

Measuring the quality of life of children with cerebral palsy: comparing the conceptual differences and psychometric properties of three instruments

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PUBLICATION DATA

Accepted for publication 2nd April 2009.

Published online 22nd June 2009.

LIST OF ABBREVIATIONS

CHQ	Child Health Questionnaire
CPQOL-Child	Cerebral Palsy Quality of Life Questionnaire for Children
HRQOL	Health-related quality of life
KIDSCREEN-10	European generic health-related quality-of-life questionnaire (10-domain version)

AIM To compare the conceptual differences, internal consistency, and validity of the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child), the Child Health Questionnaire (CHQ), and a European generic health-related quality of life (HRQOL) questionnaire (10-domain version; KIDSCREEN-10) for children with cerebral palsy (CP).

METHOD Two hundred and four primary caregivers (185 females [91%], 19 males [9%]) of children with CP aged 4 to 12 years (mean 8y 4mo [SD 2.51]; 112 males [55%], 92 females [46%], Gross Motor Function Classification System level I=18%, II=28%, III=14%, IV=11%, V=28%) provided demographic data and completed the CP QOL-Child, CHQ, and KIDSCREEN-10. Fifty-four children with CP aged 9 to 12 years completed the CP QOL-Child and KIDSCREEN-10.

RESULTS The KIDSCREEN-10 and CP QOL-Child were developed to measure general HRQOL and CP-specific QOL respectively, whereas the CHQ was developed to measure functional health and well-being. In terms of internal consistency, KIDSCREEN-10 (Cronbach's $\alpha=0.86$) and CP QOL-Child (0.74–0.91) outperformed the CHQ (0.18–0.96). In terms of validity, all instruments were moderately correlated. Floor and ceiling effects, although minimal or not evident for KIDSCREEN-10 and CP QOL-Child (1–4.9%), were apparent for CHQ (0.5–62.9%).

INTERPRETATION Conceptually and psychometrically, KIDSCREEN-10 and CP QOL-Child performed more strongly than the CHQ, for children with CP. The choice between these two instruments will depend on the questions posed and outcomes sought by the researcher or clinician.

Cerebral palsy (CP), the leading cause of physical disability in children, occurring in approximately 2 to 2.5 per 1000 live births,¹ is defined as a 'disorder of movement and posture due to a defect or lesion of the immature brain'.² In recent years there has been increasing interest in measuring the quality of life (QOL) of children with CP. QOL, defined as 'an overall assessment of well-being across various domains',³ is a multi-dimensional construct including both health (i.e. physical, emotional, social) and nonhealth domains (i.e. finances, school, autonomy).⁴ Health-related quality of life (HRQOL) is a subdomain of the more global construct of QOL, including domains such as physical, mental and social well-being.⁴

QOL instruments are increasingly being used to evaluate the effectiveness of interventions for children with CP.⁵ Commonly used instruments include the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child),⁶ the Child Health Questionnaire (CHQ),^{7–12} a European generic health-related quality of life questionnaire (KIDSCREEN),¹³ the Pediatric Quality of Life Inventory,¹⁴ the Caregiver Priorities and Child Health Index of Life with Disabilities,¹⁵ the Life-

style Assessment Questionnaire,¹⁶ the modified Caregiver Questionnaire,¹² and the Pediatric Outcomes Data Collection Instrument.¹⁷ It is now becoming increasingly difficult for researchers and clinicians to synthesize data on the effectiveness of interventions from studies that rely on different QOL questionnaires and to select the most appropriate QOL instrument for their purpose. Choice of a scale should be consistent with the conceptual framework and rationale for the instrument's development.

