College of Nursing and Health Professions

Review

Quality of life among adolescents with cerebral palsy: what does the literature tell us?

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This review describes trends in quality of life (QOL) and health-related quality of life (HRQOL) among adolescents with cerebral palsy (CP). Twenty original articles were identified by a structured search of multiple databases and grouped by design. Categories included descriptive cross-sectional studies (n=8), measurement validation studies (n=9), and exploratory qualitative studies (n=3). Several trends were apparent. First, individuals with CP are reported to have decreased QOL and HRQOL compared with a normative population in some but not all areas of well-being. Second, functional status measures such as the Gross Motor Function Classification System are reliable indicators of variations in physical function, but do not correlate consistently with psychosocial well-being. Third, although adolescents with CP have different life issues than adults or children, limited research on factors associated with QOL and HRQOL has been described for this age range. We recommend that clinicians and researchers interested in assessing well-being among adolescents with CP include participants from across the spectrum of motor impairment, allow adolescents to self-report whenever possible, and assess adolescents independently, rather than including them with individuals from other age groups or clinical populations.

See end of paper for list of abbreviations.

Cerebral palsy (CP) is a clinical description of a chronic functional disability. The definition has recently been revised 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. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.'[1] This definition follows concepts introduced by the World Health Organization's International Classification of Functioning, Disability and Health.[2]

Changes in our conception of CP reflect an expansion beyond the functional limitations associated with motor impairment towards a recognition of the personal experience of individuals in this population. Under the broad notion of 'well-being', researchers have begun to consider functional status, health status, quality of life (QOL), and health-related quality of life (HRQOL). 'Functional status' can be conceptualized as 'the degree to which an individual is able to perform socially allocated roles free of physical or mental limitations',[3] and focuses on the performance of specific tasks, such as 'activities of daily living'.[4] 'Health status' considers broader medical and functional well-being, and is sometimes reported in terms of 'impact of disability'.[5] Assessments of QOL and HRQOL shift the description of well-being into the realm of the subjective, because these outcomes are not directly observable by a third party and cannot be measured along a physical dimension.[6] Although the areas of health considered in measurements of QOL and HRQOL can be either objective or subjective, such as the ability to walk or the severity of bodily pain, the ratings for these dimensions are completed on a personal basis, and are, therefore, subjective reports.

Despite ongoing discussions of health measurement, researchers have yet to decide upon a universal definition of QOL and HRQOL.[7] What has become clear, however, is that QOL refers to the notion of holistic well-being,[8] whereas HRQOL focuses on the health-related components of life satisfaction,[9] such as self-care, mobility, and communication. Assessments of QOL and HRQOL thus reflect personal valuations of daily experience, and resonate with other subjective outcomes, such as 'life satisfaction',[10] 'sense of coherence',[11] and 'the self-concept'.[12] Some researchers have used the terms functional status, health status, and QOL interchangeably in the past,[9] but recent consideration suggests that these outcomes are fundamentally different.[13,14]

The measurement of QOL and HRQOL among individuals with CP poses significant methodological challenges. Specifically, these include the presence of communicative barriers, shortage of validated instruments, and the wide range of impairment associated with this population.[15] As a result, few researchers have attempted to assess subjective outcomes across the spectrum and little is known about broader trends in well-being. These uncertainties are confounded by the fact that many studies that attempt to capture QOL or HRQOL ultimately describe functional or health status, but fail to capture personal perspectives.[16] A recent review of paediatric QOL instruments voiced similar concern, noting that there is a lack of empirical evidence to support even the most fundamental assumptions about QOL and HRQOL.[14]

Adolescence has been recognized as an important time of transition, especially for individuals with CP, because many are thought to experience a decline in physical function during adolescence and early adulthood.[17,18] Secondary musculoskeletal impairments may be exacerbated by the fact that health service provision and contact with the health-care system become fragmented after adolescents leave school.[19,20] What implications do these changes have for clinicians, researchers, parents, and the adolescents themselves, and how do they affect QOL? To answer these questions, it is important first to consider what is already known about QOL and HRQOL among adolescents with CP. The purpose of this review was to search the recent literature and describe relevant themes. Emphasis was placed on identifying studies that used a population-based approach, reported issues specific to adolescents with CP, and described subjective well-being rather than solely objective outcomes.

