Outcome assessments in children with cerebral palsy, Part I: descriptive characteristics of GMFCS Levels I to III

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This prospective cross-sectional multicenter study assessed the relationships between Gross Motor Function Classification System (GMFCS) level and scores on outcome tools used in pediatric orthopedics. Five hundred and sixty-two participants with cerebral palsy (CP; 339 males, 223 females; age range 4–18y, mean age 11y 1mo [SD 3y 7mo]; 400 with diplegia, 162 with hemiplegia; GMFCS Levels I–III;) completed the study. The Functional Assessment Questionnaire (FAQ), Gross Motor Function Measure (GMFM) Dimensions D and E, Pediatric Quality of Life Inventory (PedsQL), the Pediatric Outcomes Data Collection Instrument (PODCI), Pediatric Functional Independence Measure (WeeFIM), temporal-spatial gait parameters, and O_2 cost were collected during one session. Descriptive characteristics are reported by GMFCS level clinicians can use for comparison with individual children. Tools with a direct relationship between outcome scores and GMFCS levels were the PODCI Parent and Child Global Function, Transfers & Basic Mobility, and Sports and Physical Function; PODCI Parent Upper Extremity Function; WeeFIM Self-care and Mobility; FAQ Question 1; GMFM Dimensions D and E; GMFM-66; O_2 cost; and temporal-spatial gait parameters. Child report scores differed significantly higher than Parent scores for six of eight PODCI subscales and three of four PedsQL dimensions. Children classified into different GMFCS levels function differently.

See end of paper for list of abbreviations.

The demand for evidence-based medicine has challenged the medical community to demonstrate that a particular treatment improves a person's functional abilities within their environment. This has resulted in an increased use of outcome tools to supplement technical measures, such as physical examinations, used in the clinical setting. Outcome tools are used for patients with cerebral palsy (CP) to measure functional performance as a baseline descriptive assessment, select treatment goals, and evaluate treatment outcomes.[1]

Outcome tools frequently used in pediatric orthopedics and selected for this study include the Gillette Functional Assessment Questionnaire (FAQ),[2] the Gross Motor Function Measure (GMFM),[3] the Pediatric Quality of Life Inventory (PedsQL),[4] the Pediatric Outcomes Data Collection Instrument (PODCI),[5] the Pediatric Functional Independence Measure (WeeFIM),[6] temporal-spatial gait parameters (velocity, stride length, and cadence), and energy cost during walking (O_2 cost). With the exception of FAQ Questions 2 and 3, and PODCI subscales of Satisfaction and Expectations, each tool has been tested individually for content validity and various types of test reliability.[4,5,7–13]

These outcome tools assess different aspects of the dimensions of the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization.[14] The ICF provides a comprehensive approach to outcome measurement and treatment goal setting among children with disabilities.[15–17] Quality of Life is not formally included in the ICF framework and is defined as 'what people "feel" about their health condition or its consequences'.[14]

The Gross Motor Function Classification System (GMFCS) classifies people with CP into five levels with Level I being the most functional and Level V the least. The GMFCS is valid and reliable[11,13,18–20] with high interrater reliability (generalizability=0.93).[11] The GMFCS has been correlated with the GMFM;[18] PODCI subscales of Transfer & Basic Mobility and Sports & Physical Function,[18] WeeFIM,[21] gait velocity,[18] O_2 cost,[18] Bimanual Fine Motor Function,[17] Child Health Questionnaire,[22] and Pediatric Evaluation of Disability Index.[16] It has also been correlated with CP distribution and type of motor impairment.[23]

In the present study, investigators from seven pediatric facilities conducted a 3-year prospective study of children with CP (GMFCS Levels I–III) with the purpose of examining the relationship between GMFCS level and scores obtained from the study tools that assess Quality of Life and ICF components of Body Functions and Structures and Activities and Participation. Data were collected during a single session from participants and their parents. The Gross Motor Activity Estimator (GMAE) software was used to calculate an interval score from the GMFM data and is reported as the GMFM-66.[3,24] Descriptive characteristics of the outcome tool scores, relationships between scores and GMFCS level, and differences between scores obtained through parent and child reports are presented. The data will assist clinicians in developing individualized treatment plans by placing the function of a child with CP within the context of a comparison population.

