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Determinants of Child-Parent Agreement in Quality-of-Life Reports: A European Study of Children With Cerebral Palsy

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ABSTRACT

OBJECTIVES. The differences between child self-reports and parent proxy reports of quality of life in a large population of children with cerebral palsy were studied. We examined whether child characteristics, severity of impairment, socioeconomic factors, and parental stress were associated with parent proxy reports being respectively higher or lower than child self-reports of quality of life.

METHODS. This study was conducted in 2004–2005 and assessed child quality of life (using the Kidscreen questionnaire, 10 domains, each scored 0–100) through self-reports and parent proxy reports of 500 children aged 8 to 12 years who had cerebral palsy and were living in 7 countries in Europe.

RESULTS. The mean child-reported scores of quality of life were significantly higher than the parent proxy reports in 8 domains, significantly lower for the finances domain, and similar for the emotions domain. The average frequency of disagreement (child-parent difference greater than half an SD of child scores) over all domains was 64%, with parents rating their child's quality of life lower than the children themselves in 29% to 57% of child-parent pairs. We found that high levels of stress in parenting negatively influenced parents' perception of their child's quality of life, whereas the main factor explaining parents' ratings of children's quality of life higher than the children themselves is self-reported severe child pain.

CONCLUSIONS. This study shows that the factors associated with disagreement are different according to the direction of disagreement. In particular, parental well-being and child pain should be taken into account in the interpretation of parent proxy reports, especially when no child self-report of quality of life is available. In the latter cases, it may be advisable to obtain additional proxy reports (from caregivers, teachers, or clinicians) to obtain complementary information on the child's quality of life.

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†Deceased.

Key Words

cerebral palsy, child, parents, proxy, quality of life

Abbreviations

CP—cerebral palsy

QoL—quality of life

SPARCLE—Study of Participation of Children With Cerebral Palsy Living in Europe

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CEREBRAL PALSY (CP) is the most common physical impairment in childhood, occurring in 2 per 1000 live births,¹ and is frequently associated with additional impairments (in particular intellectual). The assessment of the quality of life (QoL) of children with CP in the context of their physical, social, and attitudinal environment is an aim of the European Study of Participation of Children With Cerebral Palsy Living in Europe (SPARCLE; www.ncl.ac.uk/sparcle).

A literature review published in 1995² found that child QoL was assessed by proxies in 90% of studies. In 1993, the World Health Organization and the International Association for Child Psychology and Psychiatry jointly recommended that measures of QoL in children use subjective self-reporting whenever possible.³ It has since been shown that children are able to self-report even at a young age,^{4,5} and efforts have been made to obtain the children's own perspective.^{2,6-8} However, there are concerns that because of developmental problems, children's reports may not be reliable.⁹ Furthermore, some children may not be able to self-report because of their young age, the severity of their illness or disability, or cognitive impairment. For these children, proxy reports are the only way to evaluate QoL. Usually, parents are asked to assess their child's QoL because it is assumed that they have an intimate knowledge of their child and can provide reliable information. It is now widely recognized that self-reports and proxy reports both constitute important complementary information concerning children's QoL.¹⁰⁻¹²

In recent years, a review¹⁰ and a number of studies have examined the agreement in QoL reports between parents and their children from the general population¹³⁻¹⁶ and with various health conditions.¹⁷⁻³⁹ One study⁴⁰ examined the correlation between child and parent reports on a small sample of children with CP from 1 clinic in the United States. All of these studies examined both objective and subjective domains of QoL.

Studies involving healthy children found that parents generally proxy-report higher QoL than the children themselves,^{13,15,16} whereas it has widely been shown that parents of children with chronic conditions proxy-report lower QoL than the children themselves.* Concerning specific domains, some studies found lower child-parent agreement for subjective dimensions of QoL compared with objective dimensions,^{27,29,38,40} but others found the opposite^{17,19,23} and several found no such difference.^{13,15,21,34} Factors that influence child-parent agreement have mostly been examined by stratification of the correlation between respondents' reports or use of univariate analysis (exceptions are work by April et al¹⁷ and Britto et al¹⁹). No consistent findings have been reported concerning the influence of child age, gender, or socioeconomic variables.^{14,16,19,27,29,31} It has been reported

that agreement increases with severity of disease.^{14,17,19} Two studies reported that child-parent agreement was lower when parents reported low psychological well-being.^{27,29}

Despite the increasing amount of research in this area, several methodologic problems remain. First, small sample sizes have often prevented the study of patterns of child-parent agreement beyond simple correlations, methods that are now widely recognized as inadequate because of their inability to detect systematic differences in mean scores.⁴¹⁻⁴⁴ Indeed, several studies found strong correlations between child and parent ratings but statistically significant differences in mean scores.^{15,33} Second, factors that influence child-parent agreement have usually been examined using only univariate analysis (eg, refs 13-16). Third, contrary to recent recommendations,¹² the direction of disagreement has never been taken into account when determining factors that influence disagreement.