Two groups have compared outcome instruments for children with CP.^{7,12} McCarthy et al. compared health and well-being instruments, including the CHQ,^{7–12} the Pediatric Evaluation and Disability Inventory,¹⁸ and the Pediatric Outcomes Data Collection Instrument¹⁷ in a sample of children with spastic CP ($n=115$).⁷ The CHQ had more floor and ceiling effects than the other two instruments; however, the Pediatric Evaluation and Disability Inventory demonstrated higher internal consistency.⁷ Although that study provided useful information about the CHQ, the investigators did not examine other QOL instruments.

Schneider et al. compared the CHQ⁷⁻¹² with the Caregiver Questionnaire in 30 children with CP¹² and found that the Caregiver Questionnaire total score and the CHQ summary scores were not significantly correlated ($r=0.22-0.24$).¹² That study, clearly limited by a small sample size, failed to compare the conceptual differences of the instruments, including the purpose of the instrument. Additionally, the Caregiver Questionnaire does not directly measure the QOL of the child but rather measures the caregiver's satisfaction and difficulties with the child's progress in personal care, positioning or transferring, comfort, and interaction or communication.¹²

The aim of the present study was to compare the characteristics of three QOL scales for children with CP. These characteristics include conceptual differences (e.g. reason for development, number of items, domains and, reporter), reliability and internal consistency, concurrent validity with previously validated measures, frequency of missing values, and floor and ceiling effects (i.e. the proportion of participants who reported the lowest or highest possible scores). The instruments selected for this study include the CHQ, which is the most commonly used instrument to measure the QOL of children with CP.⁷⁻¹² Given the consensus that QOL domains should be based on qualitative research with parents and children, the CHQ was compared with two new instruments that are based on qualitative interviews with children: the KIDSCREEN 10-domain version (KIDSCREEN-10) and the CP QOL-Child. For both of these instruments, qualitative interviews were conducted with children and parents to determine the domains of QOL and the wording of the items. KIDSCREEN-10 is a new generic HRQOL instrument,¹³ and CP QOL-Child is a new condition-specific QOL instrument for children with CP.⁶ All three of these instruments have been used to measure the QOL of children with CP.^{6,7,12,19}

METHOD

Participants

Potential participants were identified through the Victorian Cerebral Palsy Register at the Royal Children's Hospital, Melbourne, Australia ($n=695$). Families with a child with CP between the ages of 4 and 12 years ($n=471$) were invited to participate in the study by their paediatrician. In total, 204 primary caregivers consented and completed the questionnaire. Comparisons between respondents and nonrespondents were not possible as non-respondents could not be contacted. Only a proportion of potential children were able to complete questionnaires, because of their age or severity of impairment, resulting in 53 children aged 9 to 12 years completing the questionnaires.

Measures

All parents ($n=204$) completed a questionnaire consisting of the CP QOL-Child, CHQ, KIDSCREEN-10, a measure of functioning and questions on demographics (i.e. child age, child sex, parent age, parent sex, parent highest level of education). Children aged 9 to 12 years ($n=53$) completed the CP QOL-Child and KIDSCREEN-10.

CP QOL-Child

The CP QOL-Child is a condition-specific QOL instrument for children with CP aged 4 to 12 years.⁶ The primary caregiver-proxy version was used for parents of children aged 4 to 12 years, and the child self-report version was used for children aged 9 to 12 years.⁶ This instrument is used to assess seven domains of QOL, including social well-being and acceptance, feelings about functioning, participation and physical health, and emotional well-being. This sample has been used previously to examine the psychometric properties of the CP QOL-Child:⁶ 2-week test-retest reliability for parent-proxy reports produced intraclass correlation coefficients (ICCs) varying from 0.76 to 0.89, with moderate correlations between parent-proxy and child self-report data (0.52-0.77). Furthermore, internal consistency (Cronbach's α) varied from 0.74 to 0.92 in the parent-proxy reports and 0.80 to 0.90 in the child self-reports. The questionnaire was also moderately correlated with the CHQ and KIDSCREEN-10. This study extends these psychometric analyses by providing a more comprehensive assessment of the CP QOL-Child in comparison with the performance of the KIDSCREEN and the CHQ.