Method

PARTICIPANTS

Participants were a convenience sample of all eligible patients attending motion analysis laboratories and outpatient clinics at each facility (Shriners Hospitals for Children: Lexington,

KY, Springfield, MA, Sacramento, CA, Salt Lake City, UT, and Houston, TX, and the University of Virginia, Charlottesville, VA and Washington University, St Louis, MO). Institutional Review Board approval was obtained at each site and consent and Health Insurance Portability and Accountability Act forms were completed for each participant.

Inclusion criteria were: patients with the diagnosis of CP, in GMFCS Levels I to III, between the ages of 4 and 18 years, and who were able to complete a gait evaluation with or without assistive devices. Patients were excluded if they had previously had a selective dorsal rhizotomy, lower extremity orthopedic surgery within the last year, botulinum toxin A injections in the past 6 months, or a currently implanted and operating baclofen pump.

A total of 1304 patients were assessed for inclusion in the study: 523 did not meet inclusion criteria, 70 declined to participate, 83 did not appear for their appointment, 29 cancelled their appointment, and 30 were excluded for other reasons. Demographic characteristics of these individuals were not different from the study population. This resulted in 569 participants completing the study. Data from seven participants were excluded for inconsistent or missing data, resulting in 562 participants (339 males, 223 females) in the final analysis.

OUTCOME TOOLS

GMFCS level, FAQ, GMFM Dimensions D and E (items 52–88, performed barefoot without walking aids), PedsQL, PODCI, WeeFIM, temporal-spatial gait parameters, and O_2 cost were collected from the parent and the participant, as age appropriate, for each tool during one session. These tools represent technical measures (temporal-spatial gait parameters and O_2 cost), clinician observed rating of child function (GMFM),

Table I: Application of cerebral palsy outcome assessment tools to the International Classification of Functioning, Disability and Health (ICF)[14] framework and Quality of Life construct

ICF component	*Body functions and structures*		*Activities and participation*		*Environmental factors*	*Personal factors*
ICF domain	*Body structures and functions*		*Life areas*		*External influence*	*Internal influence*
ICF construct	*Change in body function (physiological)*	*Change in body structure (anatomical)*	***Capacity:** executing tasks in a standard environment (can do)*	***Performance:** executing tasks in the current environment (does do)*	*Facilitating or hindering impact of features of the physical, social, and attitudinal world*	*Impact of attributes of the person*
Gillette FAQ[2]	Q2		Q3	Q1		Q2
GMFM[3]			Standing Walking, Running and Jumping			
PODCI[5]	Pain and Comfort			Upper extremity function Sports & Physical function Transfers & Mobility		
PedsQL[4]				Physical Functioning		
Energy cost of walking	ml O_2/kg/min ml O_2/kg/m					
Gait analysis			Temporal-Spatial			
WeeFIM[6]				Self-care Mobility Cognition		
Quality of Life:	Measurement of perception of quality of life (not within the ICF framework) i.e. what patients and families feel about the health condition					
PODCI[5]	Happiness with physical condition Satisfaction Expectations Pain and Comfort					
PedsQL[4]	School Functioning Social Functioning Emotional Functioning					

FAQ, Gillette Functional Assessment Questionnaire; GMFM, Gross Motor Function Measure; PODCI, Pediatric Outcomes Data Collection Instrument; PedsQL, Pediatric Quality of Life Inventory; WeeFIM, Pediatric Functional Independence Measure; O_2, oxygen.

Child report (PedsQL ≥5 years old and PODCI ≥11 years old), and Parent report (FAQ, PedsQL, PODCI, and WeeFIM) of a participant's function and Quality of Life. Tools were categorized according to the ICF framework (Table 1).

DATA MANAGEMENT

Before study initiation all coordinators attended a mandatory 2-day training session to review, discuss, and standardize administration of the outcome tools and data collection processes. All participant data were entered directly into a custom database designed for study management and data collection. Parent and child questionnaires were completed using a touch-screen monitor. All questions had to be answered before the participant could proceed to the next question. To reduce the possible effect of fatigue on participant responses, the order of tool administration was randomized using a random number generator embedded in the software. De-identified data from each site were compiled for analysis. The project manager ensured data integrity by a review of the data and follow-up with study coordinators to address inconsistencies.