Child characteristics such as age, gender, severity of disease, and behavioral problems^{18,27} have been shown to influence child and parent reports of QoL and therefore are likely to affect agreement. Similarly, studies have shown that family structure and socioeconomic status^{33,45} as well as parental well-being and mental health⁴⁵⁻⁴⁷ are associated to parent proxy reports of QoL but not child self-reports. All of these variables should therefore be included in any study that aims to examine and explain differences in child self-reports and parent proxy reports of QoL. Examining child self-reports and parent proxy reports of QoL is important for health care practitioners' understanding of the relationship between assessments and, in case of disagreement, to make them aware of the need to obtain both the parents' and the children's perspectives. Knowing which factors influence child-parent disagreement enables clinicians to comprehend each respondent's views on child QoL and better interpret parent proxy reports when children are unable to answer.

Our study aims to assess the extent of agreement between child self-reports and parent proxy reports of QoL and to identify the factors that influence agreement in a large European sample of children with CP. Our underlying conceptual basis is that differences between scores are not only attributable to random measurement errors but also reflect meaningful differences in child and parent perspectives. It is therefore essential to study the direction of the differences—parent scores lower than child scores or parent scores greater than child scores—and separately determine the factors that are associated with each of these situations.

On the basis of previous findings in children with chronic conditions (eg, refs 30 and 32), we expected correlation to be low to moderate and parents' proxy reports of QoL to be significantly lower than their children's self-reports. We hypothesized that the factors that influence disagreement would be different according to

*Refs 18-20, 22, 24, 27-33, 36, 37, 39, and 40.

the direction of the differences. Child age and gender, the severity of impairment, and the presence of behavioral problems, as well as socioeconomic factors and parental well-being, have been shown to influence QoL reports and therefore were tested in relation to each type of disagreement. Findings concerning child characteristics and socioeconomic factors are inconsistent,^{10,12} but we expected that there would be less disagreement when impairment was more severe^{14,17,19} and more disagreement for parents who reported more stress.^{27,29}

METHODS

Population

SPARCLE included 818 children who had CP, were aged 8 to 12 years, and were from 9 regions in 7 European countries (Denmark, France [2 centers], Germany, Ireland, Italy, Sweden, and United Kingdom [2 centers]) visited between July 2004 and July 2005. In 8 regions, children were selected from population-based registers of children with CP that are part of an existing collaboration⁴⁸; in Northern Germany, children were recruited through referrals from all clinicians and medical centers within a defined geographic area. Ethics approval from the relevant authorities, written parental informed consent, and child assent were obtained. The detailed protocol of SPARCLE is reported elsewhere.⁴⁹

QoL Measure

Kidscreen is a generic health-related QoL questionnaire for children (8–18 years) that has been psychometrically validated on 22 110 European children from the general population.⁵⁰ The instrument has child and parent/proxy versions with 52 items covering 10 dimensions: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parental relations, social support and peers, school environment, social acceptance (bullying), and financial resources. For each domain, item responses are summed and a score out of 100 is computed with higher scores indicating better QoL. If only 1 item response is missing, then it is replaced by the mean of the responses to the remaining items in the domain; otherwise, the domain score is considered missing.

One of the aims of SPARCLE was to include the children's own perspective on their QoL. However, more than half (53%) of the children of the total SPARCLE population had associated intellectual impairment (IQ ≤ 70). When it was unclear whether a child could complete questionnaires, a test was administered to determine this.⁵¹ A self-report of QoL could not be obtained for 95% of the children with severe intellectual impairment (IQ < 50), 35% of the children with moderate intellectual impairment (IQ ≥ 50 and ≤ 70), and 6% of the children with no intellectual impairment (IQ > 70). Parent proxy reports were obtained for all children. This

article compares parents' and children's reports for the 500 children (61% of total study population) who were able to self-report. Interviewers asked children and parents to answer the questionnaires alone and in separate rooms; this happened for 64% of families.

Statistical Analysis

In each domain, reliability (Cronbach's α) was examined, and Pearson and intraclass correlations between the children's and the parents' scores were computed.⁵² The means of directional differences (child score – parent score) were calculated and tested using paired Student's *t* tests. The mean difference score was standardized by relating this score to the average SDs of the child and parent scores (effect size).⁵³ The means of the absolute value of the differences between scores were calculated as indicators of agreement.⁵⁴ We further defined agreement as occurring when this absolute value was less than or equal to half of the SD of the children's scores (because these had the greatest variability), according to the widely recognized definition of clinically meaningful difference in QoL.⁵⁵ Depending on the domains, this threshold for agreement was between 8 and 15 points (Fig 1). Disagreement was separated into parents who scored lower ("parent < child disagreement") and parents who scored higher ("parent > child disagreement") than their child by more than the threshold.

