College of Nursing and Health Professions

Quality of life and health-related quality of life of adolescents with cerebral palsy

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This study assessed quality of life (QOL) and health-related quality of life (HRQOL) of 203 adolescents with cerebral palsy (111 males, 92 females; mean age 16y [SD 1y 9mo]). Participants were classified using the Gross Motor Function Classification System (GMFCS), as Level I (n=60), Level II (n=33), Level III (n=28), Level IV (n=50), or Level V (n=32). QOL was assessed by self (66.5%) or by proxy (33.5%) with the Quality of Life Instrument for People With Developmental Disabilities, which asks about the importance and satisfaction associated with the QOL domains of Being, Belonging, and Becoming; HRQOL was captured through proxy reports with the Health Utilities Index, Mark 3 (HUI3), which characterizes health in terms of eight attributes, each having five or six ordered levels of function. GMFCS level was not a source of variation for QOL domain scores but was significantly associated with the eight HRQOL attributes and overall HUI3 utility scores (p<0.05). Some QOL domain scores varied significantly by type of respondent (self vs proxy; p<0.05). Overall HUI3 utility values were significantly but weakly correlated with QOL Instrument scores for Being (r=0.37), Belonging (r=0.17), Becoming (r=0.20), and Overall QOL (r=0.28), and thus explain up to 14% of the variance (r^2). These findings suggest that although QOL and HRQOL are somewhat related conceptually, they are different constructs and need to be considered as separate dimensions of the lives of people with functional limitations.

See end of paper for list of abbreviations.

Important aspects of life for individuals with cerebral palsy (CP) include social participation and having meaning and purpose in life. During the past decade there has been a growing interest in concepts and measures associated with quality of life (QOL). Discussion continues about the meaning of various constructs of QOL,[1] as people work to describe the important conceptual variations among terms such as functional status, health status, and health-related quality of life (HRQOL). Livingston et al.[2] have reviewed the literature that reports various aspects of well-being among adolescents with CP. They concluded that measurement of QOL and HRQOL poses methodological challenges and observed that emphasis has traditionally been on functional or health status rather than personal perspectives of well-being.

In brief, 'functional status' refers to 'the degree to which an individual is able to perform socially allocated roles free of physical or mental limitations';[3] it focuses on the performance of specific tasks, such as activities of daily living. When people refer to 'health status' they generally consider broader medical and functional well-being, sometimes reported in terms of 'impact of disability'.[4] Assessments of QOL and HRQOL shift the emphasis on well-being to the realm of the subjective, toward outcomes not directly observable by a third party and not usually measured along a physical dimension.[5] Although the area of health or function measured in QOL and HRQOL may be either objective or subjective (such as the ability to walk or the severity of bodily pain), the ratings of these dimensions are necessarily subjective reports, completed by either self or proxy.[2]

Researchers have yet to decide on a universal definition of QOL and HRQOL.[6] What seems clear, however, is that QOL refers to the notion of holistic well-being,[7] such as the perceived importance of physical health, where one lives and spends time, having friends, and access to education and work; whereas HRQOL focuses on the health-related components judged to be associated with life satisfaction,[8] such as self-care, mobility, and communication. Assessments of QOL and HRQOL thus reflect personal valuations of daily experience, much like other subjective outcomes, such as life satisfaction,[9] sense of coherence,[10] and self-concept.[11]

Utility theory represents an econometric understanding of HRQOL[12] that can be used to calculate quality-adjusted life years. Operating under the assumption that functional status, health status, and QOL are effectively the same construct,[8] such an approach employs assessments of daily functioning rather than reports of perceived well-being.[13] More recent consideration suggests that these outcomes are fundamentally different – an idea that has been argued theoretically by Leplège and Hunt,[14] and supported empirically by Smith et al. after a meta-analysis of QOL and health status in 12 chronic disease studies.[15]

The present study reports self- and proxy-assessed QOL along with parental accounts of HRQOL of a cohort of adolescents with CP participating in a longitudinal study charting mobility and self-care through the adolescent years. The study provides an opportunity to describe adolescents' subjective accounts of Being, Becoming, and Belonging, and to contrast these observations with their HRQOL on the basis of parent proxy reports of health status. We hypothesized that QOL and HRQOL are different constructs and, therefore, that adolescents' perceptions of their holistic well-being do not correspond directly to their functional health status.