Method

The review of the literature considered all studies that attempted to assess QOL or HRQOL in individuals with CP. Preference was given to studies that focused on issues related to adolescence, but the paucity of such research led to the inclusion of reports of other age bands as well. (Only three studies were found that focused exclusively on QOL or HRQOL among adolescents with CP.) Articles that assessed individuals with CP as part of a larger sample of persons with chronic disabilities were included for the same reason. The search was performed by the primary author (MHL), and included all literature found in Medline, CINAHL, and PsycINFO that matched the terms 'cerebral palsy' and 'quality of life'. 'Health-related quality of life' was captured as a subset of 'quality of life'. Relevant studies cited on the reference lists of articles returned in this initial search were also included, resulting in a combined total of 287 original studies.

Two of the authors (MHL, PLR) reviewed all abstracts of papers published between 1995 and April 2006 with the intention of describing the current literature for issues related to QOL, CP, and adolescence. Studies that focused exclusively on specific aspects of well-being, such as pain,[21–23] fatigue,[24] feeding dysfunction,[25] nutrition,[26] participation,[27] or function,[28,29] were excluded because they did not assess overall QOL or HRQOL. Articles that described activities of daily living, or the impact of disability[5] were also excluded because, as discussed previously, these constructs are fundamentally different from QOL and HRQOL.[14] Studies that fit the inclusion criteria (i.e. articles that reported QOL or HRQOL among children, adolescents, or adults with CP) were discussed by the first two authors (MHL, PLR) and summarized in terms of design, participant characteristics, measures of well-being, settings, and findings. In situations where evidence to include or exclude a study was unclear, the primary author (MHL) read and summarized the article, discussed the summary with the second author (PLR), and a decision about inclusion was mutually reached.

Results

Twenty original articles were included in the final review and classified as cross-sectional descriptive studies (n=8),

Table I: Descriptive cross-sectional studies of quality of life and health-related quality of life among individuals with cerebral palsy (CP)

Study	*Setting*	*Sample size, n*		*Sex, n*		*Age, y:m*		*Measures of well-being*
		CP	*Total pop.*	*Male*	*Female*	*Mean*	*SD*	
Pirpiris et al.[36]	Tertiary centre	90	90	51	39	10:2	3:2	PedsQL, PODCI
Vargus-Adams[54]	Tertiary centre	177	177	98	79	8:7	4:2	CHQ
Tuzun et al.[56]	Tertiary centre	45	109	26	19	7:5	2:4	CHQ
Wake et al.[52]	Tertiary centre	80	80	45	35	11:4	3:6	CHQ
Hodgkinson et al.[37]	Tertiary centre	54	54	34	20	9	N/A	AUQUEI
Kennes et al.[51]	Provincial sample	408	408	221	187	8:5	1:11	HUI-3
Magill-Evans et al.[10]	Tertiary centre	90	165	48	42	range 13–15 and 19–23		LSS
Liptak et al.[38]	International multicentre	235	235	137	98	9:7	4:7	CHQ

Total pop., total population; AUQUEI, Autoquestionnaire de qualité de vie enfant imagé (Pictured Child's Quality of Life Self Questionnaire); CHQ, Child Health Questionnaire; HUI-3; Health Utilities Index – Mark 3; LSS, Life Situation Survey; N/A, not available; PedsQL, Pediatric Quality of Life Instrument; PODCI; Pediatric Outcomes Data Collection Instrument.

measurement validation studies (n=9), or exploratory qualitative studies (n=3). Descriptive cross-sectional studies used pre-existing, validated instruments to describe trends in well-being within a sample of individuals with CP (Table I). Measurement validation studies focused primarily on psychometric issues rather than the QOL or HRQOL of the participants (Table II). Exploratory qualitative studies used qualitative techniques to characterize various aspects of life experience (Table III).

PARTICIPANT CHARACTERISTICS

Fifteen studies focused exclusively on individuals with CP, while five others included such participants as part of a larger sample of persons with chronic disabilities.[8,32–35] Two of these five studies described the CP group separately,[34,35] while the other three did not.[8,32,33] Three of the twenty articles reported specifically on experiences associated with adolescence,[10,40,56] which was defined for the current study as the period of development between 13 and 18 years of age. Twelve studies described adolescents in conjunction with children or young adults, but none of these discussed variation in well-being for adolescents separately.

