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Physical activity and walking performance: Influence on quality of life in ambulatory children with cerebral palsy (CP)

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Abstract

PURPOSE: To examine the relationship of physical activity (PA) and walking performance to QOL in ambulatory children with CP, as function is not consistently associated with QOL in this population.

METHODS: A secondary analysis of a cross-sectional cohort of 128 ambulatory children with CP, ages 2.2–9.9 years and GM-FCS levels I–III, was employed. Individual multivariate regression models were developed for physical, psychosocial, and total domains of QOL as measured by the Pediatric Quality of Life Inventory (PedsQL) controlling for physical activity and walking performance, participation level and frequency, topography of CP, walking capacity, age, and satisfaction with participation.

RESULTS: Physical, psychosocial and total QOL averaged 52.2, 60.9, and 56.5 respectively. PA was positively associated with physical (0.64, $p < 0.01$) and total QOL (0.54, $p < 0.01$). Walking performance was associated with physical QOL (0.16, $p = 0.05$), participation level was positively related to psychosocial (0.44, $p < 0.01$), and age negatively for all QOL domains (> -0.43 , $p < 0.01$).

CONCLUSIONS: Physical activity, walking performance, and level of participation in daily life are associated with varying domains of QOL. Future work should explore factors that influence the relationship of daily physical/walking activity and participation to QOL in children with ambulatory CP as they age.

Keywords

Quality of life; cerebral palsy; physical activity; walking activity

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Conflict of interest

There are no conflicts of interest to report.

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1. Introduction

Cerebral palsy (CP) is described as a group of permanent disorders of the development of movement and posture causing activity limitation. CP occurs due to non-progressive disturbances that occurred in the developing fetal or infant brain and can be associated with impairments in other systems [1]. In a recent United States prevalence study of children with CP, the majority of children (76.9%) had spasticity as the primary movement disorder with 22.6% of those children having hemiplegia and 22.4% diplegia and capable of independent ambulation [2]. Parents of children with CP, report lower levels of quality of life (QOL) as compared to other pediatric disability groups [3]. Interventions for children with CP include physical and occupational therapy, oral medications, injections, and surgery all aiming to improve function and QOL.

The World Health Organization (WHO) defines QOL as an individual's perception of his or her position in life in the context of one's culture and value systems and in relation to personal goals, expectations, and concerns [4]. While the WHO definition of QOL is based on an individual's perception, proxy report by parents or caregivers is often necessary in the pediatric care setting due to a child's young age and/or limited ability to self-report. Varni and colleagues developed the Pediatric Quality of Life Inventory (PedsQL) 4.0 as a generic instrument to measure health-related QOL (HRQOL) in children with or without health issues using core scales of physical functioning, emotional functioning, social functioning, and school functioning with the proxy report parallel to the self-report version [3]. Some authors distinguish HRQOL from QOL with HRQOL a subdomain of the more global construct of QOL focusing on the impact of a disease or illness on QOL [5]. However, McDougall proposed that this creates an artificial distinction between health, function, and other factors that influence QOL, detracting from the subjective nature of QOL [6]. QOL in the present study is thus referenced with inclusion of all its domains.

The International Classification of Functioning, Disability and Health (ICF) provides a framework for discussing health and disability through the interaction of body functions and structures, activity, participation, and personal and environmental factors but does not include QOL [7]. In 2010, McDougall and colleagues proposed a modification of the ICF to incorporate human development across time and QOL [6]. A new graphical representation of the ICF was presented in the IFC-Conceptual Revision in 2013 with QOL representing the largest and most complex component of the model, influenced by components of functioning (body function and structures, activities, and participation), health, and personal and environmental factors [8]. Based on the ICF 2013 revision, we propose a model for this study with a focus on the influence of activity *capacity* (capability of a task in a clinical setting) versus *performance* (completion of a task in real life), as well as body function and structures, personal factors, and participation, on parental report of QOL in ambulatory children with CP (Fig. 1).

The relationship of activity capacity [9], function [10,11], and participation [12,13] (as captured by survey/questionnaires) to QOL has been reported in the literature. Yet to date, there is no published data specifically examining daily walking performance as measured by accelerometry to QOL. We hypothesize that physical activity and walking performance

(what a child does in real life) will have a positive relationship to all aspects of quality of life (physical, psychosocial and total QOL). Thus, we examined the relationship of physical activity and walking performance to parental report of QOL in ambulatory children with CP.