Method

This study involved 203 adolescents with CP (111 males, 92 females), ages 13 to 20 years (mean 16y [SD 1y 9mo]) at the time of the QOL assessment (Table I). On the basis of Canadian postal code designations, 38 adolescents lived in rural settings and 165 lived in an urban environment. The number and percentage of children within each of the five Gross Motor Function Classification System (GMFCS)[16] levels were 60 (29.6%) in Level I, 33 (16.2%) in Level II, 28 (13.8%) in Level III, 50 (24.6%) in Level IV, and 32 (15.8%) in Level V. Adolescents did not vary significantly by age ($p=0.62$), sex ($p=0.48$), or place of residence ($p=0.27$) across GMFCS levels.

Data for this study were collected in the course of the Adolescent Study of Quality of life, Mobility and Exercise (ASQME) coordinated at the *CanChild* Centre for Childhood Disability Research in Hamilton, Ontario, Canada. ASQME is a 5-year continuation of the Ontario Motor Growth (OMG) study, which followed a random sample of 657 children with CP from a population-based cohort drawn from across Ontario between 1996 and 2001 to describe patterns of gross motor function and development.[17] Children were originally included in the OMG study if they had a clinical diagnosis of CP or were strongly suspected to have CP by their treating therapist. Potential participants were excluded from the OMG study if they had another neuromuscular disorder or if they had previously received treatments that might significantly alter patterns of development, such as selective dorsal rhizotomy, intrathecal baclofen, or botulinum toxin. No such exclusion was made for the ASQME study.

After completion of the OMG study, all 343 children aged 11 years or older on 1 October 2002 were invited to participate in ASQME. Two hundred and forty-four (71.1%) agreed, and 230 of those individuals (94.2%) completed the first of four annual assessments. These included evaluations of physical activities and exercise, pain, health status, spinal alignment, gross motor function, anthropometry, and environmental barriers, as well as abilities and assistance associated with mobility and self-care. After the first assessment, adolescents and their caregivers were asked whether they would be willing to participate in the QOL component of the study, assessing QOL twice over 2 years. Thirteen (5.6%) declined to participate in this study, seven (3.0%) could not be contacted, and three (1.3%) had previously asked to be withdrawn from the overall ASQME study. Two hundred and seven (90.0%) consented, and 203 of those individuals (98.1%) provided the cross-sectional data reported here.

The ASQME study was approved by the Research Ethics Board at McMaster University. Written and informed consent was obtained from the caregivers of all adolescents who participated, and written assent was obtained from adolescents whenever possible.

MEASURES

Gross Motor Function Classification System

Gross motor function was categorized with the use of the GMFCS, which describes the motor performance of children with CP on the basis of their functional abilities and their need for assistive technology and wheeled mobility.[16] Functional levels range from I (independent gross motor function with few limitations) to V (complete dependence for all motor activities). As adolescent age band descriptors are not yet available, classification in the ASQME study was based on criteria validated for 6- to 12-year-olds. The GMFCS has been shown to be valid, reliable, and stable over time[18] and does not require special training to be administered reliably.[16]

Quality of Life Instrument for People With Developmental Disabilities

Perceived well-being (QOL) was assessed with the Quality of Life Instrument for People With Developmental Disabilities.[19,20] This measure conceptualizes QOL as the 'degree to which a person enjoys the important possibilities of his or her life', or simply, 'How good is your life for you?' Nine areas of life are grouped into three domains of QOL: Being (the basic aspects of who one is), Belonging (the person's fit with his or her environment), and Becoming (the purposeful activities carried out to achieve personal goals, hopes, and wishes; Table II).[20] This QOL model, developed at the Centre for Health Promotion at the University of Toronto, has been applied to people with developmental disabilities,[19,20] the elderly,[21] adolescents,[22] male homosexuals,[23] and people with physical disabilities.[24]

The measure consists of 27 items that consider both the importance and satisfaction of various aspects of life (with the exception of items for Psychological and Spiritual Being,

Table I: Age, sex, residence, and type of respondent by Gross Motor Function Classification System (GMFCS) level