Eight studies used inclusion and exclusion criteria other than age, which limited the generalizability of their findings.[8,32,33,36–40] Two studies included only individuals who were able to walk,[36,37] whereas another focused exclusively on children and adolescents with moderate to severe limitations of mobility.[38] Another assessed children, adolescents, and young adults undergoing spasticity management.[39] Five of these eight studies included individuals who were able to communicate and discuss their personal experiences, but excluded those who could not.[8,32,33,37,40]

In 12 studies, limitations in communication were addressed by having all parents and caregivers complete the measure as a proxy-report, even when the person with CP was able to self-report. Only three studies used a differential approach, whereby individuals who could communicate completed the measures independently, whereas those who could not were assessed by a proxy.[10,16,41]

MEASURES OF WELL-BEING

A 'measure of well-being' was defined as any instrument that was administered with the intention of assessing QOL or HRQOL. Quantitative instruments consisted of generic measures of health status, such as the Child Health Questionnaire (CHQ),[42] the Pediatric Outcomes Data Collection Instrument

Table II: Measurement validation studies of quality of life and health-related quality of life among individuals with cerebral palsy (CP)

Study	*Setting*	*Sample size, n*		*Sex, n*		*Age, y:m*		*Measures of well-being*
		CP	*Total pop.*	*Male*	*Female*	*Mean*	*SD*	
McCoy et al.[39]	Tertiary centre	47	47	29	18	10	4:10	CCHQ
Varni et al.[41]	Tertiary centre	148	148	84	79	10	3:5	PedsQL
Vitale et al.[55]	Tertiary centre	180	180	'slightly more males than females'		10:8	N/A	CHQ, PODCI
Petersen et al.[32]	International multicentre	21	360	189	171	12:6	2:7	DISABKIDS
Baars et al.[33]	International multicentre	43	1152	52%	48%	12:2	2:9	DISABKIDS
McCarthy et al.[57]	Tertiary centre	115	115	58%	42%	5:6	1:6	CHQ, PODCI
Schneider et al.[50]	Tertiary centre	30	30	13	17	8:6	N/A	CHQ, CQ
Vitale et al.[34]	Tertiary centre	23	242	45%	55%	12	N/A	CHQ, PODCI
Vitale et al.[35]	Tertiary centre	N/A	196	41%	59%	14:7	N/A	SF-36, EuroQol

Total pop., total population; CCHQ, Care and Comfort Hypertonicity Questionnaire; CHQ, Child Health Questionnaire; CQ, Caregiver Questionnaire; DISABKIDS, DISABKIDS Chronic Generic Measure and Condition-specific Modules; EuroQol, European Quality of Life Questionnaire; N/A, not available; PedsQL, Pediatric Quality of Life Inventory; PODCI, Pediatric Outcomes Data Collection Instrument; SF-36, Medical Outcomes Study Short Form 36.

Table III: Exploratory qualitative studies of quality of life and health-related quality of life among individuals with cerebral palsy (CP)

Study	*Setting*	*Sample size, n*		*Sex, n*		*Age, y*		*Method*
		CP	*Total pop.*	*Male*	*Female*	*Mean*	*SD*	
Waters et al.[16]	CP registry	28	28	N/A	N/A	range 4–12		Focus groups (grounded theory)
King et al.[40]	Tertiary centre	10	10	3	7	19	N/A	Semi-structured interviews (grounded theory)
Albrecht and Devlieger[8]	Informal social groups	N/A	153	N/A	N/A	53 (median)	N/A	Semi-structured interviews (grounded theory)

Total pop., total population; N/A, not available.

(PODCI),[43] and the Health Utilities Index – Mark 3 (HUI-3).[44] Questionnaires designed to capture QOL and HRQOL in children included the Pictured Child's Quality of Life Self Questionnaire, formally entitled the Autoquestionnaire de qualité de vie enfant imagé (AUQUEI),[45] and the Pediatric Quality of Life Inventory (PedsQL).[46] Studies that focused specifically on adolescents used instruments designed to measure QOL or HRQOL in adults, such as the Life Situation Survey (LSS),[47] the Medical Outcomes Study Short Form 36 (SF-36),[48] and the European Quality of Life Questionnaire (EuroQol).[49]

Four measurement validation studies described condition-specific measures of QOL or HRQOL for children and adolescents with CP. These included the Care and Comfort Hypertonicity Questionnaire (CCHQ),[39] the DISABKIDS Chronic Generic Measure and Condition-specific Modules,[32,33] and the Caregiver Questionnaire (CQ).[50] One qualitative study described the development of a disease-specific measure of QOL for children with CP.[16] All qualitative studies relied on grounded theory and used either semi-structured interviews[8,40] or focus groups[16] to describe well-being.

SETTINGS

The 'setting' was defined as the location from which participants were recruited. As in other clinical and health services research, we believe this issue to be important because the sampling method (i.e. the means of identifying participants and whence they have been recruited) usually influences who is seen and what inferences one can draw from the data. Ultimately we assume people are interested in the extent to which a particular sample represents the real-world population.