CHQ

The CHQ²⁰ is a generic instrument designed to measure functional health status, well-being, and health outcomes of children aged 0 to 18 years.⁹ The CHQ measures 12 domains of health such as behaviour, bodily pain, general health, mental health, and parent impact – emotional and physical functioning.⁹ The Australian primary caregiver-proxy report short-form version of the CHQ was used (28 items), which has adequate reliability and validity for a normative sample, with internal consistency varying from 0.19 to 0.85 and reliability varying from 0.68 to 0.93.²⁰ As in a previous study with children with CP,¹⁰ an introductory sentence was added that indicated that some questions might not be appropriate. The self-report version of the CHQ starts at 12 years of age and was therefore not used in the present study. In a recent review of the psychometric properties of the CHQ for children with CP, the authors identified several studies that have demonstrated that internal consistency was satisfactory, and that the CHQ correlates with a range of other instruments assessing disability or functional ability and health.²¹

KIDSCREEN-10

KIDSCREEN-10¹³ is a generic HRQOL instrument. The parent-proxy version was given to parents of children aged 8 to 12 years, and the child self-report version was given to children aged 9 to 12 years. KIDSCREEN-10, which has 10 domains of QOL, including physical well-being, psychological well-being, social support and peers, and financial resources, was derived from the KIDSCREEN 27-item version using Rasch analysis to identify items that represent a global unidimensional latent HRQOL trait.¹³ In European normative samples, KIDSCREEN has sound psychometric properties with reliability varying from 0.63 to 0.96 for KIDSCREEN-52 and from 0.36 to 0.63 for KIDSCREEN-27,¹³ and good internal consistency (0.82) and test-retest reliability

(ICC=0.73) for KIDSCREEN-10.¹³ According to data from the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), KIDSCREEN performs well for children with CP.¹⁹ Scores were available for more than 97% of children on all domains except perception of financial resources (89%), and the proportions of children scoring maximum and minimum values were similar to those reported for children in the general population.¹⁹ All domains had acceptable internal consistency, with Cronbach's α values of 0.70 or higher, except self-perception at 0.59.¹⁹

Functioning

The Gross Motor Function Classification System (GMFCS) is a categorical measure of gross motor function. The emphasis is on sitting and walking, but the GMFCS also distinguishes between functional limitations, the need for assistive technology (e.g. mobility devices), and, to a lesser extent, the quality of self-initiated movement.²² The parent-proxy measure for children aged 4 to 12 years was used. The ICCs between parent and clinician-reported GMFCS have been shown to be high (0.93).²³

Procedure

Ethics approval was obtained from the Royal Children's Hospital (EHRC 22055A) and Deakin University (EC 9-2005). Questionnaires, plain-language statements, and consent forms were mailed to participants' homes and were completed by primary caregivers and returned to researchers using a reply-paid envelope. Children aged 9 to 12 years with sufficient cognitive ability (determined by the primary caregiver) completed a self-report version of the questionnaire. Parents provided informed consent for themselves and their child (if their child participated), and children who participated also provided consent.

Statistical analyses

The data were analysed using SPSS version 14 (SPSS Inc, Chicago, IL, USA). All scores were converted to a scale ranging from 0 to 100, and all analyses used a significance level of $p < 0.05$. The conceptual differences examined included the original purpose of the instrument, age range, number of items, reporter, time needed for completion, and instrument domains. In addition, reliability and validity of the three instruments were examined. Internal consistency was examined using Cronbach's α coefficient where values between 0.70 and 0.90 are recommended.¹⁰ Given that the assumptions of normality were not violated, concurrent validity was assessed by examining Pearson correlations between the CP QOL-Child, CHQ and KIDSCREEN-10 for both parent-proxy reports and child self-reports. Correlations above 0.4 are considered moderate, and correlations above 0.8 are considered high.²⁴ Where parent reports and child self-reports were correlated, ICCs were used. Validity was also tested using floor and ceiling effects and missing values. Floor and ceiling effects were defined as the proportions of participants who reported the lowest (0) or highest (100) possible score for each of the three scales. A high proportion of ceiling effects in the data