Characteristic	*GMFCS*						*p*
	All levels	*Level I*	*Level II*	*Level III*	*Level IV*	*Level V*	
n	203	60	33	28	50	32	
Age (y:m), mean (SD)	16:0 (1:9)	16:3 (1:11)	15:10 (1:8)	16:2 (1:8)	15:9 (1:9)	15:9 (1:9)	0.62
Sex, *n* (%)							
Male	111 (54.7)	31 (51.7)	15 (45.5)	14 (50.0)	31 (62.0)	20 (62.5)	0.48
Female	92 (45.3)	29 (48.3)	18 (54.5)	14 (50.0)	19 (38.0)	12 (37.5)	
Residence, *n* (%)							
Urban	165 (81.3)	45 (75.0)	25 (75.8)	26 (92.9)	42 (84.0)	27 (84.4)	0.27
Rural	38 (18.7)	15 (25.0)	8 (24.2)	2 (7.1)	8 (16.0)	5 (15.6)	
Respondent, *n* (%)							
Self-report	135 (66.5)	55 (91.7)	18 (54.5)	25 (89.3)	27 (54.0)	10 (31.3)	<0.01
Proxy-report	68 (33.5)	5 (8.3)	15 (45.5)	3 (10.7)	23 (46.0)	22 (68.8)	

p values refer to variation across GMFCS levels.

which consider only satisfaction). Importance and satisfaction response options each range from 1 (not important/satisfied) to 5 (extremely important/satisfied). Ordinal item scores are combined with the use of a multiplicative algorithm to generate continuous QOL scores ranging from –10.0 (not satisfied with extremely important life issues) to 10.0 (extremely satisfied with extremely important life issues). Item responses are then averaged to generate scores for the three domains and the nine subdomains, as well as an overall QOL score. In a study of 504 people across Ontario with developmental disabilities,[19] subdomain scores ranged from –1.1 (Growth Becoming for verbal participants living in large congregate care facilities) to 5.8 (Physical Belonging for verbal participants living with their family). Overall QOL scores ranged from 0.3 (nonverbal participants living in large congregate care facilities) to 4.3 (verbal participants living with their family).

Health Utilities Index, Mark 3

HRQOL was measured by proxy with the use of the Health Utilities Index, Mark 3 (HUI3), which follows the definition of HRQOL developed by Patrick and Erickson[25] as 'the value assigned to the duration of life as modified by the impairments, functional state, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy'.[26] The HUI3 describes functional health status in eight attributes, each with five or six ordinal levels.[27] Attribute levels cover the full range of possible abilities/disabilities and are meant to be clearly distinguishable from one another. An algorithm is used to generate a utility score for each attribute and an overall utility score ranging from 1.00 (perfect health) to 0.00 (death). Negative scores are also possible and are thought by the developers to indicate health states considered worse than death.[26] The utility function is derived from the preferences for health status that members of the general public in Hamilton, Ontario, Canada, placed on each attribute during the development of the HUI3. Utility scores are believed to estimate HRQOL.[12]

PROCEDURE

A structured interview was used to complete the QOL Instrument. Adolescents were interviewed by ASQME occupational or physical therapist assessors who received training before data collection. Adolescents who were able to communicate were interviewed with the self-report version of the measure,

Table II: Domains and subdomains measured by the Quality of Life Instrument

Domain	*Subdomain*	*Item description*
Being	Physical Being	Physical health, diet, and self-care
	Psychological Being	Self-control, self-concept, and freedom from anxiety
	Spiritual Being	Morality, personal values, and celebrating life
Belonging	Physical Belonging	Place of residence, privacy, and neighbourhood
	Social Belonging	Having a spouse or special person, family, and friends
	Community Belonging	Access to employment, community places, and education
Becoming	Practical Becoming	Occupation, work around the home, and caring for others
	Leisure Becoming	Visiting friends, leisure activities, and engaging in a hobby
	Growth Becoming	Learning new things, attaining skills, and adjusting to change

Reproduced from Raphael et al.[20]

Table III: Mean Being, Belonging, Becoming, and Overall quality of life (QOL) scores on the Quality of Life Instrument by Gross Motor Function Classification System (GMFCS) level and type of respondent (self vs proxy)