Separate multilevel multivariable logistic regression analyses of each disagreement category versus the agreement category were conducted in each domain. The factors studied were entered into the models as independent variables provided that they were associated in the univariate analysis (with $P < .20$). Forward stepwise procedures were used to construct the models (significance level for entry or removal was 5%). Final multivariable models excluded only child-parent pairs with missing values on the included covariates. Multilevel modeling was used because observations within a center might be more similar than observations in different centers.⁵⁶ Goodness of fit was assessed by using the Bayesian Information Criterion, and models were rerun excluding influential observations to check stability.

The following child characteristics were studied in relation to agreement: age, gender, type of CP, presence of associated impairments (seizures, type of feeding, communication, and intellectual). The severity of motor impairment was assessed using the Gross Motor Function Classification System⁵⁷ and Bimanual Fine Motor Function measurement instrument.⁵⁸ Child behavioral and emotional health was assessed using the parent-completed Strengths and Difficulties Questionnaire⁵⁹: 4 symptom scales (conduct, hyperactivity, emotion, and peer problems) add up to a total difficulties score (range: 0–40) categorized into normal (≤ 13), borderline (14–16), and abnormal (≥ 17) behavioral and emotional health. The children assessed their pain during the past

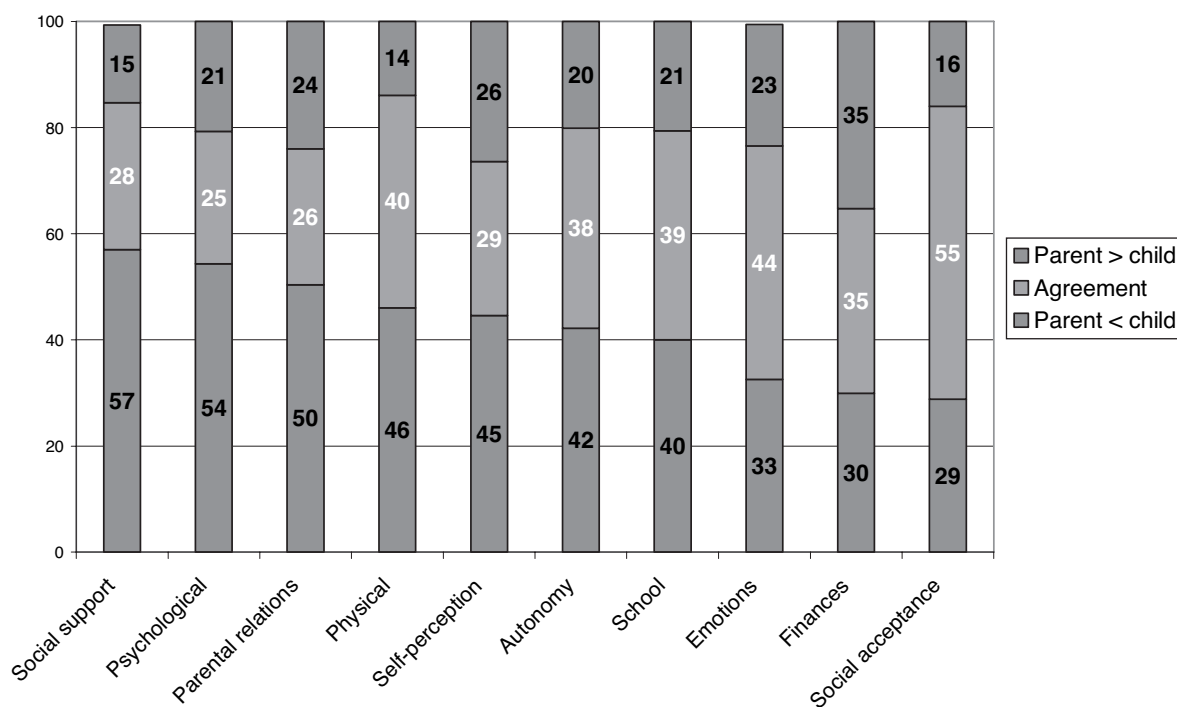


FIGURE 1

Distribution of agreement between child and parent reports (percentage of complete pairs). Agreement = $| \text{child score} - \text{parent score} | \leq \text{SD of child scores}/2$ (ie, threshold for each domain in the order specified above: social support: 12 points; psychological: 8 points; parental relations: 8 points; physical: 11 points; self-perception: 9 points; autonomy: 11 points; school: 10 points; emotions: 8 points; finances: 15 points; social acceptance: 10 points).

week using the 2 items from the Child Health Questionnaire⁶⁰ concerning frequency and intensity of pain, combined to give an overall score.