may indicate that an instrument is not sensitive enough to variation in scores, and thus does not accurately capture the QOL of children with CP. Missing values were analysed by case-wise deletion, as this method allows a true correlation matrix, with correlations observed from the same set of observations.²⁵ It was not possible to examine test-retest reliability in this study as all three questionnaires were administered only once.

RESULTS

Demographics

As shown in Table I, the mean age of the children was 8 years 4 months (SD 2.51), and the children were distributed across all five GMFCS levels. In comparison with population data, our sample was under-represented with children at GMFCS level I (17% vs 35% in the general population) and level IV (10% vs 16% respectively). Our sample was over-represented with children at GMFCS level II (28% vs 16% in the general population) and level V (27% vs 18% respectively). The proportion of children at GMFCS level III in our study was similar to that in the general population (both 14%).²⁶ Most parents had completed secondary school education, with 29% of mothers and 23% of fathers having completed university education.

Conceptual differences

A comparison of the three instruments in terms of original objective of the instrument, age range, number of items, reporter, time to complete and domains is shown in Table SI (supporting information published online). KIDSCREEN-10 and the CP QOL-Child were developed to measure HRQOL and CP-specific QOL respectively, and the CHQ was developed to measure functional health and well-being. Although

Table I: Demographic characteristics of the children and parents participating in the study

Child	
Age (mean [SD], range), y:mo	8:4 [2.51], 4–12
Sex (male:female), n (%)	112:92 (54.9:45.1)
GMFCS level, n (%)	
I	36 (17.6)
II	58 (28.4)
III	29 (14.2)
IV	22 (10.8)
V	56 (27.5)
Primary caregiver	
Age (mean [SD], range), y:mo	40:2 [6.53], 25–69
Sex (male:female), n (%)	19:185 (9.3:90.7)
Mother's education	
Primary school	3 (1.5)
High school	76 (37.2)
TAFE/trade certification	45 (22.1)
University/CAE	59 (28.9)
Father's education	
Primary school	1 (0.5)
High school	80 (39.2)
TAFE/trade certification	60 (29.4)
University/CAE	47 (23.0)

^aPercentages may not add to 100% due to missing data. TAFE, technical and further education; CAE, Council of Adult Education.

the CP QOL-Child can be used for children aged 4 to 12 years, the CHQ and KIDSCREEN-10 are applicable for children aged up to 18 years of age. All three questionnaires have parent-proxy and self-report versions, although the age when self-report commences varies from 8 to 12 years. The CP QOL-Child, CHQ, and KIDSCREEN-52 have established reliability and validity for children with CP in past studies; however, sensitivity to change has not been examined for any of the instruments.

Reliability: internal consistency

For parent-proxy reports, Cronbach's α was good for all domains of the CP QOL-Child (0.74–0.91) and the KIDSCREEN-10 summary score (0.86; Table II). Although seven domains of the CHQ demonstrated adequate internal consistency (0.68–0.91), five domains were outside the acceptable range (0.18–0.66 and 0.96). For child self-reports, internal consistency was good for all domains of the CP QOL-Child (0.80–0.90), but the KIDSCREEN-10 summary score coefficient was slightly below the acceptable range (0.65).