QOL scores	p^a	*GMFCS*					p^b
		All levels	*Level I*	*Level II*	*Level III*	*Level IV*	*Level V*	
n		203	60	33	28	50	32	
Being, mean (SD)								
Self	0.02	4.7 (2.4)	5.0 (2.0)	4.0 (2.5)	5.0 (2.5)	4.5 (2.8)	4.3 (2.8)	0.65
Proxy		3.1 (3.4)	2.2 (2.5)	3.1 (3.2)	5.0 (2.4)	2.7 (3.7)	3.4 (3.6)	
Belonging, mean (SD)								
Self	0.24	5.1 (2.8)	5.5 (2.3)	5.0 (2.8)	5.5 (2.6)	4.6 (3.6)	4.1 (3.2)	0.85
Proxy		4.6 (2.2)	3.6 (2.1)	5.1 (2.5)	3.9 (1.8)	4.1 (1.7)	5.0 (2.6)	
Becoming, mean (SD)								
Self	0.03	4.7 (2.4)	4.9 (2.1)	3.9 (2.3)	4.4 (2.7)	5.1 (2.7)	5.2 (2.5)	0.77
Proxy		3.7 (2.3)	3.2 (2.3)	3.8 (2.7)	4.1 (1.9)	3.2 (2.1)	4.1 (2.4)	
Overall QOL, mean (SD)								
Self	0.03	4.9 (2.2)	5.1 (1.8)	4.3 (2.1)	5.0 (2.4)	4.7 (2.7)	4.5 (2.4)	0.90
Proxy		3.8 (2.2)	3.0 (1.9)	4.0 (2.5)	4.3 (1.7)	3.3 (1.9)	4.3 (2.4)	

QOL scores range from –10.0 (not satisfied with extremely important life issues) to 10.0 (extremely satisfied with extremely important life issues). [a]*p* values refer to variation in QOL scores by type of respondent. [b]*p* values refer to variation in QOL scores across GMFCS levels.

whereas information from those who could not communicate (as judged by the interviewer) was collected using the proxy version with a parent or caregiver as the respondent. Caregivers completed the HUI3 and adolescents were classified with the GMFCS as part of the second annual ASQME assessment (completed a mean of 2mo [SD 3mo] before the QOL interview).

DATA ANALYSIS

Descriptive statistics included means and SDs for continuous data, and counts and frequencies for categorical data. Distribution of age across GMFCS levels was assessed with a one-way analysis of variance (ANOVA), whereas trends in sex, residence, and respondent type were analyzed with χ^2 tests. Differences in mean QOL Instrument scores were investigated with a two-way ANOVA with GMFCS level and respondent (self vs proxy) as main effects. Differences in mean HUI3 utility scores across GMFCS levels were assessed with a one-way ANOVA followed by Bonferroni correction for multiple comparisons in overall utility scores. The relationship between ability to self-report on the QOL Instrument and health status (HUI3 attribute scores) was assessed with Kendall's tau-b coefficients, using a nonparametric model. Correlations between QOL Instrument scores and HUI3 utility scores were assessed with Pearson product-moment coefficients.

All data were analyzed in SPSS for Windows (version 14.0).

Results

QUALITY OF LIFE INSTRUMENT FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

In every GMFCS level there were adolescents who were able to self-report their QOL, including almost half of those in GMFCS Levels IV and V (37/82). Although adolescents in Level III self-reported more frequently than those in Level II (89.3% vs 54.5%), those who self-reported tended to have less impairment of gross motor function than those whose parents responded on their behalf ($\chi^2=47.1$, $p<0.01$). Overall, one-third of adolescents (68/203) were assessed by proxy.

QOL domain scores for Being varied significantly by type of respondent ($p=0.02$) but not by GMFCS level ($p=0.65$). Similar patterns were evident for the Becoming domain and the Overall QOL score (Table III). Belonging domain scores did not vary significantly by any of the factors analyzed, and no interaction was found between GMFCS level and type of respondent for Being ($p=0.63$), Belonging ($p=0.40$), Becoming ($p=0.49$), or Overall QOL ($p=0.51$).

HEALTH UTILITIES INDEX, MARK 3

Because ability to self-report emerged as a correlate of QOL scores in the preliminary analysis, further investigation was conducted into the relationship between ability to self-report and functional health with the use of the HUI3 attributes. Observed correlations were consistent with an a priori hypothesis that predicted that the ability to self-report would be associated with speech and cognition, but less so with other health dimensions. As hypothesized, self-report capability was significantly associated ($p<0.01$) with parent HUI3 ratings on speech (tau-b=0.52), cognition (tau-b=0.50), dexterity (tau-b=0.35), ambulation (tau-b=0.31), vision (tau-b=0.22), and hearing (tau-b=0.19), but not emotion ($p=0.27$) or pain ($p=0.47$).

