

Functions (Mobility, Self-care, Social Ability) and Health-related Quality of Life in Children with Cerebral Palsy



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Purpose: The purpose of this study was to describe the functional (mobility, self-care, social ability) and health-related quality of life in children with cerebral palsy (CP).

Methods: A cross-sectional survey of 202 children with CP, mean age 5.91±1.57 years, was carried out using the Gross Motor Function Classification System (GMFCS), Gross Motor Function Measure (GMFM), Pediatric Evaluation of Disability Inventory (PEDI), and Child Health Questionnaire (CHQ).

Results: The functional assessment of children with CP showed that a more severe GMFCS level was associated with lower functional abilities ($p < 0.05$). The health-related quality of life assessment showed that psychosocial well-being was less impaired than physical well-being. The internal consistency of the three instruments was satisfactory (Cronbach's $\alpha > 0.80$). The three different scales were correlated from moderate to strong ($r = 0.44$ to 0.92). It was also found that mobility, tone distribution, and the parents' education level exerted a significant effect on the quality of life of children with CP ($p < 0.05$).

Conclusion: These findings suggest that children with CP have reduced function and quality of life and these are influenced by various factors. However, planning and application of various task-oriented functional interventions to childhood CP may be useful.

Keywords: Cerebral palsy, Function, Health-related quality of life

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1. Introduction

Cerebral palsy (CP) is the most common cause of childhood movement disability and is increasing in incidence.¹ CP is defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain”.¹ It affects the function and health-related quality of life of the involved subjects. Moreover it often accompanies other impairments that reduce function and health-related quality of life.²

The most well-known and frequently used framework to describe function and health-related quality of life in the field of rehabilitation medicine is International Classification of Functioning, Disability and Health (ICF) which is also applicable to

children with CP.² ICF system suggests assessing health outcomes of a disease at the level of body function and structure, daily activities and participation.³ According to this framework, we settled to describe the function and health-related quality of life of the children with CP at the levels of activities and participation. In this context, function is described in the following areas: mobility, self-care, and social ability,³ and quality of life denotes the patients' perception of well-being in physical, emotional, mental, social, and everyday life areas.⁴ To assess these domains, the Gross Motor Function Classification (GMFCS),⁵ the Gross Motor Function Measure (GMFM-88),^{6,7} the Pediatric Evaluation of Disability Inventory (PEDI),⁸ and the Child Health Questionnaire (CHQ)⁹ are available, for they have been developed for children and are known that they go beyond traditional measures of morbidity and impairment.¹⁰ Using these standardized

tools has increased objectivity of the assessment.¹¹

It seems several reports exist on assessing the function for children with CP. Actually there are some investigations of the descriptions about the functional status of children with CP. However, they have focused only on school-age children with CP, and the descriptions were limited to simple gross motor skill domain in these subjects.^{12,13} There are few reports on the function of preschoolers with CP using standardized assessment tools, such as the GMFCS, the GMFM, the WeeFIM, and the PEDI. For example, the level of function in early childhood CP stratified by GMFCS is unclear in the areas of self-care, social ability as well as mobility. So, we have chosen subjects of this study as preschool-aged early childhood CP. And about health-related quality of life of children with CP, we can say that this domain still needs our concern. Despite the prevalence of CP, researchers are just beginning to understand the ways in which having CP can impact a child's quality of life.^{14,15} Although several researchers have reported decreased health-related quality of life in children with CP, few studies have specifically addressed health-related quality of life across the full spectrum of children with this population.^{3,16} They have included only limited range of severity of illness or age, and they did not use generic outcome measures to permit comparison.^{14,15}

Finding out factors that affect quality of life of CP is another issue. It is reported that the severity of CP has a significant relationship with quality of life in children with CP.¹⁷ The parental factors, functional ability, mental health, age, gender, and type of CP are regarded as affecting factors.¹⁸ However, those are changeable by cultural background and so far it has not been available to compare worldwide different traits because of small number of reports from non-diverse nations.

Thus, the purposes of this study were to describe the function (mobility, self-care, and social ability) and health-related quality of life in early childhood CP stratified by GMFCS levels. We also needed to confirm the reliability of this assessment by measuring internal consistency and correlation among the tools. By this, we could get the relationship between the functional level and quality of life in subscales. And we analyzed the influencing factors on quality of life by variable sample characteristics such as parental factors.