STATISTICAL ANALYSIS

A priori power analysis using retrospective data from each participating site indicated that, with 600 participants and an alpha level of 0.05, the power ranged from 70 to 95%, depending on test and tool selection. At study completion it was determined that the sample size was large enough to ensure adequate power (90%) to detect small to medium effect sizes when comparing either Level I to II (detectable effect size=0.30) or II to III (detectable effect size=0.37).

Site bias effects for each parametric tool subscale were analyzed using two-way analysis of variance (ANOVA). No significant site effect was found that affected trends across GMFCS levels despite unequal participant contributions from each site. Although participants ranged in age from 4 to 18 years, age did not influence the study results. Correlations between age and scores for each GMFCS level showed the only parameter with a correlation greater than $r=0.5$ to be WeeFIM Self-care at GMFCS Level III.

Data for each tool were averaged within and compared across GMFCS levels. The temporal-spatial gait parameters were normalized to a percentage of data from age-matched, able-bodied individuals. WeeFIM data were converted to quotient scores based on normative data provided in the WeeFIM manual.[25]

Data were examined to determine if a relationship existed between tool subscales and GMFCS level. For interval subscales, a one-way ANOVA F test was used to determine if means were different among GMFCS levels. Post-hoc pair-wise comparisons (Least Significant Differences) were used to investigate whether the subscale could differentiate between any two of the three GMFCS levels. Subscale means were examined to determine if values increased or decreased monotonically as GMFCS level increased from Level I to III. The Bartlett test was performed to assess whether the variances were the same among GMFCS levels. For outcomes with unequal variances, a Linear Mixed Model was fitted. Unequal variances across GMFCS levels did not affect the results.

Table II: Participant demographics: Gross Motor Function Classification System (GMFCS)[13] level, diagnosis, sex, ethnicity, age, height, and weight (*n*=562)

Demographic category	*Total*	*GMFCS Level I*	*GMFCS Level II*	*GMFCS Level III*
GMFCS Level, *n* (%)	562 (100)	240 (43)	196 (35)	126 (22)
Diagnosis, *n* (%)				
Diplegia	400 (71)	124 (52)	151 (77)	125 (99)
Hemiplegia	162 (29)	116 (48)	45 (23)	1 (1)
Sex, *n* (%)				
Male	339 (60)	153 (64)	117 (60)	69 (55)
Female	223 (40)	87 (36)	79 (40)	57 (45)
Ethnicity, *n* (%)				
Caucasian	468 (83)	206 (86)	165 (84)	97 (77)
Hispanic	41 (7)	12 (5)	14 (7)	15 (12)
African-American	38 (7)	15 (6)	13 (7)	10 (8)
Other	15 (3)	7 (3)	4 (2)	4 (3)
Age, y:m				
n	562	240	196	126
Mean	11:1	11:3	11:0	12:6
SD	3:7	3:7	3:7	3:3
Range, y	4–19	4–19	4–19	4–18
Height, cm				
n	560	240	196	124
Mean	138	143	137	140
SD	19.7	19.6	19.1	16.6
Range	90–187	95–187	97–186	98–171
Weight, kg				
n	561	240	196	125
Mean	39.1	46.0	36.8	40.1
SD	18.2	18.7	16.5	16.0
Range	12–122	13–122	12–120	12–114

The relationships between FAQ Questions 2 and 3 responses and GMFCS level were examined using binary logistic regression. The resulting odds ratios and confidence intervals indicated whether each subscale could differentiate between any two of the three GMFCS levels. Frequencies of 'yes' responses on each item were examined to determine whether the values increased or decreased monotonically as GMFCS level increased.

Paired *t*-tests were conducted to compare means between the child and parent reports on the PODCI and PedsQL. For all tests, $p<0.05$ was considered significant.

Results

Participant demographics are reported in Table II. Of the 562 participants analyzed, 240 (43%) were classified as GMFCS Level I, 196 (35%) were classified as Level II, and 126 (22%) were classified as Level III. There was no significant difference in mean age, height, weight, sex, or ethnicity distributions among GMFCS levels.

DESCRIPTIVE STATISTICS

Sample mean, standard deviation, 95% confidence interval, and interquartile range for the interval scale study tools are reported by GMFCS Level in Table IIIa (parent) and Table IIIb (child) with ANOVA *p* values for comparisons among GMFCS levels. Frequencies of 'yes' responses for FAQ Questions 2 and 3 are reported in Tables IVa and IVb, and are shown according to their ability to differentiate among GMFCS levels.