Construct validity

For parent-proxy reports, the CP QOL-Child, CHQ, and KIDSCREEN-10 were moderately correlated, demonstrating good validity (Table III). Correlations between domains of the CP QOL-Child and CHQ varied from 0.007 to 0.51. Moderate correlations were observed between similar domains of the CP QOL-Child and CHQ: for example,

Table II: Internal consistency (Cronbach's α) of the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child), Child Health Questionnaire (CHQ), and a European generic health-related quality of life questionnaire (10-domain version; KIDSCREEN-10)

	Parent-proxy report	Child self-report
CP QOL-Child		
Social well-being and acceptance	0.91	0.87
Feelings about functioning	0.90	0.87
Participation and physical health	0.92	0.90
Emotional well-being	0.85	0.85
Access to services	0.80	n/a
Pain and feeling about disability	0.74	0.80
Family health	0.77	n/a
CHQ		
Physical functioning	0.91	n/a
Role/social limitations – emotional/behavioural	0.31	n/a
Role/social limitations – physical	0.18	n/a
Bodily pain	0.35	n/a
Behaviour	0.72	n/a
Mental health	0.66	n/a
Self-esteem	0.84	n/a
General health	0.96	n/a
Parent impact – emotional	0.68	n/a
Parent impact – time	0.69	n/a
Family activity	0.80	n/a
Family cohesion	0.47	n/a
KIDSCREEN-10		
Summary score	0.86	0.65

Table III: Correlations between parent reports on the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child), Child Health Questionnaire (CHQ), and a European generic health-related quality of life questionnaire (10-domain version; KIDSCREEN-10)

	CHQ domains												
	Physical functioning	Role/social limitations – emotional/behavioural	Role/social limitations – physical	Bodily pain	Behaviour	Mental health	Self-esteem	General health	Parent impact – emotional	Parent impact – time	Family activity	Family cohesion	KIDSCREEN-10
CP QOL-Child domains													
Social well-being and acceptance	0.21*	0.34*	0.17	0.20*	0.32*	0.37*	0.47*	0.21*	0.34*	0.17	0.30*	0.27*	0.48*
Feelings about functioning	0.42*	0.26*	0.30*	0.34*	0.16	0.36*	0.49*	0.31*	0.26*	0.30*	0.44*	0.17	0.50*
Participation and physical health	0.37*	0.18	0.37*	0.28*	0.17	0.37*	0.51*	0.22*	0.18	0.37*	0.35*	0.22*	0.51*
Emotional well-being	0.16	0.25*	0.13	0.19*	0.28*	0.39*	0.49*	0.18	0.25*	0.13	0.29*	0.29*	0.45*
Access to services	0.10	0.16	0.18	0.06	0.22*	0.27*	0.30*	0.09	0.16	0.18	0.24*	0.18*	0.30*
Pain and feeling about disability ^a	-0.31*	-0.21*	-0.29*	-0.44*	-0.01	-0.33*	-0.26*	-0.25*	-0.21*	-0.29*	-0.31*	-0.06	-0.14*
Family health	0.23*	0.23*	0.30*	0.23*	0.32*	0.34*	0.28*	0.24*	0.23*	0.30*	0.43*	0.32*	0.34*
KIDSCREEN-10	0.42*	0.26*	0.36*	0.32*	0.33*	0.30*	0.35*	0.36*	0.26*	0.36*	0.48*	0.16	–

^aThe CP QOL-Child domain of pain and feeling about disability scores increase with increasing levels of pain and discomfort. * $p < 0.01$.

feelings about functioning was correlated with physical functioning ($r=0.42$), and emotional well-being was correlated with self-esteem ($r=0.49$). However, different domains were also moderately correlated; for example, feelings about functioning was moderately correlated with self-esteem ($r=0.49$) and family activity ($r=0.44$). Correlations between CP QOL-Child and KIDSCREEN-10 were good, ranging from 0.30 to 0.51; the only exception was pain and feelings about disability ($r=-0.14$). Correlations between the CHQ and KIDSCREEN-10 were also good, ranging from 0.26 to 0.48; the only exception was family cohesion ($r=0.16$). For child self-reports, moderate correlations were observed between KIDSCREEN-10 and all domains of the CP QOL-Child, varying from 0.61 to 0.70 (social well-being and acceptance $r=0.68$, functioning $r=0.67$, participation and physical health $r=0.70$, emotional well-being and self-esteem $r=0.68$, pain and feeling about disability $r=-0.61$).