Proxy-reported utility scores were calculated for the eight attributes and reported by GMFCS level (Table IV). The results of the one-way ANOVA indicated that utility values varied by GMFCS level for all attributes including vision, hearing, speech, ambulation, dexterity, and cognition ($p<0.01$), as well as emotion and pain ($p<0.05$), such that mean utility scores tended to be lower for adolescents with more limitations in gross motor function.

Overall utility scores were available for 192 adolescents (seven participants [3.4%] skipped their second annual ASQME assessment and did not complete the HUI3, and four others [2.0%] were excluded because of missing values in one or more of the eight HUI3 domains). Scores ranged from –0.33 to 1.00, with a mean of 0.42 (SD 0.41) and a median of 0.42. Eighteen adolescents (9.4%) were reported to have perfect health, 140 (72.9%) had utility scores between 0.00 and 1.00, and 34 (17.7%) reported values less than zero, indicating health states that could be interpreted on the HUI3 as worse than death.

Mean overall HUI3 utility scores decreased significantly by

Table IV: Mean Health Utilities Index, Mark 3 (HUI3) utility scores by Gross Motor Function Classification System (GMFCS) level

Parameter	*GMFCS*						*p*
	All levels	*Level I*	*Level II*	*Level III*	*Level IV*	*Level V*	
n	196	60	33	27	46	30	
HUI3 utility scores, mean (SD)							
Vision (*n*=193)	0.88 (0.24)	0.97 (0.09)	0.93 (0.21)	0.94 (0.16)	0.82 (0.28)	0.72 (0.35)	<0.01
Hearing (*n*=196)	0.97 (0.13)	1.00 (0.00)	0.99 (0.05)	1.00 (0.00)	0.98 (0.09)	0.90 (0.31)	<0.01
Speech (*n*=196)	0.84 (0.30)	0.97 (0.09)	0.85 (0.24)	0.98 (0.07)	0.81 (0.32)	0.46 (0.41)	<0.01
Ambulation (*n*=196)	0.48 (0.44)	0.99 (0.06)	0.68 (0.36)	0.29 (0.21)	0.08 (0.10)	0.03 (0.06)	<0.01
Dexterity (*n*=196)	0.75 (0.40)	0.99 (0.07)	0.81 (0.33)	0.88 (0.27)	0.68 (0.42)	0.23 (0.40)	<0.01
Emotion (*n*=196)	0.98 (0.07)	0.99 (0.04)	0.99 (0.03)	0.94 (0.09)	0.97 (0.11)	0.98 (0.04)	0.021
Cognition (*n*=195)	0.75 (0.33)	0.89 (0.18)	0.79 (0.26)	0.81 (0.23)	0.68 (0.37)	0.46 (0.44)	<0.01
Pain (*n*=195)	0.92 (0.18)	0.93 (0.17)	0.91 (0.16)	0.98 (0.05)	0.94 (0.18)	0.84 (0.23)	0.047
Overall (*n*=192)	0.42 (0.41)	0.84 (0.20)	0.50 (0.31)	0.39 (0.21)	0.16 (0.26)	–0.08 (0.23)	<0.01

Utility scores range from 1.00 (perfect health) to 0.00 (death), although scores less than zero are also possible and are thought to indicate health states considered worse than death. *p* values indicate significance of within-attribute utility score variation by GMFCS level.

GMFCS level ($p<0.01$). Post-hoc analysis with a Bonferonni correction confirmed significant differences in mean overall utility scores between all GMFCS levels, except GMFCS Levels II and III ($p=0.82$), indicating a strong, negative relationship between health status (HRQOL) and gross motor function ($r=-0.81$). Utility values were significantly but weakly correlated with scores on the QOL Instrument for Being ($r=0.37$), Belonging ($r=0.17$), Becoming ($r=0.20$), and Overall QOL ($r=0.28$). The coefficient of variation (r^2) indicates that HUI3 utility scores explained between 2.9% (Belonging) and 14% (Being) of variance in QOL Instrument scores.