II. Methods

1. Subjects

This study used a cross sectional design. The 202 CP participants and their mothers represented a convenience sample recruited from the CP clinic of the 3 Hospitals and one health care center located in Seoul and Gyeonggi-do. All participants (when appropriate) and mothers signed a consent forms. The CP participants had no history of newly developed neurological problems or musculoskeletal disorders, botulinum toxin injection within the previous six months. Almost of the subjects' mothers reported that cognitive ability of their child was generally lower than that of peer group of the age. The general characteristics of subjects are presented in Table 1. The majority of the participants (84.16%) were spastic-typed CP in this study (Table 1).

2. Procedures

Participants with CP were categorized by GMFCS levels I to level V (I: walks without restrictions, II: walks with limitations, III: walks using a hand-held mobility device, IV: self mobility with limitations, V: transported in a manual wheelchair).⁵ We assessed the function and health-related quality of life with the GMFM-88, the PEDI, and the CHQ-PF28 respectively.

The GMFM-88 is a standardized observational instrument that has been developed to measure the gross motor function in CP. The GMFM-88 consists of 5 dimensions of gross motor function: lying and rolling; sitting; crawling; and kneeling; standing; walking, running and jumping. Each item is scored on a 4-point likert scale (0: does not initiate, 1: initiate, 2: partially completes, 3: completes). Totals from each category for a participant were divided by the total possible points to produce a category percentage score. These percentages were averaged to yield an overall score ranging from 0 to 100, with higher numbers indicating a better gross motor function.¹⁹

The PEDI was also used to assess the function, or the self-care and social ability, as well as mobility. The PEDI is a standardized assessment instrument using parental reports through structured interviews.⁸ The PEDI measures capability by the Functional Skills scale (197 items), which assesses what a child can do in daily environment. Each question is scored as positive (score 1) or negative (score 0). A positive score is given when the child is capable of accomplishing the activity.⁸ We used the scaled scores (0-100), reflecting an increasing level of

Table 1. Characteristics of the participants

Demographic	GMFCS I (n=40)	GMFCS II (n=42)	GMFCS III (n=22)	GMFCS IV (n=44)	GMFCS V (n=54)	Total (N=202)
Gender						
Male	20 (50.00)	24 (57.14)	14 (63.64)	14 (31.82)	26 (48.15)	104 (51.49)
Female	20 (50.00)	18 (42.86)	8 (36.36)	30 (68.18)	28 (51.85)	98 (48.51)
Age (y)	5.60±1.57	5.76±1.68	6.61±1.39	5.80±1.54	5.79±1.74	5.91±1.57
Birth weight (kg)	2.17±1.00	2.37±0.91	2.38±0.86	2.06±0.83	2.49±1.16	2.29±0.95
Tone distribution						
Hemiplegia	18 (45.00)	6 (14.29)	0 (0.00)	0 (0.00)	0 (0.00)	24 (11.88)
Diplegia	16 (40.00)	30 (71.43)	18 (81.82)	38 (86.36)	14 (25.93)	116 (57.43)
Triplegia	2 (5.00)	2 (4.76)	2 (9.02)	2 (4.55)	2 (3.70)	10 (4.95)
Quadriplegia	4 (10.00)	4 (9.52)	0 (0.00)	4 (9.09)	38 (70.37)	52 (25.74)
Tone type						
Spastic	38 (95.00)	36 (85.71)	18 (81.82)	38 (86.36)	40 (74.07)	170 (84.16)
Athetoid	2 (5.00)	2 (4.76)	0 (0.00)	2 (4.55)	4 (7.41)	10 (4.95)
Ataxia	0 (0.00)	2 (4.76)	0 (0.00)	4 (9.09)	0 (0.00)	6 (2.97)
Hypotonia	0 (0.00)	2 (4.76)	0 (0.00)	0 (0.00)	6 (11.11)	8 (3.96)
Mixed	0 (0.00)	0 (0.00)	4 (18.18)	0 (0.00)	4 (7.41)	8 (3.96)
Father's education level						
High school	6 (15.00)	20 (47.61)	12 (54.54)	16 (36.36)	20 (37.03)	74 (36.63)
College/university	32 (80.00)	22 (52.38)	8 (36.36)	28 (63.63)	30 (55.56)	120 (59.40)
Graduate school	2 (5.00)	0 (0.00)	2 (9.09)	0 (0.00)	4 (7.40)	8 (3.96)
Mother's education level						
High school	12 (30.00)	14 (33.33)	10 (45.45)	18 (40.90)	24 (44.44)	78 (38.61)
College/university	26 (65.00)	26 (61.90)	10 (45.45)	26 (59.09)	26 (48.14)	114 (56.43)
Graduate school	2 (5.00)	2 (4.76)	2 (9.09)	0 (0.00)	4 (7.40)	10 (4.95)
Income						
Low	2 (5.00)	4 (9.52)	0 (0.00)	2 (4.54)	6 (11.11)	14 (6.93)
Middle	6 (15.00)	18 (42.85)	12 (54.54)	18 (40.90)	28 (51.85)	82 (40.59)
High	32 (80.00)	20 (47.61)	10 (45.45)	24 (54.54)	20 (37.03)	106 (52.47)
Father's job						
Office job	28 (70.00)	16 (38.09)	8 (36.36)	22 (50.00)	28 (51.85)	96 (47.52)
Non-office job	12 (30.00)	26 (61.90)	14 (63.63)	22 (50.00)	26 (48.14)	106 (52.47)
Delivery method						
NSVD	22 (55.00)	28 (66.66)	8 (36.36)	22 (50.00)	26 (48.14)	106 (52.47)
C-sec	18 (45.00)	14 (33.33)	14 (63.63)	22 (50.00)	28 (51.85)	96 (47.52)
Number of sibling						
None	12 (30.00)	10 (23.80)	4 (18.18)	12 (27.27)	20 (37.03)	58 (28.71)
One	24 (60.00)	24 (57.14)	14 (63.63)	28 (63.63)	24 (44.44)	114 (56.43)
More than two	4 (10.00)	8 (1.90)	4 (18.18)	4 (9.09)	10 (18.51)	30 (14.85)