Parent-proxy and child self-report scores for the CP QOL-Child and KIDSCREEN-10 are provided in Table IV. ICCs for parent and child reports were moderate for all domains of the CP QOL-Child (social well-being ICC=0.66, functioning ICC=0.76, participation and physical health ICC=0.66, emotional well-being ICC=0.75 and pain and impact of disability ICC=0.52), and slightly lower for parent and child reports of KIDSCREEN-10 (ICC=0.45).

Missing values

For parent-proxy reports, very few of the domains on any instrument had missing data (Tables SII and SIII, supporting information published online): 0.5% of data were missing for the pain and feelings about disability domain of the CP QOL-Child, and 0.5 to 4.4% of data were missing on six domains of the CHQ. There were no missing values for KIDSCREEN-10 or for the child self-reported data.

Table IV: Parent- and child-reported scores on the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) and a European generic health-related quality of life questionnaire (10-domain version; KIDSCREEN-10)

Domain	Parent proxy ($n=204$) Mean (SD)	Child self-report ($n=54$) Mean (SD)
CP QOL-Child		
Social well-being and acceptance	78.09 (12.18)	81.26 (12.71)
Feelings about functioning	63.50 (15.88)	73.45 (17.25)
Participation and physical health	59.92 (16.61)	72.32 (18.21)
Emotional well-being	77.11 (13.40)	83.38 (15.77)
Access to services ^a	66.67 (18.68)	
Pain and feeling about disability ^b	33.18 (17.94)	33.28 (21.66)
Family health ^a	60.73 (18.24)	
KIDSCREEN-10	56.63 (10.98)	63.01 (12.41)

^aChildren do not complete the CP QOL-Child domains of access to services and family Health. ^bThe CP QOL-Child domain of pain and feeling about disability scores increase with increasing levels of pain and discomfort.

Floor and ceiling effects

For parent-proxy reports, floor effects were observed for only one CP QOL-Child domain (pain and feelings about disability, 1%) and for all domains of the CHQ except general health (0.5–25%, see Table SII online). The largest floor effects were for the physical functioning domain, which is composed of items such as ‘during the past 4 weeks, has your child been limited in doing things that take a lot of energy such as playing soccer, or limited in bending, lifting, or stooping?’ The greatest floor effects were evident for children with GMFCS level V, particularly in the domains of physical functioning, parent impact – time, and role/social limitations – physical. No floor effects were observed for KIDSCREEN-10. For child self-reports, no floor effects were apparent in the CP QOL-Child (1.0%, see Table SIII online).

For parent-proxy reports, weak ceiling effects were observed for four of the seven CP QOL-Child domains (2.0–4.9%), and weak to strong ceiling effects were observed for all of the 12 CHQ domains (2.9–62.9%, see Table SII online). No clear pattern of ceiling effects was seen in terms of GMFCS levels. No ceiling effects were observed for KIDSCREEN-10. For child self-reports, ceiling effects were observed for the CP QOL-Child domains of emotional well-being (12%), social well-being and acceptance (6.0%), participation and physical health (6%), and feelings about functioning (2.0%, see Table SIII online). No ceiling effects were observed for KIDSCREEN-10.

DISCUSSION

The results of this study provide important information about the conceptual differences, reliability and validity of three instruments used to measure the QOL of children with CP. With respect to internal consistency, and floor and ceiling effects, the CHQ, although it is clearly the most commonly used instrument,^{7–12} did not perform psychometrically as well as KIDSCREEN-10 (which had no ceiling effects) or CP QOL-Child. Although large numbers of floor and ceiling effects may indicate that an instrument is not sensitive enough to accurately capture the QOL of children with CP, floor and ceiling effects are complex and may be attributed to deficiencies in the wording of the items or the response options, or they may actually reflect an optimal state.