Tools with direct relationships between scores and GMFCS levels were the PODCI parent and child report of Global Function, Transfers and Basic Mobility, and Sports and Physical Function, the PODCI parent report of Upper Extremity Function, WeeFIM domains of Self-care and Mobility, FAQ Question 1, GMFM Dimensions D and E, GMFM-66, O_2 cost, and temporal-spatial gait parameters. As severity level increased, temporal-spatial parameters and tool scores decreased and O_2 cost increased.

There was no difference among GMFCS levels ($p>0.05$) for the PODCI parent and child report of Pain/Comfort, Happiness, and Expectations, and the PedsQL parent and child report of Emotional Functioning. Differences between GMFCS Levels I and II, and Levels I and III were seen for WeeFIM Cognition, the PODCI parent report of Satisfaction, and PedsQL Social Functioning and School Functioning.

The interquartile ranges illustrate the range of scores obtained by the middle 50% of the participants for each GMFCS level and illustrate variability within GMFCS level and degree of overlap between GMFCS levels (Tables IIIa and IIIb).

For FAQ Question 2 (Table IVa) parents reported that the primary factors that limited walking was balance in 81% of the children and endurance in 70%. GMFCS Level I children were reported to have less of a problem with balance than Levels II and III. Factors least frequently reported to limit walking ability were pain and mental ability. For FAQ Question 3 (Table IVb) parents indicated that nearly all children were able to walk up and down stairs using a railing (87% vs 92% for kicking a ball and 90% for stepping over an object); only 11% of the children were able to jump rope and 15% to ice or roller skate.

PARENT VERSUS CHILD REPORT

Parent and child report scores were significantly different for six of eight PODCI subscales and for three of four PedsQL dimensions, with the child report values higher than the parent report values in every case (Table V). The magnitude of difference in scores increased with the level of severity. Physical subscales of PODCI Sports and Physical Function and PedsQL Physical Functioning demonstrated the greatest differences. For those subscales with significant differences, a direct relationship between outcome scores and GMFCS level was seen for both the parent and child reports, despite the differences noted in scores.

No difference was noted between parent and child report on the PODCI subscales of Pain/Comfort, Satisfaction, and Expectations, and the PedsQL dimensions of Emotional Functioning and School Functioning for GMFCS Levels I and II. For GMFCS Level III, no difference was noted on the PODCI subscales of Satisfaction and Expectations, and the PedsQL dimension of Emotional Functioning. Children in GMFCS Level III reported higher (better) scores than the parents for PODCI Pain/Comfort and PedsQL School Functioning.

Discussion

In this multicenter, prospective, cross-sectional study, participants were administered a range of outcome tools during one visit. Standardized protocol ensured data collection consistency across the seven sites. The descriptive statistics reported are representative of a group of ambulatory children with CP ranging in age from 4 to 18 years and in severity from GMFCS Levels I to III.

ANOVA results showed significant differences in mean scores among GMFCS levels. Within the ICF framework (Table I), tools that addressed Activities and Participation were able to differentiate among the mean scores of each GMFCS level, with the exception of WeeFIM Cognition, PedsQL Physical Functioning, and Child report of PODCI Upper Extremity Function. Only one measure of Body Functions and Structures, O_2 cost, was significantly different among GMFCS levels. None of the Quality of Life measures (Table I) showed a difference among all GMFCS levels.

DESCRIPTIVE STATISTICS

The large sample size in this study may have contributed to finding statistically significant differences among GMFCS levels that may not have clinical significance. The ANOVA examines if the means of the groups are different and provides little information about the variation within the groups. Therefore, the degree of separation and overlap of interquartile ranges among GMFCS levels were reviewed. The overlap between lower end scores of GMFCS Level I and the higher end scores of Level III was minimal, while substantial overlap was seen between the lower end of Level I and the upper end of Level II. These findings are consistent with the difficulties reported in classifying patients between Level I and II.[13,26] The overlap between levels also illustrates the heterogeneity of CP.

The GMFCS was designed as a broad classification system based on function.[13] The significant differences in mean outcome tool scores indicate that children classified into different GMFCS levels function differently. These findings support the use of the GMFCS as an appropriate method of classifying severity despite the overlap.