Values are Mean±SD or n(%)

GMFCS: Gross motor function classification system, NSVD: Normal spontaneous vaginal delivery, C-sec: Cesarean section

function.

The CHQ-28 is a generic questionnaire that evaluates physical and psychosocial well-being of children across 15 subscales of physical, emotional, and behavioral health with 28 questions. The 15 domains were transformed a scores with a range of 0-100, with 0 indicating the worst and 100 indicating optimum

health-related quality of life. Two summary scores, the physical summary score (PHS) and psychosocial summary score (PSS) were derived from weighted combinations of domain subscale score following the United States norms.⁹

The general methods used in this investigation to measure the function and quality of life have been described else-

Table 2. Function (mobility, self-care, and social ability) in CP stratified by GMFCS

GMFCS	GMFM	PEDI		
		Mobility	Self-care	Social ability
I (n=40)	92.65±5.98 ²⁻⁵	79.73±14.83 ^{2-5*}	74.09±13.77 ²⁻⁵	76.52±13.59 ²⁻⁵
II (n=42)	81.81±5.99 ^{1,3-5}	58.46±10.91 ^{1,4,5*}	63.42±20.29 ^{1,5}	62.30±20.75 ^{1,5}
III (n=22)	67.18±9.65 ^{1,2,5}	50.95±13.10 ^{1,5*}	56.74±13.38 ^{1,5}	61.08±20.39 ^{1,5}
IV (n=44)	59.27±8.64 ^{1,2,5}	41.48±9.76 ^{1,2,5*}	54.28±8.80 ^{1,5}	56.08±12.55 ^{1,5}
V (n=54)	26.26±16.63 ¹⁻⁴	17.73±12.77 ^{1-4*}	37.53±4.06 ¹⁻⁴	39.74±22.42 ¹⁻⁴

Values are mean±SD

GMFCS: Gross motor function classification system, GMFM: Gross motor function measure, PEDI: Pediatric evaluation of disability inventory

¹significantly different compared with GMFCS I

²significantly different compared with GMFCS II

³significantly different compared with GMFCS III

⁴significantly different compared with GMFCS IV

⁵significantly different compared with GMFCS V

*p<0.05: significant difference between GMFM and PEDI-mobility

Table 3. Health-related quality of life in CP stratified by GMFCS

	I (n=40)	II (n=42)	III (n=22)	IV (n=44)	V (n=54)
PHS	31.50±8.40	31.04±10.13	33.15±8.74	34.50±6.45 ⁵	28.16±10.32 ⁴
PSS	44.56±8.81	44.20±9.34	43.68±8.95	46.71±10.35	42.48±8.79

Values are mean±SD

PHS: Physical summary score, PSS: Psychosocial summary score

⁴significantly different compared with GMFCS IV

⁵significantly different compared with GMFCS V

where.^{8,9,15,19} They will be briefly summarized here. The GMFCS and the GMFM were measured by the child’s physical therapist. The PEDI, the CHQ, and information about the parent’s information were assessed through a structured interview with the participant’s mother. Review of medical records to obtain information about the child’s general characteristics was carried out by one researcher of our team.