The results highlight that the three instruments are designed to measure three different constructs (refer to Table SI online): condition-specific QOL for children with CP, generic HRQOL for healthy and chronically ill children, and a generic measure of functional health and well-being. Nonetheless, some of the domains are similar, such as role/social limitations – emotional/behavioural (CHQ) and emotional well-being (CP QOL-Child), and bodily pain (CHQ) and pain and feelings about disability (CP QOL-Child). Furthermore, moderate correlations among many of the domains were found for parent-proxy report ($r=0.40–0.53$) and child self-report ($r=0.61–0.71$). The moderate correlations between the instruments do not provide insight into which instrument is superior but do provide some support for the validity of the domains.

It is important for researchers and clinicians to understand the original purpose of QOL instruments, because this may influence the direction and focus of the domains and items. For example, items in the CHQ are focused on whether the child is limited in aspects of his or her life, whereas items in the CP QOL-Child are focused on how the child feels about aspects of his or her life. Given that KIDSCREEN-10 is a generic HRQOL instrument and CP QOL-Child is a condition-specific QOL instrument, the choice between these two instruments depends on the research question. If a researcher is interested in comparing the QOL of children with CP with that of children with other conditions, KIDSCREEN-10 is suitable. If a researcher is interested in examining the effectiveness of an intervention or gaining insight into the issues that children with CP face, the CP QOL-Child may be better suited. However, it may be limiting to base a decision on the construct that the instrument purports to measure, given the overlap among the domains.

The performance of the instruments varied by reporter. The correlations between CP QOL-Child and KIDSCREEN-10 were higher for child self-report than for parent-proxy report. Furthermore, there were considerably fewer floor and ceiling effects for child self-report than for parent-proxy reported data. These differences, although clearly limited by a small sample size for child self-reports, may be attributed to the context, experience, and expectations of the reporters.

This study did not measure test-retest reliability, but this should be examined in further studies, because one of the most pressing information needs is an understanding of the instruments' sensitivity to change. Sensitivity to change is necessary if instruments are to be used with confidence to assess the effectiveness of interventions.²⁷ This is particularly important given that researchers have suggested that children with chronic conditions adapt to their current state.²⁸

Limitations

This study has some limitations. First, this study used KIDSCREEN-10, which produces only one summary score. Although the 10-item measure was derived from the 27-item measure (which has five domains), the results of this study might have been different if the 27-item or the 52-item (10-domain) version had been used; however, the KIDSCREEN-

10 is a valid generic HRQOL instrument. Second, the sample included in this study was used to develop and validate the CP QOL-Child. Items of the CP QOL-Child that had large numbers of missing values were deleted, in order to develop an instrument that is applicable to children across the spectrum of functioning, and thus the missing values are lower than for other instruments. Third, the size of the sample of self-report data was limited, because children were required to be between the ages of 9 and 12 years and to be able to understand and respond to the questions. Fourth, the GMFCS was used to classify children with CP, but, because of ethical considerations, we obtained only basic details from the Victoria Cerebral Palsy Register, which did not contain information on motor types or typology.

CONCLUSION

This study contributes to our understanding about how the CP QOL-Child and KIDSCREEN-10 perform when completed by children with CP and by their parents. The results provide useful information about some aspects of the conceptual differences and psychometric properties, and highlight the need for further research to investigate sensitivity to change.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Table SI: Comparison of instruments used to measure the quality of life (QOL) of children with cerebral palsy (CP).

Table SII: Floor and ceiling effects on the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child), Child Health Questionnaire (CHQ), and a European generic health-related quality of life questionnaire (10-domain version; KIDSCREEN-10): parent-proxy reports.

Table SIII: Floor and ceiling effects on the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) and a European generic health-related quality of life questionnaire (10-domain version; KIDSCREEN-10): child self-reports.

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