2. Methods

This study was a secondary data analysis of a cross-sectional cohort of ambulatory children with CP with approach, recruitment, and final enrollment previously published [14]. After receiving institutional review board approval and informed consent and assent, measures of walking and physical activity capacity, performance, and parental report of physical activity participation frequency and intensity, and QOL were collected. Data collection was completed by the third author during a single study visit conducted either in child's home or in the clinical research center. Participant and family characteristics were collected via interview of the parent (or child as able) and direct assessment or observation by the third author during the study visit.

2.1. Quality of life

QOL was sampled via the proxy report version of the PedsQL with the core scales combined to give physical, psychosocial, and total QOL scores. The PedsQL 4.0 is a reliable and valid tool designed to measure physical, mental, and social health dimensions of HRQOL for children and adolescents ages 2 to 18 years. Developed through focus groups and interviews, it integrates generic core scales and disease-specific modules into one measurement system and takes only 5 minutes to complete by self report or parent-proxy report [15]. The 23-item PedsQL 4.0 Generic Core Scales consist of Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items). These scales combine to give a physical health summary score, psychosocial health summary scale, and a total score with a maximum score of 92.

2.2. Physical activity

Physical activity (PA) performance in daily life was sampled via parental report of the Activities Scale for Kids (performance version, ASKp-30) total score. A self- and parent-report questionnaire of childhood physical activity performance, the ASKp-30 was developed and validated for youth ages 5–15 years [16]. The performance version (ASKp-30) specifically queries what a child “usually does” within the context of his or her unique daily life (experiences and environment) and is referenced to the past 7 days. Parents completed the ASKp-30 at the end of a 7-day sampling of walking activity with the ankle worn accelerometer.

2.3. Walking performance

The StepWatch, a two-dimensional accelerometer, captured walking performance in daily life [17]. The previously published methods for the StepWatch individualized calibration, donning methods and data processing were employed; children wore the StepWatch 7 days for all waking hours with data from 4 week days and 1 weekend day analyzed [18]. Raw StepWatch data were processed for the walking performance outcomes of average total strides/day, percent time walking each day, and intensity of strides based on normative

pediatric data of low (1–30 strides/min), medium (31–60 stride/min), and high (> 60 strides/min) [18,19]. Walking activity greater than 30 strides/min has documented association to mobility-based participation in children with CP [20]. Strides/day greater than 30 strides/min had the largest preliminary univariate relationship to the PedsQL domains (versus average strides/day or percent time walking) for this dataset and thus was chosen to document walking performance for this project.

2.4. Participation frequency

Frequency of participation in everyday life was documented via the Children's Assessment of Participation and Enjoyment (CAPE) or Assessment of Preschool Children's Participation (APCP) as appropriate by age [21–23]. The CAPE is a 55-item questionnaire developed to examine how children (ages 6–12 years) participate in everyday activities outside the school setting [21]. The preschool version of the CAPE for children less than 6 years of age is the Assessment of Preschool Children's Participation (APCP). The CAPE captures daily participation through five dimensions via diversity (number of activities done), intensity (frequency of participation measured as a function of the number of possible activities within a category), and enjoyment of activities [23,24]. The third author administered the CAPE via interview format to the child (if able) and parent at the same time. Parents completed the APCP for participants less than 6 years of age.

2.5. Participation level and satisfaction with participation

The Life-H for children (Life-H) was developed from the Disability Creation Process model, which proposes that the accomplishment of life habits is an interaction of individual identities, choices, impairment of body organs, abilities, disabilities, as well as the characteristics of the environment in which we live. Validated and designed to capture the social participation of children with disabilities, the Life-H for Children has parental report versions for youth ages 0–4 years and 5–13 years completed by the parent [25]. The individual Life-H items are scored relative to level of accomplishment and type of assistance with a weighted single score from 0–9 with 0 corresponding to inability to perform an activity and 9 the ability to perform without difficulty and without assistance. Satisfaction with participation in daily life was captured through the average of the LIFE-H total satisfaction score.

2.6. Topography and walking capacity

Topography was classified as either unilateral or bilateral and walking capacity was captured with Gross Motor Function Measure-66-Item Set (GMFM-66-IS). To decrease the burden of testing, the GMFM-66-IS was developed to allow valid measurement of the GMFM-66 score from a subset of items. Three decision items were employed to determine which of the four-item sets to administer with the GMFM-66 score then calculated using the Gross Motor Ability Estimator software [26].