The characteristics of the child's environment that were studied in relation to agreement were family structure, general health of the child's siblings (able or disabled/chronically ill), parental educational qualifications and occupation (characteristics of both parents were combined into a single 4-category score), and type of school attended by the child. Parental stress was assessed using the Parental Stress Index–Short Form and categorized into normal (≤ 71), borderline (72–90), and abnormal (> 90) levels.⁶¹

RESULTS

Five hundred pairs of child and parent assessments of the child's QoL were available for comparison. The parent responders were mainly mothers ($n = 478$ [96%]), with only 21 fathers and 1 other member of the family. A full description of the group characteristics is given in Tables 1 and 2. The children generally had moderate impairment with 68% in the 2 highest categories of walking ability and 73% with an IQ of > 70 .

The response rate was very high ($> 95\%$ in 9 of 10 domains; Table 3). Reliability as calculated by Cronbach's α was very good ($\geq .70$) except for self-perception (.59 in children, .68 in parents). The mean child self-reports and parent proxy reports for each domain of QoL

are given in Table 3. Correlation between child and parent scores was low (between 0.24 and 0.44 for Pearson and between 0.21 and 0.41 for intraclass correlation; Table 4). In 8 of 10 domains, children reported, on average, significantly better QoL than their parents did (Table 4). Finances was the only domain for which parents proxy-reported significantly higher QoL than did the children themselves (-3.4 points). There was no significant difference between mean scores in the emotions domain. The size of the effect was moderate in most domains (< 0.50), except in the social support domain (0.69), for which it was large. Rates of agreement were between 25% and 40% in most domains and higher for emotions (44%) and social acceptance (55%; Fig 1). Disagreement mainly consisted of parents rating lower than their children (between 29% and 57%), the finances domain being the only one for which there was more "parent $>$ child disagreement" (35%) than "parent $<$ child disagreement" (30%).

Tables 5 and 6 show the final multilevel multivariable models explaining, respectively, "parent $<$ child disagreement" and "parent $>$ child disagreement" versus "agreement." In these models, no variables were significantly associated with either type of disagreement in 2 domains (self-perception and finances), and 4 variables (child gender, type of CP, type of feeding, and family structure) were not significantly associated with either type of disagreement in any domain.

TABLE 1 Child Characteristics (All Centers, N = 500 Children)

Characteristic	n (%)
Age, y	
7/8	105 (21)
9	105 (21)
10	93 (19)
11	105 (21)
12/13	92 (18)
Gender	
Boys	286 (57)
Girls	214 (43)
Gross motor function (GMFCS)	
Walks, climbs stairs	218 (44)
Walks inside	118 (24)
Walks with limitation	93 (18)
Moving about limited	49 (10)
Moving about severely limited	22 (4)
Two-hand motor function (BFMF)	
No limitation	241 (48)
Both hands limited fine skills	146 (29)
Help needed	73 (15)
Help and equipment needed	32 (6)
Total assistance	8 (2)
Type of CP	
Spastic unilateral	220 (44)
Spastic bilateral	235 (47)
Dyskinetic	32 (7)
Ataxic	12 (2)
Missing	1 (0)
IQ	
>70	363 (73)
50–70	121 (24)
<50	13 (3)
Missing	3 (0)
Seizures	
No seizures (with or without medication)	456 (91)
Seizures	44 (9)
Feeding	
By mouth without difficulty	446 (89)
By mouth with difficulty	54 (11)
Communication	
Normal	409 (82)
Speech problems	66 (13)
Alternative forms of communication	25 (5)
Child pain (self-report)	
No pain	217 (43)
Slight pain	69 (14)
Moderate pain	104 (21)
Severe pain	61 (12)
Very severe pain	38 (8)
Missing	11 (2)
Child behavior and emotions (SDQ)	
Normal	318 (63)
Borderline	73 (15)
Abnormal	109 (22)

GMFCS indicates Gross Motor Function Classification System; BFMF, Bimanual Fine Motor Function; SDQ, Strength and Difficulties Questionnaire.