In the authors' previous retrospective multicenter study,[18] the mean scores of the PODCI, GMFM, temporal-

spatial gait parameters, and O_2 cost were lower and the standard deviations greater than the current prospective data, yet results followed the same trends. These differences are probably due to improved methodology in the prospective study, which included the same population across all tools and standardized assessment.

FAQ Question 1 showed a difference among all GMFCS levels indicating that parent report of their child's ability is consistent with the clinician's rating utilizing the GMFCS. Parents reported what they felt limited their child's walking ability on

Table IIIa: Descriptive data for parent outcome tools by Gross Motor Function Classification System (GMFCS)[13] for Levels I to III

*Instrument subscale**		*GMFCS Level I*				
	p	*n*	*Mean*	*SD*	*95% CI*	*Q1–Q3*
FAQ Question 1[2]	<0.000[a,b,c]	238	9	1	9–9	9–10
WeeFIM[6] Self-care Functional Quotient	<0.000[a,b,c]	237	93	11	91–94	88–100
WeeFIM[6] Mobility Functional Quotient	<0.000[a,b,c]	237	96	5	96–97	94–100
WeeFIM[6] Cognition Functional Quotient	0.002[a,b]	237	97	10	95–98	94–100
PODCI[5] Parent Global Function	<0.000[a,b,c]	240	81	11	79–82	74–90
PODCI[5] Parent Upper Extremity & Physical Function	<0.000[a,b,c]	240	83	15	82–85	75–96
PODCI[5] Parent Transfers & Basic Mobility	<0.000[a,b,c]	240	90	10	89–91	85–97
PODCI[5] Parent Sports & Physical Function	<0.000[a,b,c]	240	68	17	65–70	56–81
PODCI[5] Parent Pain & Comfort	0.200	240	82	20	79–84	67–100
PODCI[5] Parent Happiness	0.450	234	77	18	75–80	65–90
PODCI[5] Parent Satisfaction	0.009[a,b]	240	54	31	50–57	25–75
PODCI[5] Parent Expectations	0.998	240	72	21	69–74	58–89
PedsQL[4] Parent Physical Functioning	<0.000[a,b]	239	64	18	62–66	53–78
PedsQL[4] Parent Emotional Functioning	0.520	239	67	18	64–69	55–80
PedsQL[4] Parent Social Functioning	0.003[a,b]	239	60	20	58–63	50–70
PedsQL[4] Parent School Functioning	0.027[b]	239	65	18	63–68	50–80

*All instrument subscales score 0–100 except for FAQ1 with scores 0–10. [a]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level I and II. [b]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level I and III. [c]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level II and III. FAQ, Gillette Functional Assessment Questionnaire; WeeFIM, Pediatric Functional Independence Measure; PODCI, Pediatric Outcomes Data Collection Instrument; PedsQL, Pediatric Quality of Life Inventory; CI, confidence interval.

Table IIIb: Descriptive data for child outcome tools by Gross Motor Function Classification System (GMFCS)[13] for Levels I to III

Instrument subscale		*GMFCS Level I*				
	p	*n*	*Mean*	*SD*	*95% CI*	*Q1–Q3*
GMFM[3] Dimension D- Standing	<0.000[a,b,c]	239	94	6	94–95	92–97
GMFM[3] Dimension E- Walking, Running, Jumping	<0.000[a,b,c]	239	93	8	92–94	93–97
GMFM-66[3,24] score	<0.000[a,b,c]	239	85	9	84–86	80–90
Energy (O_2) Cost	<0.000[a,b,c]	180	0.28	0.1	0.26–0.29	0.22–0.32
Cadence, % normal	<0.000[a,b,c]	240	106	10	105–107	99–112
Stride length, % normal	<0.000[a,b,c]	240	88	11	86–89	80–96
Velocity, % normal	<0.000[a,b,c]	240	93	15	91–95	84–104
PODCI[5] Child Global Function	<0.000[a,b,c]	117	89	9	87–91	85–96
PODCI[5] Child Upper Extremity & Physical Function	<0.000[a,b]	117	96	6	95–97	92–100
PODCI[5] Child Transfers & Basic Mobility	<0.000[a,b,c]	117	97	5	96–98	97–100
PODCI[5] Child Sports & Physical Function	<0.000[a,b,c]	117	80	15	77–83	69–92
PODCI[5] Child & Pain Comfort	0.100	117	85	19	81–88	75–100
PODCI[5] Child Happiness	0.330	117	84	15	81–87	75–95
PODCI[5] Child Satisfaction	0.061[b]	117	60	32	54–65	50–100
PODCI[5] Child Expectations	0.210	117	67	23	63–72	53–86
PedsQL[4] Child Physical Functioning	<0.000[a,b]	224	74	17	72–76	62–88
PedsQL[4] Child Emotional Functioning	0.740	224	68	19	65–71	55–85
PedsQL[4] Child Social Functioning	0.054[b]	224	68	23	64–71	53–85
PedsQL[4] Child School Functioning	0.068[b]	224	68	18	65–70	55–80

