Parent and professional reports of the quality of life of children with cerebral palsy and associated intellectual impairment

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To examine parent-professional agreement in proxy-reports of child quality of life (QoL) and the factors associated with low child QoL in children with cerebral palsy (CP) and associated intellectual impairment. Professional (teacher, therapist, or residential carer) and parent reports of QoL for 204 children (127 males, 77 females, mean age 10y 4mo [SD 1y 6mo]; range 8–12y) with CP and IQ≤70 were obtained in 2004 to 2005 in nine European regions, using the KIDSCREEN questionnaire. Parent-professional agreement was studied using correlation and mean differences; multilevel logistic regression was used to determine factors influencing QoL reports and agreement. The mean parent-reported scores of child QoL were significantly higher than the professional reports in the Psychological well-being domain and significantly lower for Social support. The average frequency of disagreement (parent-professional difference >0.5SD of scores) over all domains was 62%. High levels of stress in parenting negatively influenced parent reports of child QoL compared with professional reports, while child pain was associated with professionals rating lower than parents. Proxies do not always agree when reporting the QoL of children with severe disabilities. Parental well-being and child pain should be taken into account in the interpretation of QoL reports in such children.

Although cerebral palsy (CP) is frequently associated with additional impairments, the quality of life (QoL) of the children with the most severe impairments is often overlooked. The assessment of the QoL of all children with CP is an aim of the European Study of PARticipation of children with Cerebral palsy Living in Europe (SPARCLE) project. The World Health Organization has recommended that measures of QoL in children use self-reporting wherever possible. Although children with CP and severe intellectual impairment are unable to self-report, the need to assess these children's QoL is no less important. Parents are often asked to report their child's QoL but our previous work[1] showed that parents and children frequently disagree. Thus, parent reports should not be considered as substitutes for child self-reports but rather as complementary information. It has been suggested that other proxies should be sought to complement parent reports.[1] In the few paediatric studies involving professionals, clinicians are the most frequent non-parent proxy-reporters of child QoL (e.g.[2–4]), although some studies asked nurses[5] or teachers.[6] A number of important methodological issues have not been addressed in the studies concerning parent and professional proxy-reports of child QoL. First, most studies rely only on correlation, which is insufficient to detect systematic differences, and only two studies examined factors that might explain parent-professional disagreement.[3,6] Second, in several studies,[2,4] the instruments used to measure child QoL were not the same for parents and professionals, thereby limiting the interpretability of the comparisons. Finally, none of these studies concerned children with significant intellectual impairment. The existing studies on the QoL of children with severe CP all rely exclusively on parent reports.[7–11] However, a number of studies have shown that parent reports of child QoL are influenced by their own health and psychological well-being (e.g.[12]). Medical staff, carers, and teachers are also likely to be influenced in their proxy-reports by the limited settings in which they know the child, but their experience with a broader cross-section of children may provide a valuable alternative perspective. Relying on a single informant is likely to lead to an incomplete assessment of the child's QoL. When several sources of information can be obtained, it is essential to understand the differences and the factors which influence disagreement.

The aim of this study was to compare the reports of parents and professionals of the QoL of 8 to 12-year-old children with CP and associated intellectual impairment (IQ≤70) from several countries in Europe. Our underlying conceptual basis was that each report provides complementary information on the child's well-being. We chose to study the direction of differences in reports – parent scores lower or higher than professional scores – and separately determine the factors associated with each of these situations. We also examined which factors were associated with low child QoL according to the parents and professionals.

As has been suggested in children with other chronic conditions,[3] we expected the agreement between parent and professional reports to be lower in subjective domains. Our main hypothesis was that the factors influencing disagreement would be different according to the direction of the differences. Child characteristics, socioeconomic factors, and parental well-being were tested for association with child QoL as reported by parents and professionals.

Method

POPULATION

In the SPARCLE study, children with CP were recruited from eight population-based CP registers in Denmark, France (two regions), Ireland, Italy, Sweden, and the UK (two regions), and from another region in noth-west Germany. The details of recruitment, sampling procedures and inclusion criteria are described elsewhere.[13] The children were visited at home by trained researchers between July 2004 and July 2005 and were 8 to 12 years old at the time of interview. Parent reports of child QoL were obtained for 818 children of all intellectual abilities. All children who could self-report (as judged by a standardized assessment[14]) reported their own QoL and these results have been published.[15] Two-hundred and ninety-six children with associated intellectual impairment (IQ≤70) could not self-report. As our aim was to obtain two reports of QoL for each child, permission from the parents was then sought to ask a professional of their choice, who knew the child well, to complete the same QoL questionnaire. QoL reports by professionals were available for 204 (69%) of the children.

