

Child's quality of life and mother's burden in spastic cerebral palsy: a topographical classification perspective

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Abstract

Objective: To evaluate the child's quality of life (QoL), mother's burden, and correlation between these parameters in children with spastic cerebral palsy (CP).

Methods: Children with spastic CP ($n = 120$; mean age: 8.64 ± 3.45 years; range: 2–17 years) were classified into three groups of diplegia, hemiplegia, and quadriplegia based on topographical classification. The Pediatric Quality of Life Inventory and Zarit Burden Interview were used to determine the child's QoL and the mother's burden scores, respectively.

Results: Children's QoL scores were lower in the quadriplegia group than in the hemiplegia and diplegia groups (except for emotional functioning). The mother's burden was lower in the quadriplegia group than in the other groups, and it was lower in the diplegia group than in the hemiplegia group. Increases in children's QoL scores were associated with decreases in the mothers' burden scores.

Conclusion: Children's QoL is associated with the mother's burden in spastic CP, and quadriplegic children and their mothers are more affected. The burden of mothers ranked the highest in the quadriplegia group, followed by the diplegia group and the hemiplegia group. Topographical classification is a good indicator for children's QoL and the mother's burden in spastic CP.

Keywords

Cerebral palsy, child's quality of life, mother's burden, topographical classification, diplegia, hemiplegia, quadriplegia

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Introduction

Cerebral palsy (CP) is the most common cause of paediatric motor disabilities, affecting approximately 2.1 per 1000 live births.¹ CP is traditionally considered to be a group of disorders in the development of movement patterns, motor coordination, and posture due to permanent and non-progressive disruptions in the developing foetal brain.² Although some risk factors have been identified, including placental abruption, birth asphyxia, and neonatal medical problems, the aetiology of CP is heterogeneous or often not well understood.³

The diagnosis of CP is based on clinical presentation consisting of movement patterns, and not on laboratory test results and radiological findings.⁴ Clinicians classify CP by taking into account movement patterns, including spastic, dyskinetic (dystonia or choreoathetosis), ataxic, and mixed forms.⁵ In spastic CP, spasticity is the predominant movement pattern and exclusive impairment is present. Spastic CP is the most common type of overall CP, comprising up to 70% to 80% of cases.⁶ According to topographical classification, children with spastic CP are usually quadriplegic (bilateral spasticity with arm involvement equal to or greater than the leg), hemiplegic (unilateral spasticity, usually the arm more than the leg), or diplegic (bilateral spasticity with leg involvement greater than the arm) subtypes.^{4,6}

Motor impairment leading to long-term functional limitations are the hallmarks of CP. There are common medical comorbidities associated with CP, such as cognitive, sensory, communicative, and intellectual impairments, speech disturbance, epilepsy, and dental and nutritional problems.^{7,8} Therefore, management of children with CP depends on a multidisciplinary, comprehensive, and coordinated approach, and goals are the child's independence and community engagement.^{4,5,7-9}

Caregiver burden is a stress that is perceived by caregivers. This burden refers to a negative outcome of the care situation for the caregivers themselves, as well as for the person who requires care. In general, caring for a child affected by a disabling illness may lead to high levels of caregiver stress. Considering the common comorbidities and multidisciplinary management of CP, it remarkably influences the life of those affected and also their mothers who are the primary caregivers. However, the burden of caregivers who are mothers has yet to be specifically and adequately examined.¹⁰ Although topographical classification may be related to the quality of life (QoL) of children with CP, there does not appear to be any published literature on this subject. Additionally, no studies have investigated the association between the child's QoL and the mother's burden as a caregiver.

Determining the associations among topographical classifications and the child's QoL and the mother's burden in CP may have important implications for planning and implementation of more effective multidisciplinary interventions. Therefore, the aims of this study were: (i) to identify the QoL profiles of children with CP considering topographical classification; (ii) to determine the burden of mothers who are primary caregivers of children with CP; and (iii) to assess the correlation between the child's QoL and the mother's burden.

Materials and methods

Patients who were diagnosed with spastic CP according to the patients' medical history, a physical examination, a medical record review, and brain imaging findings were recruited between 15 April 2017 and 21 July 2017. The patients' mothers were also included in the study. A local ethical review board approved the study protocol. Written informed consent was obtained from each mother and child assent was

also obtained. The study was conducted in accordance with the principles of the Declaration of Helsinki.

All children and mothers included in the study were evaluated by the Pediatric Quality of Life (PedsQL) 4.0 Generic Core Scales¹¹ and by the Zarit Burden Interview,¹² respectively. The PedsQL 4.0 Generic Core Scales evaluate physical functioning, emotional functioning, social functioning, school functioning, and psychosocial health. Higher scores of the PedsQL 4.0 Generic Core Scales indicate better QoL.¹¹ The Zarit Burden Interview, which is a scale made up by 22 items, is the most widely used instrument for assessing the burden level of caregivers. In this scale, the higher the score, the greater is the perceived overload.¹² The obtained scores were compared between the subtypes, and correlations between the child's QoL and the mother's burden were analysed.