3. Data Analysis

Demographic and descriptive statistics were computed. For the comparison by the GMFCS levels, ANOVA followed by the Scheffe test was done for the GMFM scores, the PEDI scores, and scores on the CHQ. Internal consistency was estimated by computing Cronbach’s α coefficient for each scale. Because we used multidimensional instruments, Cronbach’s α was computed for each subscale. The relation between the function and quality of life was calculated with Pearson correlation. Also, the Multiple regression using stepwise selection method was used to explain the factors influencing the quality of life in CP according to the demographic and parental factors. All analysis was completed with SAS (v1.0) with a statistical significance set at the 0.05 level.

III. Results

1. Function in CP stratified by GMFCS

The mean scores for the function according to the GMFCS levels and levels of significance are presented in Table 2. When stratified by GMFCS levels, more severe GMFCS level was associated with lower functional ability (p<0.05). There were significant differences between GMFM and PEDI-functional skills-mobility in all GMFCS levels (p<0.05)(Table 2).

2. Quality of life in CP stratified by GMFCS

The PHS was also very low, and lower than the PSS (Table 3). The greatest effect with CP severity was seen in the physical summary domain (between IV and V) (p<0.05)(Table 3).

3. The relation between function and quality of life in CP

The internal consistency of the different instruments is presented on the diagonal in Table 4 by the cronbach’s α coefficients. All of the scales have satisfactory internal consistency (at least 0.80). The GMFM and PEDI scales are particularly high (at least 0.95). Table 4 also presents Pearson’s correlation co-

Table 4. Correlation between function and health-related quality of life in CP (N=202)

	GMFM	PEDI			CHQ	
		M	SC	S	PHS	PSS
GMFM	0.99					
PEDI - M	0.89*	0.95				
SC	0.74*	0.81*	0.95			
S	0.65*	0.73*	0.92*	0.95		
CHQ - PHS	0.14	0.15*	0.15*	0.05	0.80	
PSS	0.05	0.07	0.07	0.07	0.44*	0.81

Chronbach's α coefficients are presented on the diagonal

GMFM: Gross motor function measure, PEDI: Pediatric evaluation of disability inventory, M: Mobility, SC: Self-care, S: Social ability, CHQ: Child health questionnaire, PHS: Physical summary, PSS: Psychosocial summary

* $p < 0.05$

Table 5. Factor affecting quality of life of CP (N=202)

CHQ	Variables	β	Model R^2	Partial R^2	F
Physical summary	Tone distribution	-8.55718	0.0569	0.0569	11.94*
	Age	0.00375	0.0861	0.0292	6.30*
	Father's education level	5.34904	0.1200	0.0338	7.54*
	Mother's education level	-2.59499	0.1471	0.0271	6.21*
	Income	-2.24813	0.1605	0.0134	3.09
	GMFCS level	3.53601	0.1745	0.0140	3.28
	Birth weight	0.00110	0.1909	0.0164	3.90*
	Quadriplegia	-2.63931	0.1998	0.0089	2.12
Psychosocial summary	Tone distribution	-8.68888	0.0711	0.0711	15.17*
	Delivery method	-5.41700	0.1405	0.0693	15.89*
	GMFM	-0.16990	0.1681	0.0276	6.56*
	Mother's education level	-2.66932	0.1898	0.0217	5.23*
	PEDI-mobility	0.11258	0.2130	0.0232	5.72*
	Birth weight	0.00119	0.2256	0.0126	3.15
	GMFCS level	2.56572	0.2368	0.0112	2.82

CHQ: Child health questionnaire, PEDI: Pediatric evaluation of disability inventory, GMFM: Gross motor function measure, GMFCS: Gross motor function classification system

* $p < 0.05$

efficients for selected function and quality of life scales. In general, the three different scales were correlated from moderate to strong ($r=0.44$ to 0.92).

4. Factor affecting quality of life of CP

Furthermore, physical quality of life and psychosocial well-being were explained by parental factor such as mother's education level and father's education level. Also, tone distribution, GMFM, PEDI-mobility affected quality of life in CP (Table 5).

IV. Discussion

Description of the function and health-related quality of life of the preschoolers with CP are important in order to improve the knowledge about developmental status of children with CP, to form a basis for treatment goals, and to guide practitioners in their choice of medical intervention.²⁰ As the population of children with CP is heterogeneous and have various needs according to each of their functional ability, it is necessary to classify the children according to the 'severity' of the CP.