High parental educational qualifications was the only factor associated with higher odds of disagreement in both directions. Otherwise, “parent<child disagreement” and “parent>child disagreement” were not explained by the same mechanisms. Parents with higher levels of stress were more likely to rate their children’s QoL lower

TABLE 2 Characteristics of the Child’s Environment (All Centers, N = 500 Children)

Characteristic	n (%)
Parental stress (PSI)	
Normal	185 (37)
Borderline	183 (37)
Abnormally high	121 (24)
Missing	11 (2)
Family structure	
Married	351 (70)
Living with partner	56 (11)
Single living with parents	11 (2)
Single living alone	82 (17)
Siblings	
At least 1 sibling (none disabled)	347 (69)
At least 1 disabled sibling	58 (12)
No siblings	87 (17)
Missing	8 (2)
Parental educational qualifications	
None or lowest qualification	111 (22)
Above lowest and below university	319 (64)
University degree completed	67 (13)
Missing	3 (1)
Parental occupation	
1 parent full-time professional	131 (26)
1 parent full-time trade	261 (52)
1 parent part-time; other does not work	38 (8)
Neither works	67 (13)
Missing	3 (1)
School type	
Mainstream	290 (58)
Split mainstream and special unit	65 (13)
Special unit in mainstream school	46 (9)
Special school	97 (20)
Missing	2 (0)

PSI indicates Parental Stress Index.

than the children themselves in the parental relations, physical, and school domains. Parents of older children were more likely to proxy-report a lower QoL in parental relations than their children, whereas parents of younger children were more likely to proxy-report lower than the children themselves in school. Poor behavioral and emotional child health increased the odds of parents proxy reporting lower than the children themselves in the social support and social acceptance domains. Parents of children with an IQ of <50 (school domain) and those of children with communication impairments (emotions and social acceptance domains) were less likely to proxy report a lower QoL than their children.

In 5 domains (psychological well-being, physical well-being, autonomy, school, and emotions), parents of children who self-reported pain were significantly more likely to proxy-report a higher QoL than their child, and the odds ratios of this disagreement increased with increasing pain. Moderately impaired fine motor function (emotions domain) and the presence of seizures (parental relations and social acceptance domains) were also

TABLE 3 Mean and Reliability of Child and Parent Reports (Domains Ordered by Decreasing Child Mean)

Domain	Complete Pairs, <i>n</i> (%)	Child Reports		Parent Reports	
		Mean (SD)	Reliability, Cronbach's α	Mean (SD)	Reliability, Cronbach's α
Social acceptance	475 (95)	86.5 (20.4)	.72	83.2 (17.8)	.83
Parental relations	488 (98)	82.6 (16.8)	.76	76.6 (15.9)	.86
Emotions	485 (97)	81.7 (16.7)	.76	80.6 (13.6)	.84
Self-perception	489 (98)	80.0 (18.7)	.59	75.5 (15.8)	.68
Psychological well-being	493 (99)	79.2 (16.2)	.74	71.7 (14.9)	.87
School	490 (98)	76.0 (20.3)	.80	71.2 (17.6)	.87
Autonomy	493 (99)	72.6 (21.0)	.70	65.2 (18.5)	.81
Physical well-being	489 (98)	70.7 (21.9)	.73	60.7 (18.8)	.76
Social support	484 (97)	70.4 (23.3)	.82	55.0 (21.4)	.91
Finances	411 (82)	66.4 (30.8)	.83	69.8 (28.2)	.91

TABLE 4 Correlation, Bias, and Agreement Between Child and Parent Reports (Based on Complete Child-Parent Pairs for Each Domain)

Domain	Correlation		Directional Difference ^a		Absolute Difference ^b
	Pearson	ICC	Mean (SD)	Effect Size ^c	Mean (SD)
Social acceptance	0.34	0.32	3.3 (22.0) ^d	0.17	15.0 (16.4)
Parental relations	0.25	0.21	6.0 (20.0) ^e	0.37	16.2 (13.1)
Emotions	0.24	0.24	1.1 (18.8)	0.07	13.8 (12.7)
Self-perception	0.26	0.23	4.5 (21.0) ^e	0.26	16.7 (13.6)
Psychological well-being	0.28	0.22	7.5 (18.7) ^e	0.48	15.9 (12.4)
School	0.44	0.41	4.8 (20.2) ^e	0.25	16.3 (12.8)
Autonomy	0.27	0.22	7.4 (23.9) ^e	0.37	20.0 (15.1)
Physical well-being	0.37	0.28	9.9 (23.0) ^e	0.49	19.8 (15.4)
Social support	0.40	0.25	15.4 (24.6) ^e	0.69	23.4 (17.2)
Finances	0.38	0.38	−3.4 (32.8) ^f	0.12	24.7 (21.8)

ICC indicates intraclass correlation coefficient.