Discussion

This study afforded an unusual opportunity to report and contrast two importantly different perspectives on QOL and functional status of young people with CP. The Quality of Life Instrument for People With Developmental Disabilities provides an assessment of adolescents' perceptions of 'the degree to which the important possibilities of his or her life' are enjoyed.[19] The HUI3 describes adolescents' functional health status and HRQOL as reported by their parents.[27]

Although two-thirds of the adolescents self-reported their QOL, all HRQOL information was derived from parent reports. The results show clearly that the relationship between these constructs is variable and weak, and that HUI3 utility scores explain only a small proportion of the variance in QOL scores. Thus, any assumptions about a proportionality between severity of CP or its associated functional impacts and QOL need to be reconsidered. This observation is reinforced by the finding that all HUI3 attributes vary significantly by GMFCS level, whereas the same is not true for the domain scores of the QOL Instrument, for which GMFCS levels are not a source of variation. In addition, although there is a statistically significant overall effect of GMFCS level on capacity to self-report (correlated most strongly with HUI3 attributes of cognition and speech), there were adolescents in every GMFCS level who could self-report their QOL despite the severity of their CP.

The finding that GMFCS level is associated with HUI3 scores is similar to the results reported by Kennes et al.[28] in a population-based sample of 408 school-aged children with CP. The adolescents who participated in the current study are a subset of the Kennes et al. sample,[28] reported at a different stage in their lives. The similar findings at different ages suggests that HRQOL does not change importantly over time, but this question is being explored longitudinally in related ASQME studies by our group.

It is important to discuss briefly the pattern of scores for each of the measures separately. The mean overall utility scores varied from 0.84 (adolescents in Level I) to –0.08 (adolescents in Level V). There is a steady decrease in utility scores with higher GMFCS levels, with a Spearman's rank correlation coefficient of –0.81 for the 192 adolescents for whom full data were available. Thus, GMFCS level differentiates multidimensional HRQOL as assessed with the HUI3, although as shown in Table IV the relationships between GMFCS levels and attributes of the HUI3 vary considerably. It is also important to observe that parents of 18 youths reported that their adolescents had perfect health (an overall utility of 1.00), of whom 16 were classified in Level I and two in Level II. Thus, despite having some level of motor impairment (due to CP), these adolescents were judged by their parents to have excellent functional abilities.

In contrast, the findings from the QOL Instrument show clearly that there is little, if any, important variation in self-reported QOL by GMFCS level, although adolescents whose QOL was reported by a proxy had a pattern of lower scores than those who self-reported. This suggests that these young people's self-assessment of QOL is not primarily determined by the objective assessment of their functional abilities, and, as expressed by Albrecht and Devlieger,[7] speaks to the importance of obtaining people's subjective assessment of their life quality.

The purpose of this report was to describe aspects of the QOL of adolescents with CP, and to explore possible sources of variation in the data. No effort has been made in the present study to relate or contrast QOL or HRQOL findings from this group of adolescents to reports of QOL in other populations of people with disabilities. In follow-up work now being completed we are collecting both HUI3 and QOL reports for the same adolescents 1 year later, and will then be able to explore stability and change in these aspects of the young people's lives.

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References

1. Davis E, Waters E, Mackinnon A, Reddihough, Graham HK, Mehmet-Radji O, Boyd R. (2006) Paediatric quality of life instruments: a review of the impact of conceptual frameworks on outcomes. *Dev Med Child Neurol* **48:** 311–318.
2. Livingston MH, Rosenbaum PL, Russell DJ, Palisano RJ. (2007) Quality of life among adolescents with cerebral palsy: what does the literature tell us? *Dev Med Child Neurol* **49:** 225–231.
3. Bowling A. (1991) *Measuring Health. A Review of Quality of Life Measurement Scales.* Milton Keynes: Open University Press.
4. Bergner M. (1989) Quality of life, health status, and clinical research. *Med Care* **27:** S148–S156.
5. Schipper H, Clinch JJ, Olweny CLM. (1996) Quality of Life Studies: Definitions and Conceptual Issues. In: Spilker B, editor. *Quality of Life and Pharmacoeconomics in Clinical Trials.* 2nd edn. Philadelphia: Lippincott-Raven. p 11–23.
6. Spilker B. (1996) Introduction. In: Spilker B, editor. *Quality of Life and Pharmacoeconomics in Clinical Trials.* 2nd edn. Philadelphia: Lippincott-Raven. p 1–10.
7. Albrecht GL, Devlieger PJ. (1999) The disability paradox: high quality of life against all odds. *Soc Sci Med* **48:** 977–988.
8. Guyatt GH, Feeny DH, Patrick DL. (1993) Measuring health-related quality of life. *Ann Intern Med* **118:** 622–629.
9. Magill-Evans J, Darrah J, Pain K, Adkins R, Kratochvil M. (2001) Are families with adolescents and young adults with cerebral palsy the same as other families? *Dev Med Child Neurol* **43:** 466–472.
10. Jahnsen R, Villien L, Stanghelle JK, Holm I. (2002) Coping potential and disability – sense of coherence in adults with cerebral palsy. *Disabil Rehabil* **24:** 511–518.