[a]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level I and II. [b]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level I and III. [c]Subscale is related to GMFCS level. Specifically, it is able to differentiate between GMFCS Level II and III. GMFM, Gross Motor Function Measure; GMFM-66, Gross Motor Function Measure score calculated using the Gross Motor Activity Estimator program; PODCI, Pediatric Outcomes Data Collection Instrument; PedsQL, Pediatric Quality of Life Inventory; CI, confidence interval.

FAQ Question 2 and what skills their child was able to perform under typical conditions on FAQ Question 3. Only 27% of parents reported that pain limited their child's walking ability and 39% reported safety as a limiting factor. As severity level increased, a greater percentage reported safety as a problem. Regardless of GMFCS level, the majority of parents felt balance, endurance, and weakness were limiting factors for walking. The parent's perspective is important to help focus goals and clinicians should be sensitive to these concerns when developing treatment plans.

Table IIIa: continued

GMFCS Level II					*GMFCS Level III*				
n	*Mean*	*SD*	*95% CI*	*Q1–Q3*	*n*	*Mean*	*SD*	*95% CI*	*Q1–Q3*
190	8	1	8–9	8–9	119	7	2	7–8	6–8
194	86	17	83–88	79–98	123	78	19	75–82	66–93
194	91	8	90–93	89–97	123	80	15	78–83	71–91
194	93	15	91–95	89–100	123	93	14	90–95	86–100
196	72	12	70–73	65–80	123	62	13	60–64	52–73
196	76	18	73–78	67–92	123	70	19	66–73	54–83
196	82	11	80–84	76–91	123	64	18	61–67	52–79
196	51	17	48–53	39–63	123	35	17	32–38	22–45
196	78	22	75–81	67–100	123	79	21	75–82	67–100
193	75	19	72–78	60–90	121	77	21	73–81	65–95
196	46	33	41–51	25–75	123	44	31	39–50	25–75
196	72	20	69–75	58–89	123	72	20	68–75	53–89
194	51	19	48–54	41–62	124	48	19	45–51	36–61
194	66	17	63–68	55–75	124	68	15	65–71	55–80
194	54	20	51–57	40–70	124	55	18	52–58	45–65
194	62	18	60–65	50–75	124	60	17	57–63	50–70

Table IIIb: continued

GMFCS Level II					*GMFCS Level III*				
n	*Mean*	*SD*	*95% CI*	*Q1–Q3*	*n*	*Mean*	*SD*	*95% CI*	*Q1–Q3*
195	84	8	83–85	79–90	119	52	24	48–57	31–74
195	75	16	73–78	64–89	119	32	20	28–35	17–47
195	72	7	71–73	68–75	119	57	9	55–59	51–63
140	0.38	0.2	0.36–0.41	0.29–0.46	65	0.57	0.3	0.51–60	0.39–69
196	102	14	100–104	94–110	123	83	22	79–-87	69–99
196	79	15	77–81	71–87	123	64	18	60–67	53–73
196	80	19	78–83	71–92	123	54	22	50–58	39–69
80	82	10	80–85	77–90	51	77	9	74–79	70–84
80	92	13	89–94	88–100	51	89	11	86–92	79–96
80	92	8	91–94	88–99	51	84	10	81–86	79–91
80	67	17	64–71	58–79	51	53	17	48–57	42–64
80	78	23	73–83	67–100	51	81	23	75–87	67–100
80	81	20	76–85	70–95	51	83	19	77–88	75–100
80	51	34	44–59	25–75	51	48	33	39–57	25–75
80	73	20	68–77	61–89	51	68	20	62–74	56–83
166	66	18	63–69	53–81	105	62	19	58–65	47–75
166	67	21	63–70	50–80	105	67	20	63–71	50–80
166	62	21	59–65	50–75	105	66	18	62–69	55–80
166	63	19	60–66	50–75	105	66	19	62–70	55–80