^a Directional difference = child score − parent score.^b Absolute difference = |child score − parent score|.^c Effect size = |mean of directional differences|/[$(SD_{\text{child}} + SD_{\text{parent}})/2$].^d Two-sided $P = .001$.^e Two-sided $P < .0001$.^f Two-sided $P = .04$.

associated with increased odds of “parent>child disagreement.”

DISCUSSION

To our knowledge, this study is the first to compare self-reports and parent proxy reports of children's QoL in a large international population of children with CP. As found in previous studies,^{30–32} correlations between child self-reports and parent proxy reports were low; slightly more so than those reported in the study validating the Kidscreen proxy questionnaire.¹⁴ This is unlikely to be attributable to poor reliability because the Cronbach's α values were high and close to those that they found. No additional comparison with this Kidscreen study was possible because their comparisons were solely based on correlation and group mean scores were not reported. The average rate of disagreement over all domains was high (64%) and examination of mean differences revealed that, in most domains, children reported significantly higher QoL than their parents

proxy reported for them. This is consistent with most previous studies in children with chronic conditions,* where it was found that parents have a tendency to rate children's QoL lower than the children's own ratings. Conflicting results have been reported concerning agreement in specific domains (objective versus subjective).^{13,23,38} Although Kidscreen aims to measure subjective QoL in all domains, some domains (social acceptance and social support) could be considered more objective because they include mostly factual questions. In our study, correlation was lowest in the subjective emotions and parental relations domains and higher in the more objective social acceptance and social support domains, which is consistent with the tendencies found in some studies on the basis of correlation.^{27,29,38} Similarly, the only other study on children with CP⁴⁰ (67 child-parent pairs, PedsQL questionnaire) found that correlation was lowest in the emotions scale. However, our results confirm that correlation cannot be interpreted as indicating agreement.^{41–44} Indeed, the

TABLE 5 "Parent < Child Disagreement"

Parameter	Social Support, OR (95% CI)	Psychological, OR (95% CI)	Parental Relations, OR (95% CI)	Physical, OR (95% CI)	Autonomy, OR (95% CI)	School, OR (95% CI)	Emotions, OR (95% CI)	Social Acceptance, OR (95% CI)
No. of complete pairs ^a	413	391	360	411	391	376	374	399
Age, y								
7/8	—	1	1	—	—	1	—	—
9	—	1.2 (0.6–2.2)	0.9 (0.4–1.7)	—	—	2.9 (1.5–5.6)	—	—
10	—	3.5 (1.6–8.0)	1.9 (0.9–3.8)	—	—	2.0 (1.0–4.0)	—	—
11	—	1.2 (0.6–2.3)	2.3 (1.1–4.8)	—	—	1.6 (0.8–3.1)	—	—
12/13	—	1.0 (0.5–1.8)	2.4 (1.1–5.3)	—	—	1.3 (0.7–2.7)	—	—
P	—	.009	.01	—	—	.02	—	—
Gross motor function								
Walks, climbs stairs	—	—	—	—	1	—	—	—
Walks inside	—	—	—	—	0.8 (0.5–1.4)	—	—	—
Walks with limitations	—	—	—	—	2.7 (1.5–4.9)	—	—	—
Moving limited	—	—	—	—	0.6 (0.3–1.2)	—	—	—
Moving severely limited	—	—	—	—	1.0 (0.4–3.1)	—	—	—
P	—	—	—	—	.001	—	—	—
IQ								
>70	—	—	—	—	1	1	—	—
50–70	—	—	—	—	1.8 (1.1–3.0)	1.2 (0.7–1.9)	—	—
<50	—	—	—	—	^b	0.1 (0.01–0.9)	—	—
P	—	—	—	—	.02	.03	—	—
Communication								
Normal	—	—	—	—	—	—	1	1
Speech problems	—	—	—	—	—	—	0.8 (0.4–1.5)	0.6 (0.3–1.2)
Alternative forms of communication	—	—	—	—	—	—	0.2 (0.1–0.9)	0.2 (0.0–0.8)
P	—	—	—	—	—	—	.048	.01
Child behavior and emotions								
Normal	1	—	—	—	—	—	—	1
Borderline	1.7 (0.9–3.1)	—	—	—	—	—	—	2.3 (1.3–4.3)
Abnormal	1.9 (1.1–3.3)	—	—	—	—	—	—	2.6 (1.5–4.5)
P	.04	—	—	—	—	—	—	.0005
Parental stress								
Normal	—	—	1	1	—	1	—	—
Borderline	—	—	1.9 (1.1–3.2)	2.2 (1.4–3.4)	—	2.4 (1.5–4.0)	—	—
Abnormally high	—	—	2.2 (1.2–4.1)	2.7 (1.6–4.6)	—	2.0 (1.1–3.5)	—	—
P	—	—	.01	.0002	—	.002	—	—
Parental educational qualifications								
None or lowest qualification	—	—	1	—	—	—	—	—
Above lowest and below university	—	—	1.4 (0.8–2.5)	—	—	—	—	—
University degree completed	—	—	2.9 (1.2–6.6)	—	—	—	—	—
P	—	—	.04	—	—	—	—	—
Type of school								
Mainstream	—	—	1	—	—	—	—	—
Split mainstream and special unit	—	—	0.4 (0.2–0.9)	—	—	—	—	—
Special unit in mainstream school	—	—	0.4 (0.2–0.8)	—	—	—	—	—
Special school	—	—	1.4 (0.7–2.7)	—	—	—	—	—
P	—	—	.005	—	—	—	—	—