All parents gave written consent, and all children with sufficient cognitive capacity gave written assent or communicated assent if unable to write. Ethics approval was obtained from the ethics committee in each country.

INSTRUMENTS USED

KIDSCREEN is a generic QoL questionnaire for children and adolescents (8–18y) validated on 22 110 European children from the general population.[16] It has child and parent/proxy versions which have the same 52 items covering 10 dimensions of QoL. For each domain, item responses are summed and a score out of 100 is computed with higher scores indicating better QoL; there is no global score. If only one item response in a domain is missing, it is replaced by the mean of the other responses in the domain; otherwise the domain score is considered missing.

The children's motor function was classified using the Gross Motor Function Classification System[17] and the Bimanual Fine Motor Function measurement.[18] Child pain was assessed by the parents and professionals using the two items from the Child Health Questionnaire[19] concerning frequency and intensity of pain, combined to give an overall score. Parental stress was measured using the Parenting Stress Index/Short form which consists of 36 items concerning three domains: Parental distress, Parent-child dysfunctional interaction, and Difficult child. The Total Stress score can be categorized into normal (71), borderline (72–90), and abnormal (>90) levels.[20]

STATISTICAL ANALYSIS

Cronbach's alphas were used to assess the reliability of professional and parent reports, and Pearson and intraclass correlations were used to examine the strength of the association between the professionals' and the parents' scores. Absolute values of the differences between parent and professional scores were calculated and we further defined agreement as occurring when this absolute value was less than or equal to half the SD of the scores (of the parents or the professionals, according to which had the largest variability), based on the widely recognized definition of clinically meaningful difference in QoL.[21] This threshold for agreement was between 6 and 11 points for the nine domains studied (Fig. 1). 'Parent<professional

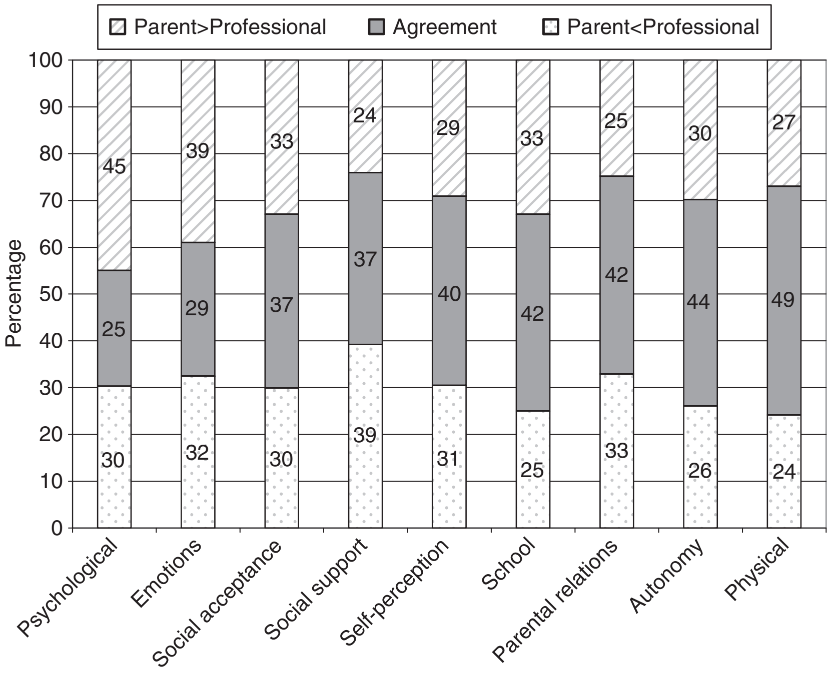

Figure 1: *Distribution of agreement between professional and parent reports (percentage of complete pairs. Agreement = parent – professional score ≤0.5 greatest SD of scores, i.e. threshold for each domain in the above order: Psychological: 8 points, Emotions: 7 points, Social acceptance: 6 points, Social support: 11 points, Self-perception: 7 points, School: 9 points, Parental relations: 9 points, Autonomy: 11 points, Physical: 10 points.*

disagreement' (respectively 'parent>professional disagreement') was defined as occurring when parents rated their child's QoL lower (respectively higher) than the professional's rating by more than the threshold for agreement.