PARENT VERSUS CHILD REPORT

Comparison of parent and child perspectives on the PODCI and PedsQL found that children scored themselves higher than their parents for almost all subscales and dimensions. As the child's GMFCS level increased, the differences between parent and child scores increased. This is not the case for able-bodied children who tend to report the same scores as their parents.[27,28] A review of the literature in English did not reveal any study that investigated differences in parent and child perspectives on congenital disabilities. The authors speculate that these findings are probably related to perspectives of disability. The child's perception is one of *ability* as the impairment was not acquired after a period of normal development. Children tend to score themselves at the highest level and emphasize what they *can* do. Parents have the expectation that their child should be able to do everything able-bodied children can do. Therefore, the parent's perspective is more likely one of *disability* and emphasizes what the child *cannot* do.

STUDY LIMITATIONS

To minimize the potential for misclassification of GMFCS

Table IVa: Functional Assessment Questionnaire Question 2, percentage of Yes responses by Gross Motor Function Classification System (GMFCS) level

Instrument subscale	*Overall test[a] (p value)*	*GMFCS level*			*Overall % Yes*
		I (n=238) % Yes	*II (n=190) % Yes*	*III (n=119) % Yes*	
Pain	0.039[d]	26	34	22	27
Weakness	0.017[b,c]	50	62	61	57
Safety concerns	<0.000[b,c]	21	46	50	39
Balance	<0.000[b,c]	67	87	89	81
Mental ability, lack of concentration or awareness	0.012[b]	16	27	22	22
Endurance (tolerance of activity for long periods)	0.150	65	74	71	70

[a]Logistic model was fitted. Wald χ^2 test was used for overall test, and confidence intervals of odds ratios were used for pair-wise comparisons. [b]Item is able to differentiate between GMFCS Level I and II. [c]Item is able to differentiate between GMFCS Level I and III. [d]Item is able to differentiate between GMFCS Level II and III.

Table IVb: Functional Assessment Questionnaire, Question 3, percentage of Yes responses by Gross Motor Function Classification System (GMFCS) level

	Level I (n=239) % Yes	*Level II (n=190) % Yes*	*Level III (n=119) % Yes*	*Overall (n=548) % Yes*
Skills able to differentiate among all GMFCS levels ($p<0.001$)[a]				
Get on and off a bus by him/herself	87	66	36	63
Jumps off on single step	90	69	31	63
Ride two-wheel bike	53	18	5	25
Ride three-wheel bike	83	69	57	70
Ride an escalator, without help	74	50	20	48
Hop on one foot	82	35	22	46
Run	92	82	55	73
Step up and down curb independently	92	75	59	75
Walk up and down stairs without needing railing	55	20	13	29
Skills able to differentiate between GMFCS Levels I and II, and Levels I and III ($p<0.003$)[a]				
Runs well including around a corner with good control	49	22	17	29
Can take steps backwards	89	82	73	81
Can maneuver in tight areas	82	71	67	73
Ice skate or roller skate	26	10	10	15
Skills able to differentiate between GMFCS Levels I and III, and Levels II and III ($p<0.036$)[a]				
Walk carrying an object	93	94	71	86
Walk carrying a fragile object or glass of liquid	80	73	27	60
Walk up and down stairs using railing	93	97	72	87
Step over an object, one foot	95	95	81	90
Kick a ball with one foot	96	94	87	92
Skills unable to differentiate between GMFCS levels ($p>0.05$)[a]				
Jump rope	24	8	0	11

[a]Logistic model was fitted. Wald χ^2 test was used for overall test, and confidence intervals of odds ratios were used for pair-wise comparisons.

levels, all clinicians were trained, focusing on the differentiating criteria for each level. Each clinician directly observed the participant's motor ability. This approach should improve the accuracy compared with that reported by Palisano et al.[13] where clinicians with no training performed classification from recall of the individual's motor ability.

The project manager ensured data quality and consistency across sites. Within a given GMFCS level, if a score was outside four standard deviations of the mean it was determined to be a potential outlier. Inconsistencies were reviewed and corrected on a case-by-case basis via communication with local site coordinators.