We have used the GMFM and PEDI to assess the participants' functional ability, and found that the GMFM scores were higher than the PEDI scores in the mobility domain. Previous

studies also showed similar tendencies.^{3,15} Function in the GMFM is defined in terms of the child's ability to perform a given motor task upon instruction in a specific test situation. The GMFM is designed to measure the child's best performance, the best he or she can or wants to achieve in a particular test situation, not the quality of movement or performance in the child's daily environment.²¹ Contrarily, function in the PEDI is defined as capacity to perform essential functional skills and complex activities of daily life in the child's environment.⁸ While the more severe form of CP always correlated with the lower function in mobility and self-care domains, the correlation between severity and function in social ability area was not robust, especially between the GMFCS levels II and III. The weak correlation of social ability with severity of CP was also reported by another researcher.³ According to McCarthy et al, the correlation coefficients of the social ability with mobility and self-care were 0.55 and 0.70 respectively and that of self-care with social ability was 0.70.¹⁵ In this study, while the correlation between the mobility and self-care were similar to the previous report, the correlation coefficients of social ability with mobility and self-care were 0.73 and 0.92, which were higher than McCarthy's previous results. Since self-care and social ability areas were developed based on motor performance in the early childhood, higher correlation of these areas with GMFCS level is reasonable by their nature.

Pediatric health-related quality of life is dependent on age, function, feelings about function, existence, and discrepancy between actual and ideal self.²² Since CP is a motor disorder that, the severity of CP, especially in motor function, is considered an important factor in the quality of life in CP.²³ In this study, quality of life of the subjects was evaluated in terms of physical and psychosocial well-being. Psychosocial quality of life was higher than physical quality of life in accordance with the previous findings.^{16,24} When stratified by GMFCS, CP with GMFCS level V showed significantly poorer score than CP with GMFCS level IV in physical quality of life. This result suggests that even the restricted mobility contributes significantly to the quality of life in CP. However, as the previous results reported by Aran et al. show,²⁵ CP with GMFCS levels I, II, III who were classified as mild or moderate CP showed no significant differences among levels in physical well-being. Parents of a children with CP have concerns related to their child's diagnosis, age, and level of disability.^{26,27} It is believed that the

parents' expectations of those levels of CP to have a much better mobility than GMFCS levels IV, V may have affected the results. Interestingly, psychosocial quality of life in children with CP wasn't correlated with the severity of their condition as measured by the GMFCS. This apparently absurd result might be explained by the previous report that children with CP incorporate their impairment into sense of self from birth and didn't recognized it as unhealthy status.²⁷

The GMFM, the PEDI, and the CHQ are frequently used in evaluating intervention outcome in pediatric settings.²⁸ In this study, the GMFM, the PEDI, and the CHQ demonstrated high internal consistency (all α values 0.80-0.99). The PEDI mobility scale was more highly correlated with GMFM ($r=0.89$). The PEDI was developed for children with disabilities. Its item selection is deliberately skewed toward the lower end of the functional skills continuum to identify subtle changes in functional performance of children with limited or slowly emerging competences.²⁹

Outcome, such as the function (e.g. mobility, self-care, social ability) and quality of life is influenced by numerous extrinsic and intrinsic variables.³⁰ In this study, not only medical factors such as severity and tone distribution but also parental factors such as mother's and father's education level were significant variables that affect quality of life in CP. Previous reports also pointed out the parents' education level as important factor in quality of life of disabled children.³¹ According to our study, the higher the father's education level, the higher the level of physical well-being of life. However, the higher the mother's education level, the lower the level of physical, psychosocial well-being. It is thought that the mothers have excessive concerns about their children's health conditions, while the fathers have an increased understanding of their children's health conditions in Korean culture.

There were some limitations in this study. Not all variables that might affect the function and quality of life in CP were considered in this study. Evaluation of cognitive status was relied on the parental report and parent's perception to their children. In the future, gathering more objectively comprehensive information regarding children's cognitive level and status of parental stress would help physical therapists to gain better understanding of their health-related quality of life.

V. Conclusions

In function, CP of more severe GMFCS levels showed lower functional abilities. As for quality of life, physical quality of life was lower than psychosocial quality of life. And parental factors, severity of CP, and morbidity were influencing factors on quality of life. Moreover, long-term follow-up study on the extent of improvement in the function and quality of life of children with CP and its impact on the children and their families will further elucidate the concept of function and QOL and their role in CP intervention.

Author Contributions

Research design: Ko JY

Acquisition of data: Ko JY, Lee SM

Analysis and interpretation of data: Ko JY

Drafting of the manuscript: Ko JY, Lee SM

Administrative, technical, and material support: Ko JY

Research supervision: Lee SM

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