2.7. Baseline sample characteristics

A total of 128 ambulatory children with CP ages 2.2 to 9.9 years participated, with 35% representing Gross Motor Function Classification System (GMFCS) level I 35%, 42% level

II, and 23% level III (Table 1). Consistent with the epidemiology of CP, the study sample demonstrated spasticity as the primary movement disorder, over half of the sample was female, and 50% had unilateral distribution of motor impairment. Forty-five percent of participants functioned at a level II on the Manual Abilities Classification System, a classification on the daily use of both hands together [27]. Over half of the sample functioned at level I on the Communication Function Classification System (CFCS), a measure of functional communication in children with CP [27]. The study population was primarily Caucasian with approximately a third of the parents having attended vocational school/some college and 73% reporting home ownership.

3. Analysis

Key characteristics of the study sample and the parental report of QOL for each PedsQL domain (physical, psychosocial and total) were described via frequencies and percentages. The PedsQL total, physical and psychosocial QOL scores by motor function levels (GMFCS) were examined via Kruskal-Wallis and Mann-Whitney U tests. A unique multiple linear regression model was developed for each dependent variable (physical, psychosocial and total QOL domains of the PedsQL). Given the small sample size of this secondary cohort analysis and in order to avoid overfitting the models, we limited the number of independent variables (predictors) in the model such that we had an effective sample size of at least 10 for each regression coefficient [28]. The independent variables (predictors) included in the initial models were chosen based on size preliminary univariate regression to the dependent variables of the study cohort and expression of components of the ICF framework. We intentionally included predictors relative to the ICF framework measures of *personal factors* (age, satisfaction with participation), *body/function/structure* (topography), *activity capacity* (walking capacity), and *participation* (level and frequency). All initial models included the independent variables (predictors) of physical activity performance (ASKp), walking activity performance (StepWatch data), functional level (GMFCS), Communication Function Classification System (CFCS), topography of motor impairment (bilateral or unilateral), one-minute walk test, Gross Motor Function Measure (GMFM-66 – walk/run/jump), ASKp total scores, CAPE diversity, frequency and intensity scores, and Life-H (10 subscales and total score). Independent variables (predictors) were retained in each of the three final models (PedsQL total, physical and psychosocial QOL) based on level of relationship (strongest univariate relationship > 0.50). Walking capacity was only included for the PedsQL physical health domain model, as it was not found to have a strong univariate relationship to psychosocial and total QOL domains. All analyses were conducted using SPSS version 19.0 [29].

4. Results

Parents reported an average PedsQL physical QOL score of 52.15, psychosocial QOL of 60.94, and total QOL of 56.55 out of a maximum total score of 92. PedsQL scores were significantly different by GMFCS levels ($p < 0.01$) for all domains, with level I significantly higher for all domains than level II and III ($p < 0.05$) (Table 2).

Physical activity performance (ASKp-30 total score) showed a moderately strong positive association and walking performance (average number of stride/day greater than 30 strides/min) a weak positive association with parental report of PedsQL physical health (0.64, $p < 0.01$; 0.16, $p = 0.05$ respectively) with 56% of the variance explained by the model (Table 3). Physical activity performance was moderately associated with total QOL (0.54, $p < 0.01$); however, neither physical activity nor walking performance was associated with parental report of psychosocial QOL (0.25, $p = 0.11$; 0.07, $p = 0.44$ respectively). Both psychosocial and total QOL had a weak negative association with participation frequency (CAPE total activity frequency) (-0.24 , $p < 0.01$; -0.20 , $p < 0.01$) with psychosocial QOL (0.44, $p < 0.01$) having a moderately positive association with participation level (LIFE-H total weighted score). Neither participation level (-0.02 , $p = 0.84$) nor frequency (-0.09 , $p = 0.06$) had a significant association with physical QOL. None of the QOL domains were associated with satisfaction with participation in daily life (LIFE-H total satisfaction score) or topography of CP. Walking capacity was not associated with physical QOL, while age had a moderately weak negative association with all three domains (physical -0.46 , $p < 0.01$; psychosocial -0.43 , $p < 0.01$; total -0.46 , $p < 0.01$).