Some areas of the ICF were not addressed by the study tools. During study development the National Center for Medical Rehabilitation Research (NCMRR) model was the accepted model for reporting disability. Therefore, the tools selected initially covered the components of Impairment, Functional Limitations, and Disability of the NCMRR model.[29] Tools were selected to have minimal overlap across components and the ability to be completed within a reasonable time frame. Following the introduction of the ICF, the study terminology was changed to conform to those standards.

The study sample is limited by the inclusion of only English-speaking patients and families, minimal diversity in ethnicity, and only patients without significant cognitive delay. Several of the study tools are validated only for English-speaking populations. Although the participants were English speaking and predominantly Caucasian, they represented many geographical regions across the US. The seven participating facilities are in different states and treat patients from surrounding states. The study population was limited to individuals without significant cognitive delay so they could appropriately complete the child versions of the PedsQL and PODCI.

Limitations were minimized by study methodology and are felt to be of minor consequence to the study results and conclusions.

Conclusions

The results of this study demonstrate a direct relationship between GMFCS level and outcome measures of ICF Activities and Participation and Body Functions and Structures. Participants with greater functional impairment scored lower on these tool subscales. The tool subscales that reflect Quality of Life did not show a direct relationship with GMFCS level. Participants of higher severity level do not report a lower Quality of Life than patients with a lower severity level. Outcome scores related to physical function and Quality of Life obtained by child report are not the same as parent report. Children rate themselves higher than their parents and the difference increases with GMFCS level.

The study data illustrate that children with varying levels of severity function differently yet have a similar Quality of Life. Utilizing outcome tools to assess function objectively is important in clinical care to establish treatment efficacy by describing the current functional level of a child and documenting changes over time. The study results provide comparison data for clinicians to use when assessing individual children with CP in GMFCS Levels I to III. By comparing a child's score to typical scores obtained from a large sample of similar children, the clinician can identify areas where the child is excelling and where the child is below average, which provides a direction to focus treatment efforts.

Table V: Difference scores between parent and child reports for Pediatric Outcomes Data Collection Instrument[5] (PODCI) and Pediatric Quality of Life Inventory[4] (PedsQL)

	Difference Child–Parent[a]		
	Mean	*SD*	*p*[b]
PODCI (n=247)			
Global Function	8	10	<0.000
Upper Extremity Function	9	13	<0.000
Transfers & Basic Mobility	7	10	<0.000
Sports & Physical Function	13	15	<0.000
Pain/Comfort	4	21	0.003
Happiness	9	20	<0.000
Satisfaction	5	41	0.072
Expectations	–2	25	0.174
PedsQL (n=495)			
Physical Functioning	12	20	<0.000
Emotional Functioning	1	22	0.410
Social Functioning	8	25	<0.000
School Functioning	2	22	0.021

[a]Difference is mean child report score minus mean parent report score.
[b]Paired *t*-test.

Future work from this study includes analysis of the tools' discriminatory ability,[30] the relationships among tools and their redundancy,[31] and the differences in scoring profiles of patients with hemiplegia and diplegia.[32] Future work from the longitudinal component of this study will provide data on sensitivity to change over time in both non-treatment and treatment groups.

Accepted for publication 11th September 2006.

Acknowledgements

This work was funded by Shriners Hospitals for Children, Clinical Outcomes Study Advisory Board, Grant no. 9140 – 'A Cross-sectional and longitudinal assessment of outcome instruments in patients with ambulatory cerebral palsy'. The authors acknowledge the participation of the Functional Assessment Research Group (Chester Tylkowski MD, Donna Oeffinger PhD, Rebecca Davis BS, Sarah Rogers MPH, Richard Kryscio PhD, George Gorton BS, Janine Calmes MS, PT, Douglas Barnes MD, Richard Haynes MD, Diane Nicholson PhD, PT, Diane Damiano PhD, PT, Mark Abel MD, and Anita Bagley PhD) along with the contributions of the study coordinators at each site. We would also like to acknowledge the patients and their families for their participation.

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List of abbreviations

FAQ	Functional Assessment Questionnaire
GMAE	Gross Motor Activity Estimator
GMFM-66	Gross Motor Function Measure score calculated using the GMAE program
ICF	International Classification of Functioning, Disability and Health
O_2 cost	Energy (oxygen) cost during walking
PedsQL	Pediatric Quality of Life Inventory
PODCI	Pediatric Outcomes Data Collection Instrument
WeeFIM	Pediatric Functional Independence Measure