Final multilevel multivariable logistic regression models explaining disagreement (parent ratings lower than child ratings by more than half of an SD) versus agreement (absolute difference less than half of an SD) for each domain. Two domains were significantly associated with none of the studied variables at the multivariate level: self-perception and finances. OR indicates odds ratio; CI, confidence interval; —, no significant association at the multivariate level between the studied parameter and "parent < child disagreement."

^a Rates of agreement and "parent < child disagreement" are different in each domain, which explains the differences in numbers of complete pairs.

^b This category was grouped with the previous category because the model did not converge (all 5 children with IQ < 50 were in the disagreement group).

emotions domain has the second highest rate of agreement, whereas social support has one of the lowest rates.

As hypothesized, the factors that affect parent–child disagreement are not the same depending on the direction of disagreement, emphasizing the relevance of separately studying whether parents report higher or lower

QoL than the children themselves. The previously reported finding that agreement increases with the severity of the child's disease^{17,19} was partly supported by our data, which showed less disagreement for children with more severe intellectual and communication impairment. The factor most consistently associated with parents proxy reporting lower QoL than the child's own

TABLE 6 "Parent > Child Disagreement"

Parameter	Social Support, OR (95% CI)	Psychological, OR (95% CI)	Parental Relations, OR (95% CI)	Physical, OR (95% CI)	Autonomy, OR (95% CI)	School, OR (95% CI)	Emotions, OR (95% CI)	Social Acceptance, OR (95% CI)
No. of complete pairs ^a	201	217	242	256	278	286	318	333
Fine motor function								
No limitation	—	—	—	—	—	—	1	—
Both hands limited fine skills	—	—	—	—	—	—	2.7 (1.5–4.7)	—
Help needed	—	—	—	—	—	—	2.2 (1.1–4.5)	—
Help and equipment needed	—	—	—	—	—	—	0.7 (0.2–2.4)	—
Total assistance	—	—	—	—	—	—	1.8 (0.3–10.4)	—
<i>P</i>	—	—	—	—	—	—	.004	—
Seizures								
No seizures (with or without medication)	—	—	1	—	—	—	—	1
Seizures	—	—	7.4 (2.1–25.8)	—	—	—	—	3.0 (1.3–7.0)
<i>P</i>	—	—	.0002	—	—	—	—	.01
Child pain (child report)								
No pain	—	1	—	1	1	1	1	—
Slight pain	—	1.0 (0.4–2.3)	—	0.7 (0.3–1.7)	1.7 (0.8–3.7)	1.5 (0.8–3.1)	0.9 (0.4–2.0)	—
Moderate pain	—	1.6 (0.8–3.5)	—	1.4 (0.7–2.8)	2.0 (1.0–3.8)	1.4 (0.7–2.7)	1.5 (0.8–2.8)	—
Severe pain	—	1.8 (0.7–4.3)	—	2.0 (0.8–4.8)	2.1 (1.0–4.6)	2.4 (1.1–5.2)	2.3 (1.1–5.0)	—
Very severe pain	—	4.8 (1.5–15.5)	—	3.4 (1.2–9.7)	5.0 (1.9–13.3)	5.7 (2.2–14.6)	4.1 (1.7–9.9)	—
<i>P</i>	—	.05	—	.05	.01	.003	.009	—
Siblings								
At least 1 sibling (none disabled)	1	—	—	—	—	—	—	—
At least 1 disabled sibling	3.3 (1.1–9.7)	—	—	—	—	—	—	—
No siblings	1.7 (0.8–3.8)	—	—	—	—	—	—	—
<i>P</i>	.05	—	—	—	—	—	—	—
Parent educational qualifications								
None or lowest qualification	1	—	—	—	—	—	—	—
Above lowest and below university	2.6 (1.0–6.4)	—	—	—	—	—	—	—
University degree completed	4.0 (1.3–12.9)	—	—	—	—	—	—	—
<i>P</i>	.03	—	—	—	—	—	—	—
Parent occupation								
1 parent full-time professional	—	—	—	—	—	—	—	1
1 parent full-time trade	—	—	—	—	—	—	—	1.5 (0.8–3.0)
1 part-time; other does not work	—	—	—	—	—	—	—	0.4 (0.1–2.0)
Neither works	—	—	—	—	—	—	—	2.5 (1.1–6.0)
<i>P</i>	—	—	—	—	—	—	—	.04