Inclusion criteria were children who were provided care and diagnosed with spastic CP (children with non-spastic CP were excluded), and aged between 2 and 18 years. Inclusion criteria for mothers providing care to children were the following: (1) housewives or those who gave up a job for illness of their children; (2) aged 18 years or older; and (3) primary caregivers.

Statistical analysis

Statistical analyses were performed using the SPSS version 16.0 software program (SPSS Inc., Chicago, IL, USA). The Kolmogorov–Smirnov normality test was used to determine whether continuous data were normally distributed. One-way analysis of variance with Bonferroni post-hoc tests were performed for comparison of continuous variables between groups. Categorical variables were evaluated by the chi-square test. Descriptive data are presented as mean \pm standard deviation for continuous variables and number (%) for categorical variables. Pearson's correlation

analysis was used to analyse the level of the correlation between variables. A $p < 0.05$ was considered as statistically significant.

Results

A total of 120 children with spastic CP (mean age: 8.64 ± 3.45 years) were included and classified into three subtypes considering the topographical classification as follows: spastic diplegia, spastic hemiplegia, and spastic quadriplegia. There were no significant differences in age, sex, and mother's education among the three groups. Considering the mother's burden, the quadriplegia group had a significantly higher score than did the hemiplegia ($p < 0.001$) and diplegia ($p < 0.001$) groups, and the diplegia group had a higher score than did the hemiplegia group ($p = 0.001$) (Table 1).

However, children's QoL scores were significantly lower in the quadriplegia group than in the hemiplegia group (all $p < 0.05$) and diplegia group (except for the emotional functioning score, all $p < 0.01$). The diplegia group had a significantly lower score of physical functioning than did the hemiplegia group ($p < 0.001$), while they were similar in terms of other profiles of QoL (Table 2).

There were significant negative correlations between the mother's burden and the child's QoL profiles, including physical functioning ($r = -0.546$, $p < 0.001$), emotional functioning ($r = -0.595$, $p < 0.001$), social functioning ($r = -0.489$, $p < 0.001$), school functioning ($r = -0.464$, $p < 0.001$), psychosocial health ($r = -0.428$, $p < 0.001$), and the total score ($r = -0.400$, $p < 0.001$) (Table 3). No significant correlation was found between the mother's burden and the child's age parameters ($r = -0.120$).

Discussion

The present study evaluated the QoL profiles of children with spastic CP, the burden

Table 1. Comparison of cerebral palsy subtypes for age, sex, mother's education, and mother's burden.

	Hemiplegia (n = 34)	Diplegia (n = 42)	Quadriplegia (n = 44)	p values
Age (years)	7.91 ± 3.08	8.57 ± 3.37	9.27 ± 3.74	0.224
Sex				0.690
Male	14 (41.2%)	20 (47.6%)	17 (38.6%)	
Female	20 (58.8%)	22 (52.4%)	27 (61.4%)	
Mother's education				0.648
Primary school	16 (47.1%)	27 (64.3%)	24 (54.5%)	
High school	12 (35.3%)	11 (26.2%)	14 (31.8%)	
University	6 (17.6%)	4 (9.5%)	6 (13.6%)	
Mother's burden	52.50 ± 3.75	60.74 ± 13.76	75.43 ± 6.19	0.001* <0.001** <0.001***

*Comparison between the hemiplegia and diplegia groups.

**Comparison between the hemiplegia and quadriplegia groups.

***Comparison between the diplegia and quadriplegia groups.

Data are expressed as mean ± standard deviation or number (%).

Table 2. Comparison of cerebral palsy subtypes for the child's quality of life profiles.

	Hemiplegia (n = 34)	Diplegia (n = 42)	Quadriplegia (n = 44)	p values
Physical functioning	42.50 ± 11.02	34.26 ± 7.30	26.16 ± 3.11	<0.001* <0.001** <0.001***
Emotional functioning	57.38 ± 5.60	54.79 ± 8.22	53.36 ± 3.92	0.213* 0.016** 0.864***
Social functioning	58.88 ± 6.22	57.86 ± 7.15	52.84 ± 6.40	1.000* <0.001** 0.002***
School functioning	60.88 ± 6.14	61.48 ± 5.17	56.39 ± 6.20	1.000* 0.003** <0.001***
Psychosocial health	60.18 ± 7.23	60.64 ± 4.92	54.98 ± 5.28	1.000* <0.001** <0.001***
Total score	57.38 ± 8.62	54.79 ± 6.99	47.91 ± 8.55	0.496* <0.001** <0.001***

*Comparison between the hemiplegia and diplegia groups.