Fourteen studies used a convenience sample and recruited participants from tertiary centres, including rehabilitation, spasticity, and orthopaedic clinics. Three studies reported on an international multicentre sample[32,33,38] and two relied on a population-based approach.[16,51] One of the qualitative studies assessed individuals in the community, recruiting participants from informal social networks rather than from institutions or registries.[8]

WELL-BEING COMPARED WITH A NORMATIVE POPULATION

Seven studies contrasted perceptions of well-being among individuals with CP compared with those in the general population.[36,38,41,52,54–56] All of these reported decreased health status among CP groups in some aspect of well-being. Liptak et al.[38] used the CHQ to compare the health status of 235 children and adolescents with moderate to severe CP to that of a normative American population.[42] Well-being was lowest among those who used a feeding tube and experienced the most severe impairments of mobility. Wake et al. also used the CHQ to assess well-being, but included participants from across the gross motor spectrum.[52] In contrast to American[42] and Australian[53] norms, individuals with CP had significantly lower indices in every aspect of health described by the CHQ. In another study of 177 American children and adolescents with CP, well-being was lower in all CHQ domains except behaviour.[54] Similar findings were reported by Vitale et al. with the CHQ and PODCI.[55] An assessment of 45 children and adolescents with CP in Turkey revealed significantly lower scores compared with those of a normative sample of 64 'healthy' children in all CHQ domains except mental health and bodily pain.[56]

Varni et al. used the PedsQL to demonstrate that children and adolescents with CP experience HRQOL that is lower than normative values and approximately the same as that of children diagnosed with cancer undergoing treatment.[41] This was one of three studies[10,16,41] that used a differential approach to assess well-being, whereby children and adolescents who could communicate self-reported, whereas those who could not were assessed by proxy-report. Pirpiris et al. also reported decreased PedsQL-assessed HRQOL compared with a normative population.[36]

DISCORDANCE BETWEEN FUNCTION AND WELL-BEING

Eight studies described the relation between well-being and functional status among individuals with CP.[8,36,37,50,51,54,56,57] In a sample of 30 children and adolescents with CP, Schneider et al. concluded that QOL issues are not directly associated with functional status.[50] McCarthy et al. reported a similar discrepancy in an assessment of 115 younger children with CP.[57] Discordance between function and well-being was also found in a sample of 90 children and adolescents with spastic diplegia who were able to walk.[36] Correlations between function (Gillette Functional Assessment Questionnaire, Gross Motor Function Measure, Gross Motor Function Classification System [GMFCS],[58] and walking speed) and well-being (PedsQL and PODCI) were highly variable (ranging in magnitude from 0.16–0.66 for functional well-being, and 0.06–0.48 for psychosocial well-being), and led the authors to conclude that functional status was associated with physical, but not necessarily psychosocial, well-being.[36]

The relation between HRQOL and GMFCS was also investigated by Vargus-Adams,[54] who reported significant associations between gross motor function and physical functioning, overall physical health, general health, physical role functioning, impact on parents' time, and behaviour. The strongest correlation with gross motor function was in the area of physical functioning (r=–0.51), which led the author to conclude that HRQOL decreased significantly with increasing severity of motor impairment due to CP.[54] Psychosocial well-being, however, did not vary by GMFCS level.[54] In a similar study, Tuzun et al. controlled for associated medical problems and still found correlations between GMFCS level and CHQ-measured physical functioning (r=–0.69), physical role functioning (r=–0.33), and social role functioning (r=–0.35). Significant correlations were also found in the domains of general health, self-esteem, mental health, and behaviour (coefficients not reported).[56] Contrary to Pirpiris et al.,[36] Tuzun et al. concluded that gross motor function is associated not only with physical well-being, but also with psychological well-being.[56]

Associations between well-being and motor function were reported in a population-based sample of 408 children with CP using the HUI-3 and GMFCS.[51] Level of motor impairment was significantly but variably associated with ambulation, dexterity, speech, vision, hearing, and cognition, but not with emotion or pain. The authors concluded that, although gross motor function may be a reliable predictor of some aspects of functional capacity, it is not a valid indicator of well-being in all domains.[51]

In their qualitative analysis of 153 adults with chronic conditions, including CP, Albrecht and Devlieger found that over half (54.3%) of the participants with moderate to severe disabilities, limited income and benefits, limitations with activities of daily living, and social isolation issues, self-reported a high QOL.[8] Achieving this 'good' state of well-being was associated with a sense of balance between body, mind, and

spirit, whereas 'poor' well-being was linked to the presence of chronic conditions such as pain, fatigue, and communicative barriers. The authors claimed that such findings provide further evidence of the 'disability paradox,' which questions why so many people with significant disabilities report good or even excellent QOL when, to most external observers, these individuals seem to live an undesirable existence.[8] An equally curious paradox was observed among 54 children with CP who were able to walk, because higher motor function was associated with lower life satisfaction.[37]