5. Discussion

We documented that parents of ambulatory children with CP report low physical, psychosocial and total QOL scores as compared to those same PedsQL scores for typically developing children obtained by Varni and colleagues in 2007 [3]. Our results confirmed our hypothesis that physical activity is associated with physical and total QOL, but not psychosocial. Our hypothesis relative to daily walking intensity was only confirmed for physical QOL. Participation level alone had a moderate positive association with psychosocial QOL. This study confirms that children with CP and their parents report low QOL scores. Our work suggests the need for further research to elucidate the potentially modifiable factors of physical activity and walking performance to improve QOL for this population.

Our data is consistent with the 2007 work of Varni and colleagues, comparing QOL using the PedsQL across pediatric disability groups. In that study, both children with CP and their proxies reported the lowest scores overall (66.85 and 51.28 respectively) compared to children with other pediatric disorders [3]. That disparity and the low values in our study suggest that there is room for improvement in treatment and management of CP to improve QOL. While another study using a different QOL measure does not show a similar disparity between children with CP and the general population [30], this may reflect the differences in the QOL measures used.

Physical activity performance showed a strong association and walking performance showed a weak positive association with physical QOL within our study, but neither outcome measure demonstrated a significant relationship with psychosocial QOL. This mirrors the findings of outcomes after multi-level surgery in children with CP, in which both children and parents noted improvement in total and physical QOL but no significant difference in psychosocial well-being despite improvements in walking measures [31]. These results suggest that physical function may not be directly correlated with psychosocial QOL.

Participation level as measured by Life-H demonstrated a moderately positive relationship with psychosocial QOL in our study, while participation frequency was found to have a small negative association with physical, psychosocial, and total QOL. Given that a higher participation level score on the Life-H indicates less assistance needed to perform a social role or activity, these results may imply the importance of participation independence for a child or adolescence with CP. Similarly, Dahan-Oliel et al. highlighted the negative impact on QOL when children with neurodevelopmental disabilities are limited in their leisure participation secondary to their disability or environmental barriers [32]. Further research is needed to explore the potential comorbidities and external factors that contribute to the social and emotional well-being of children with CP.

Age was documented to have a moderate negative association with physical, psychosocial and total QOL. Topography of CP and capacity measures were not associated with QOL. Findlay and colleagues reported that both age and pain negatively predicted HRQOL in children with CP regardless of sex or GMFCS level [33]. Pain has been documented to be related to lower QOL in children with CP across all GMFCS levels [30,33]. While pain was not specifically examined in our study, age as a negative predictor of QOL suggests that it is a potential dynamic influence on QOL in the course of development for children. The differences between children with CP and their typically developing counterparts may be highlighted with increasing age, which may have a greater influence on QOL than the children's motor limitations alone.

5.1. Study limitations

The results of this work should be interpreted in context of known limitations. First, secondary data analysis and sample size limited the variety of potential covariates that could be examined. There was not a unique pain variable available for examination in the models developed. Similarly, no environmental variables related to socioeconomic or physical environment were available. The age range of the available dataset also mandated that QOL was captured via proxy report, and differences between self- and proxy-report are well documented.

6. Conclusion

QOL in ambulatory children with CP appears lower than typically-developing children and children with other disabling conditions as measured by parental reports of the PedsQL, consistent with previous work. Physical activity performance had a positive association with physical and total QOL; however, walking performance had a low association only with physical QOL. Participation in habits of daily life had a moderate positive association with psychosocial QOL. Notably, age had a negative association for all domains of parental report of QOL. Replication of this work with a larger sample is needed with self and proxy report, as well as examination of these relationships as a child matures through middle school and into adulthood. Future work should explore factors that influence the relationship of daily physical/walking activity to QOL in children with ambulatory CP as they age.

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List of abbreviations

APCP	Assessment of Preschool Children's Participation
ASKp-30	Activity Scale for Kids-Performance
CAPE	Children's Assessment of Participation and Enjoyment
CP	Cerebral Palsy
GMFM	Gross Motor Function Measure
ICF	International Classification of Functioning, Disability and Health
LIFE-H	Assessment of Life Habits
QOL	Quality of Life
PedsQL	Pediatric Quality of Life Inventory

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Fig. 1.

Model of influences of activity capacity, activity performance, body function and structures, personal factors, and participation on parental report of QOL in ambulatory children with CP.