**Comparison between the hemiplegia and quadriplegia groups.

***Comparison between the diplegia and quadriplegia groups.

Data are expressed as mean ± standard deviation.

Table 3. Correlations between the mother's burden and the child's quality of life scores.

	Physical functioning	Emotional functioning	Social functioning	School functioning	Psychosocial health	Total score
Mother's burden	$r = -0.546$ $p < 0.001$	$r = -0.595$ $p < 0.001$	$r = -0.489$ $p < 0.001$	$r = -0.464$ $p < 0.001$	$r = -0.428$ $p < 0.001$	$r = -0.400$ $p < 0.001$

of mothers who are primary caregivers of these children, and the association between the child's QoL and the mother's burden. The current study showed that children's QoL was significantly lower and the mother's burden was higher in the quadriplegia group than in the hemiplegia and diplegia groups. The mother's burden score was lower and physical functioning score was higher in the hemiplegia group than in the diplegia group. There were also significant negative linear correlations between the mother's burden and children's QoL scores.

Although mothers are the main people involved in the care process of CP, the burden of caregiver mothers and its relation to their children's QoL has yet to be specifically and adequately examined.¹⁰ Additionally, previous studies used the Gross Motor Function Classification System (GMFCS) and reported inconsistent findings on the QoL of children with CP and the burden of their mothers.^{13,14} However, there does not appear to be any published literature on this issue based on topographical classification. The hypothesis in the current study was that topographical classification is related to children's QoL and caregiver mothers' burden in spastic CP.

The present study showed that children with quadriplegia had lower QoL scores than did those with hemiplegia and diplegia. Additionally, children with diplegia had lower scores of physical functioning than did those with hemiplegia. Previous studies that used the GMFCS showed no association between the GMFCS level and the child's QoL, while others reported that

the severe group (children with GMFCS level V) had a greater deterioration in the child's QoL scores compared with the mild group.^{13,14} This latter finding is consistent with the current study results based on topographical classification. This suggests that topographical classification, which is a simple evaluation method, may be a good indicator for the child's QoL in spastic CP.

Parents, especially mothers, who have children with CP can be negatively affected and may have high levels of burden.^{13,15} Previous studies have shown high levels of stress and depression, and low QoL among parents of children with CP.¹⁶ Nonetheless, a positive effect of caring for a child with CP on a parent's life has also been reported, suggesting the families' potential for adaptation.¹⁷ However, why some parents cope well with the difficulty of caring for their child and others do not is not fully understood.¹⁸ This may be related to the common medical comorbidities associated with CP, leading to a relative reduction or induction of parents' demands. Parkes et al.¹⁹ reported that among parents who have children with CP who suffer from psychological problems, 42% said they burdened the family at least "quite a lot". Other factors that are consistently related to an increased the burden of caregiver have been identified as child behaviour and cognitive problems, low caregiver self-efficacy, and low social support.¹⁶ Besides these factors, severity of the condition has been investigated, and milder conditions have been found to be associated with better outcomes for parents of children with CP.²⁰ Similarly, according

to topographical classification, the current study showed that the burden of mothers ranked the highest in the quadriplegia group, followed by the diplegia group, and then the hemiplegia group. Taken together, previous research and the present study indicate that severe disability in children with CP is associated with a lower QoL and higher burden in mothers.

Previous studies have shown that the caregivers of children with CP are at greater risk for a deterioration in mental health and QoL.^{13,21} The present study showed that an increase in the child's QoL was correlated with a decrease in the mother's burden. This is the first study to investigate the correlation between the child's QoL and the caregiver mother's burden. These findings support the notion that family-focussed intervention strategies tend to replace child-focussed methods.²² Rearing a child with CP is associated with the mental health and QoL of the caregiver,¹³ and parents' wellbeing is positively influenced by the health and psychosocial functioning of children with paediatric disabilities,²⁰ which are in accordance with the current results. Therefore, therapy planning should encompass not only children who are affected, but also caregiver mothers.

The present study has some limitations. The study had a small sample size, which may have reduced statistical power. Additionally, to achieve homogeneity, children with non-spastic CP were excluded, and only mothers who were primary caregivers and housewives or who gave up work to care for their children were included. Therefore, the current results cannot be generalised to all children with CP and all mothers who have children with CP.

In conclusion, in children with spastic CP, scores of the mother's burden and the child's QoL are higher in children with quadriplegia than in children with hemiplegia or diplegia. Additionally, these scores show a significant negative correlation

with each other. Topographical classification is a good and simple indicator for the mother's burden and the child's QoL in spastic CP. These results may be useful in multidisciplinary evaluation and intervention planning.

Declaration of conflicting interest

The author declare that there is no conflict of interest.

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