Final multilevel multivariable logistic regression models explaining disagreement (parent ratings higher than child ratings by more than half of as SD) versus agreement (absolute difference less than half of an SD) for each domain. Two domains were significantly associated with none of the studied variables at the multivariate level: self-perception and finances. OR indicates odds ratio; CI, confidence interval; —, no significant association at the multivariate level between the studied parameter and "parent > child disagreement."

^a Rates of agreement and "parent > child disagreement" are different in each domain, which explains the differences in numbers of complete pairs.

rating is parental stress, with high levels significantly increasing the odds of "parent < child disagreement." This is consistent with Bastiaansen et al,⁴⁵ who found that mothers' parenting stress (measured using the Parental Stress Index) was associated with a poor child QoL in parent proxy reports but not in the child self-reports. There is evidence that agreement is affected by parental stress^{27,29} and that mothers who report their own health⁴⁷ or well-being⁶² as poor tend to rate their child's QoL more poorly. Several studies found statistically significant associations between parents' own QoL^{13,27} or their anxiety and depression^{22,46,63} and their proxy reports of child QoL. Another reported a significant effect of the interaction of parental QoL and child self-reported QoL in predicting parental proxy reports of their children's QoL.²³ In our study, parents rarely rated their children's QoL higher than the children's self-reports,

with severe self-reported pain being the predominant explanatory factor. This could be attributable to the previously demonstrated result that parents generally rate child pain as lower than the child's own rating.^{64,65} Four variables were never independently associated with disagreement in either direction: gender, family structure, feeding, and type of CP. As in other studies, we found no evidence that gender or family structure affected agreement.²⁹ Feeding and type of CP were weakly associated with disagreement at the univariate level, but this was no longer the case after adjustment for other indicators of the severity of impairment.

The major strength of this study is having sufficient numbers to examine predictors of parent-child agreement and study the direction of differences separately. The latter distinction has to our knowledge never been made before in studies of agreement. In 2 domains (self-

perception and finances), disagreement remains unexplained by any of the factors included in our study. This could be attributable to the statistical properties of the domain scores. The child and parent finances scores have substantially greater variability than other domains, and the self-perception score has the lowest reliability. Also, the Cronbach's α values of the children's scores were lower in all domains than the parents', suggesting less coherence in the children's responses. This may partly explain the greater variability of the children's scores as shown by the larger SDs. In cases in which another person was present while the child completed the questionnaire (usually the mother and/or siblings), this could have influenced the results. However, in 9 domains, another person's presence was not significantly associated with the rate of agreement (in the social support domain, agreement was greater when another person was present).

In this large European population of children with CP, children and parents did not give similar assessments of child QoL. Lack of agreement between children and their parents reflects their different views, and Eiser⁶⁶ even suggested that close parent-child agreement may be indicative of poorer QoL because "childhood is about gaining autonomy and independence from parental views." Such disagreement does, however, become problematic when the child's self-report of QoL cannot be obtained. We found that most parents consider their children's QoL to be lower than the children do. It seems that adverse circumstances in the parents' own lives negatively influence their perception of their child's QoL and lead them to report more difficulties for their child. Conversely, parents seem less able to assess the extent to which pain affects their child's life. Therefore, parental well-being and child pain should be taken into account by clinicians and researchers in the interpretation of parent proxy reports, especially when no child self-report of QoL is available. Because disagreement is less frequent when the child has lower IQ or lower ability to communicate, it would seem reasonable to use parental proxy reports in the latter cases, always bearing in mind that high parental stress and anxiety are likely to lead them to report low QoL for their child. It may also be advisable to try to obtain additional proxy reports (from caregivers, teachers, or medical staff) as complementary information on the child's QoL.

CONCLUSIONS

Parents have been and are still very often asked to assess their child's QoL, which is commendable provided that it is not used as a substitute for the child's own report. Research should continue to explore the relationship between proxy reports and self-reports for 2 fundamental reasons. The first is methodologic: some children, because of age or severe intellectual or physical impairment, may not be able to give an assessment of their

QoL. The second is conceptual: the parent and child have different perspectives on the child's life, both of which are valid and constitute important information concerning the child's well-being.

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