pain, depression, and feelings of being overwhelmed were common among the mothers. Similarly, in a study by Resch et al.,[24] the relationship between stress, burnout, and psychological burden in parents of children with disabilities and depression was analyzed. The prevalence of depression in parents was found to be significantly higher than in the general population. Recent research has framed this phenomenon within the concept of 'parental burnout.' For instance, Findling et al.[25] (2024) identified and elaborated on factors that elevate the risk of burnout in mothers of children with special needs, such as high levels of parenting stress, perfectionism, and pessimistic cognitive patterns.

Ketelaar and colleagues,[26] aiming to analyze the sources of stress experienced by parents of children with CP in detail, concluded that the source of stress was less related to the child's physical condition and level of disability and more related to the parents' daily life challenges, uncertainties about the future, and the feeling of being misunderstood by society. However, it is noteworthy that no significant relationship was found between the "Parent-Family Problems" parameter and the WeeFIM scores. This suggests that the issues faced by families are not solely dependent on the child's functional level, but more on socio-economic conditions, social support mechanisms, and psychological resilience. Recent studies also confirm the association between functional level and parental mental health. Güneş et al.[27] (2024) reported that the functional independence levels of children with spina bifida were associated with their mothers' levels of depression and fatigue. Similar mechanisms may also apply to CP.

Mothers' education level is positively correlated with their knowledge and practices regarding their children's condition, suggesting that higher education may enhance their coping mechanisms and reduce pessimism.[28] In particular, the relationship between the mother's education level and pessimism highlights the potential of education to strengthen psychological coping mechanisms. This finding aligns with the study by Coşkun et al.[29,] which noted that the education level of mothers is an important protective factor in coping with stress and depression. The authors emphasized that as mothers' education and family income levels increase, their levels of constant anxiety decrease, while their perceived social support levels increase. Similarly, the correlation between spouses' employment status and family issues indicates that financial security plays an important role in alleviating family stress. This finding is also consistent with the study by Lima et al.[30] (2021), who demonstrated that the quality of life of parents of children with CP is directly associated with socioeconomic factors. Kaytez and colleagues[31] emphasize that economic insecurity is a primary source of stress, particularly in families with children with disabilities.

The findings of this study reveal that there are significant relationships between the functional independence levels of children and the pessimism levels of families, while family problems may not be directly related to the functional competence of the child, but rather to socioeconomic factors and psychological resources of the parents.

Limitations

This study has some limitations. The limited number of children with CP and families participating in the study reduces the statistical power of the analyses and restricts the generalizability of the results. Different results may be obtained in studies with larger sample groups. The fact that the data were collected from a single center makes it difficult to generalize the results to different socio-cultural and geographical contexts. This particularly limits the socio-economic and cultural diversity of the families. Emotional responses such as "pessimism" can vary over time. However, this study measured this only at a single time point, without considering the individuals' psychological changes over time. The lack of detailed analysis regarding the causes of low WeeFIM scores (e.g., CP subtype, comorbidities, level of access to physical therapy) may lead to a limited contextual interpretation of the findings. Since the research includes only the parents' (mostly mothers') perspective, the issues and emotional responses experienced by other family members (fathers, siblings) are excluded from the study. This is a gap in terms of family system integrity.

A limitation of this study is that only the WeeFIM was used to assess functional independence. No additional assessment scales were included, which may have limited the evaluation of other aspects of parental psychological status.

In this study, besides the main domains of the WeeFIM, other potential comorbid conditions that could accompany parents' pessimism (e.g., depression, anxiety, chronic stress) were not assessed and were not included in the study. This limits a more comprehensive evaluation of parental psychological status. Future studies should consider these factors to provide a broader understanding of parental experiences.

Conclusion

This study highlights the significant psychological impact of caring for a child with cerebral palsy (CP) on parents, particularly in relation to pessimism and stress levels. The findings demonstrate that decreased functional independence in children, especially in self-care and mobility, is associated with higher levels of pessimism in parents. Moreover, socioeconomic factors such as maternal education and employment status of the parents appear to influence psychological resilience and perceived family burden. These results underline the importance of holistic and family-centered approaches in pediatric rehabilitation, which address not only the child's physical needs but also the emotional and socioeconomic challenges faced by families. Future research with larger and more diverse samples is needed to deepen our understanding of these complex dynamics and to guide the development of effective support mechanisms for families of children with CP.

Conflict of Interest

The authors have no conflicts of interest to disclose.

Compliance of Ethical Statement

This study was conducted following the receipt of ethical approval and institutional permission from the Kocaeli University Non-Interventional Clinical Research Ethics Committee, under decision number KÜ GOKAEK-2018/326

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Author's Contributions

ÇÇ, BÇT, IS: Hypothesis; ÇÇ, BÇT: Design; ÇÇ, BÇT: Data Collection; ÇÇ, BÇT, IS: Literature review; ÇÇ, BÇT, IS: Analysis and Interpretation of Results; ÇÇ, BÇT: Writing; ÇÇ, BÇT: Critical Review

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