Table 1Combined sample characteristics [mean (SD) or frequency (%), ($n = 128$)]

Age mean (SD) [range]	6.2 (2.3) [2.2–9.9]
Age Group: n (%)	
2–3 years	24 (19)
4–5 years	34 (27)
6–7 years	39 (30)
8–9 years	31 (24)
Gender (% female)	52 (41)
Gross Motor Function Classification System (GMFCS) n (%)	
Level I	44 (35)
Level II	54 (42)
Level III	30 (23)
Topography of CP, n (%)	
Bilateral	64 (50)
Unilateral	64 (50)
Primary movement disorder, n (%)	
Spasticity	91 (72)
Dystonia	8(6)
Mixed	13 (10)
Ataxia	3 (2)
Hypotonia/low tone	12 (10)
Manual Abilities Classification System (MACS), n (%)	
Level I	46 (36)
Level II	58 (45)
Level III	24 (19)
Communication Function Classification System (CFCFS) n (%)	
Level I	73 (57)
Level II	25 (20)
Level III	18 (14)
Level IV	12(9)
Race, n (%)	
Caucasian	105 (82)
Hispanic	19 (15)
Black	5 (4)
Asian/Pacific Islander	10(8)
Native American	2 (2)
Mixed	3 (2)
Other	3 (2)
Parental characteristics, n (%)	
Maternal % vocational school/some college	39 (31)
Home ownership	94 (73)

Pediatric quality of life (PedsQL) scores for all participants ($n = 128$) and by gross motor function classification levels (GMFCS)

Table 2

	PedsQL physical QOL mean (SD) ^{##}	PedsQL psychosocial QOL mean (SD) ^{##}	PedsQL total QOL mean (SD) ^{###}
Full sample ($n = 128$) GMFCS 1–3	52.15 (21.36)	60.94 (14.72)	56.55 (16.44)
GMFCS-Level I ($n = 44$)	65.17 (19.28)	67.44 (14.88)	66.30 (15.92)
GMFCS-Level II ($n = 54$)	50.91 (18.37)	56.61 (14.25)	53.76 (15.16)
GMFCS-Level III ($n = 30$)	35.31 (16.62)	59.21 (12.11)	47.26(11.79)

Kruskal-Wallis Test

* $p < 0.01$

** $p < 0.05$ between GMFCS levels I, II, and III. Mann-Whitney U

$p < 0.01$

$p < 0.01–0.05$ between GMFCS levels I, II, and III

Table 3

Multivariable linear regression analysis of the relationship of physical activity and walking performance to parental report of physical, psychosocial and total QOL measured by the PedsQL controlling for age, participation frequency, participation levels, satisfaction with participation in daily life, topography of CP and walking capacity ($n = 128$)

	PedsQL physical domain		PedsQL psychosocial domain		PedsQL total	
	β (CI)	P values	β (CI)	P values	β (CI)	P values
Predictors						
Physical activity performance (ASKp-30 total score)	0.64 (0.32–0.78)	< 0.01	0.25 (–0.03–0.33)	0.11	0.54 (0.18–0.54)	< 0.01
Walking performance (average number of strides faster than 30 strides per minute)	0.16 (< 0.01–< 0.001)	0.05	0.07 (< 0.01–< 0.001)	0.44	0.15 (< 0.01–< 0.001)	0.06
Participation frequency (CAPE total activity frequency)	–0.09 (–0.18–< 0.01)	0.06	–0.24 (–0.17–0.03)	0.01	–0.20 (–0.16–0.02)	0.01
Participation level (LIFE-H total weighted score)	–0.02 (–2.24–1.82)	0.84	0.44 (1.28–4.70)	< 0.01	0.18 (–0.23–2.99)	0.09
Satisfaction with participation in daily life (LIFE-H total satisfaction score)	–0.02 (–4.35–2.93)	0.70	–0.03 (–3.56–2.41)	0.70	–0.03 (–0.03–0.48)	0.63
Topography of CP (bilateral or unilateral)	0.13 (–1.08–11.92)	0.10	–0.05 (–6.95–3.77)	0.56	0.07 (–2.80–7.40)	0.37
Walking capacity (GMFIM dimension E)	0.08 (–0.26–0.57)	0.46	–	–	–	–
Age	–0.46 (–6.12–2.62)	< 0.01	–0.43 (–4.19–1.46)	< 0.01	–0.46 (–4.82–2.16)	< 0.01
Partial correlation (R2)	0.56		0.38		0.522	

Partial Correlation R2 = variance explained by the full model. Bold values indicate statistically significant findings.