WELL-BEING AMONG ADOLESCENTS WITH CP

Few QOL or HRQOL outcomes have been reported specifically for adolescents with CP. One of the exceptions was a cross-sectional study that assessed well-being among a relatively large group of adolescents and young adults with and without CP and their families.[10] Family members from CP and non-CP samples reported varying levels of family functioning, life satisfaction, and social support. This led the authors[10] to conclude that the presence of an adolescent or young adult with CP is not necessarily a determinant of family functioning and, paradoxically, that adolescence is no more challenging for families of adolescents and young adults with CP than for families of those without disabilities.

Variation in well-being among adolescents with CP was also described by Vitale et al.[35] By having the adolescents complete the SF-36[48] and the EuroQol,[49] the authors attempted to determine if adult measures of well-being are appropriate for use in an adolescent population. Having observed the presence of ceiling effects and lack of discriminatory power, the authors[35] concluded that instruments designed for adults are not valid for adolescents with physical disabilities such as CP, and, moreover, that these individuals should be treated as a separate subgroup with specific QOL issues.

King et al. used a qualitative approach to investigate QOL among older adolescents with CP.[40] In this setting, participants defined 'success in life' as being happy, which was linked thematically to meeting personal goals, feeling fulfilled, and enjoying occupational roles. The authors[40] suggested that the importance of psychosocial well-being was discordant with the healthcare system's focus on improving functional status. This study included only 10 adolescents, all enrolled in secondary or postsecondary education and demonstrating well-developed communication skills, which may have limited its generalizability.

Discussion

This review offers a broad overview of qualitative and quantitative assessments of well-being among individuals with CP over the past 10 years. Although some findings appear contradictory, such as those that describe the relation between function and well-being,[8,36,37,50,51,54,56,57] several themes emerged.

First, well-being is reported as being lower among children and adolescents with CP compared with normative data. Second, across the spectrum of physical impairment in CP, only physical well-being is positively correlated with gross motor function. Some researchers concluded that this may be the case for psychosocial satisfaction as well, but this finding emerged in two studies only.[37,56] Third, although adolescents with CP appear to have different life issues than adults or children, only a limited body of research on factors associated with well-being has been reported for this age group.

As areas of future research, we suggest that investigators use a population-based approach and involve participants from across the spectrum of gross motor impairment. Although studies of subpopulations of individuals with CP may be useful for describing functional issues[36,37] or evaluating clinical interventions,[39] attention should be directed to assessing QOL and HRQOL across the entire population.

Researchers and clinicians should also be careful not to use instruments designed to measure health or functional status when they intend to assess QOL or HRQOL. For example, eight studies in this review used the CHQ to describe well-being when a subjective measure designed for this purpose would have been more appropriate. These sentiments echo those expressed in a recent review of paediatric QOL instruments,[14] which argues that the CHQ is a measure of health status rather than QOL or HRQOL.

We also recommend that researchers and clinicians allow individuals to report their own well-being whenever possible. Varni et al. reported low correlations between child self-report and parent proxy-report among children and adolescents with CP in some domains of well-being, resulting in a 'hidden morbidity' in areas such as emotional functioning.[41] This discrepancy is well recognized in QOL research,[59–61] but few studies of individuals with CP have embraced this differential approach.

Finally, we suggest that researchers and clinicians interested in assessing QOL or HRQOL among adolescents with CP study these individuals independently, rather than including them with individuals from other age groups or clinical populations. Work underway by the authors and their colleagues with a community-based sample of adolescents with CP will enable us to describe subjectively reported QOL as well as objective health status, in an effort to explore these complementary dimensions of the lives of this important and often-neglected group.

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List of abbreviations

AUQUEI	Autoquestionnaire de qualité de vie enfant imagé (Pictured Child's Quality of Life Self Questionnaire)
CCHQ	Care and Comfort Hypertonicity Questionnaire
CHQ	Child Health Questionnaire
CQ	Caregiver Questionnaire
EuroQol	European Quality of Life Questionnaire
HRQOL	Health-related quality of life
HUI-3	Health Utilities Index – Mark 3
LSS	Life Situation Survey
PedsQL	Pediatric Quality of Life Inventory
PODCI	Pediatric Outcomes Data Collection Instrument
QOL	Quality of life
SF-36	Medical Outcomes Study Short Form 36