11. Shields N, Murdoch A, Loy Y, Dodd KJ, Taylor NF. (2006) A systematic review of the self-concept of children with cerebral palsy compared with children without cerebral palsy. *Dev Med Child Neurol* **48:** 151–157.
12. Furlong W, Feeny D, Torrance GW, Goldsmith C, DePauw S, Zhu Z, Denton M, Boyle M. (1998) *Multiplicative Multi-attribute Utility Function for the Health Utilities Index Mark 3 (HUI-3) Systems: A Technical Report.* Hamilton, ON: McMaster University Centre for Health Economics and Policy Analysis, Working Paper 98-11.
13. Muldoon MF, Barger SD, Flory JF, Manuck SB. (1998) What are quality of life measurements measuring? *BMJ* **316:** 542–545.
14. Leplège A, Hunt S. (1997) The Problem of Quality of Life in Medicine. *JAMA* **278:** 47–50.
15. Smith KW, Avis NE, Assmann SF. (1999) Distinguishing between quality of life and health status in quality of life research: a meta-analysis. *Qual Life Res* **8:** 447–459.
16. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. (1997) Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol* **39:** 214–223.
17. Rosenbaum PL, Walter SD, Hanna SE, Palisano RJ, Russell DJ, Raina P, Wood E, Bartlett DJ, Galuppi BE. (2002) Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *JAMA* **288:** 1357–1363.
18. Palisano RJ, Cameron D, Rosenbaum PL, Walter SD, Russell D. (2006) Stability of the gross motor function classification system. *Dev Med Child Neurol* **48:** 424–428.
19. Brown I, Raphael D, Renwick R. (1997) *Quality of Life – Dream or Reality? Life for People with Developmental Disabilities in Ontario.* Toronto: University of Toronto, Centre for Health Promotion.
20. Raphael D, Brown I, Renwick R. (1999) Psychometric properties of the Full and Short Versions of the Quality of Life Instrument Package: results from the Ontario province-wide study. *Int J Disabil Dev Educ* **46:** 157–168.
21. Raphael D, Brown I, Renwick R, Cava M, Weir N, Heathcote K. (1997) Measuring the quality of life of older persons: a model with implications for community and public health nursing. *Int J Nurs Stud* **34:** 231–239.
22. Raphael D, Rukholm E, Brown I, Hill-Bailey P, Donato E. (1996) The quality of life profile – adolescent version: background, description, and initial validation. *J Adolesc Health* **19:** 366–375.
23. Raphael D, Waalen J, Karabanow A. (2001) Factor analytic properties of the quality of life profile: examination of the nine subdomain quality of life model. *Psychol Rep* **88:** 265–276.
24. Renwick R, Nourhaghighi N, Manns PJ, Rudman DL. (2003) Quality of life for people with physical disabilities: a new instrument. *Int J Rehabil Res* **26:** 279–287.
25. Patrick DL, Erickson P. (1993) *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation.* New York: Oxford University Press.
26. Horsman J, Furlong W, Feeny D, Torrance G. (2003) The Health Utilities Index (HUI): concepts, measurement properties and applications. *Health Qual Life Outcomes* **1:** 54.
27. Feeny DH, Torrance GW, Furlong WJ. (1996) Health Utilities Index. In: Spilker B, editor. *Quality of Life and Pharmacoeconomics in Clinical Trials.* 2nd edn. Philadelphia: Lippincott-Raven. p 239–252.
28. Kennes J, Rosenbaum P, Hanna SE, Walter S, Russell D, Raina P, Bartlett D, Galuppi B. (2002) Health status of school-aged children with cerebral palsy: information from a population-based sample. *Dev Med Child Neurol* **44:** 240–247.

List of abbreviations

ASQME	Adolescent Study of Quality of life, Mobility and Exercise
HRQOL	Health-related quality of life
HUI3	Health Utilities Index, Mark 3
OMG	Ontario Motor Growth
QOL	Quality of life