Separate multilevel[22] logistic regression analyses of each disagreement category versus the agreement category were carried out in each domain (equivalent to multinomial regression). The following child characteristics were studied in relation to parent-professional disagreement: child age and sex, severity of gross and fine motor impairment, presence of associated impairments (type of feeding, communication, and IQ), and pain. The characteristics of the child's environment studied were: parental educational qualifications and occupation (characteristics of both parents were combined into a single 4-category score) and parental stress.

In order to determine which factors were associated with poor child QoL, parent and professional-reported domain scores were dichotomized using the lowest quartiles from the parent reports of the entire SPARCLE population of children with CP (i.e. including all degrees of severity).[23] Separate multilevel multivariable logistic regression analyses for parent and professional reports were carried out in each domain. All the factors listed above and the following additional variables were tested for association with poor child QoL: visual impairment, seizures, type of CP, family structure, and type of school attended by the child.

In all the regressions, multilevel modelling (two-level random effects models with a random intercept allowing for differences between regions) was used since observations within a region might be correlated. The factors studied were entered into the models as independent variables provided they were associated in the univariate analysis (with $p<0.20$). Backwards selection procedures were used (significance level for entry or removal: 5%). Final models excluded only observations with missing values on the included covariates. Goodness-of-fit was assessed using the Bayesian Information Criterion and models were rerun excluding influential observations to check stability.

Stata (version 9.2) (StataCorp, College Station, Texas) was used for all statistical analyses and the gllamm program (by S Rabe-Hesketh and A Skrondal) for the multilevel modelling.

Results

A full description of the group of children under study is given in Table I. The majority of children had severe motor and intellectual impairment and more than two-thirds of them could not communicate using speech. Of the parent respondents, 181 were mothers and 23 fathers. The professionals who completed the questionnaire were teachers (n=107, 52%), carers (n=54, 27%), or therapists (n=43, 21%). The median number of months the professionals had known the child was 36 (interquartile range [IQR]: 16–80) and the median number of hours per week spent with the child was 25.5 (IQR: 15–40.5). The children in the participant group (P, n=204 complete parent and professional QoL reports available) and non-participant (NP, n=92, only

Table I: Child, family, and environment characteristics (all regions, 204 children)

Age, y mean (SD)	10.3	(1.5)	IQ		
Sex			IQ 50–70	41	(20)
Males	127	(62)	IQ<50	163	(80)
Females	77	(38)	Vision		
Type of cerebral palsy			Has useful vision (>1/10 corrected)	159	(78)
Spastic unilateral	34	(17)	No useful vision	45	(22)
Spastic bilateral	123	(60)	Feeding		
Dyskinetic	40	(20)	By mouth without difficulty	73	(36)
Ataxic	7	(3)	By mouth with difficulty	86	(42)
Gross motor function (GMFCS) level			By tube (gastrostomy)	45	(22)
I Walks, climbs stairs	19	(9)	Child pain (parent report)		
II Walks inside	25	(12)	No pain	43	(21)
III Walks with limitation	26	(13)	Moderate pain	111	(55)
IV Moving limited	50	(25)	Severe pain	47	(23)
V Moving severely limited	84	(41)	*Missing*	3	(1)
Two-hand motor function (BFMF) level			Child pain (professional report)		
I No limitation	22	(11)	No pain	39	(19)
II Both hands limited fine skills	28	(14)	Moderate pain	111	(55)
III Help needed	41	(20)	Severe pain	37	(18)
IV Help and equipment needed	38	(18)	*Missing*	*17*	*(8)*
V Total assistance	75	(37)	Parent qualifications		
Communication			None or lowest qualification	56	(28)
Normal	21	(10)	Above lowest and below univ.	111	(54)
Speech problems	45	(22)	University degree completed	35	(17)
Alternative forms of communication	51	(25)	*Missing*	2	(1)
No formal communication	87	(43)	School type		
Parental stress			Mainstream	10	(5)
Normal	41	(20)	Mainstream and special unit	41	(20)
Borderline	63	(31)	Special unit	17	(8)
Abnormal (high)	89	(44)	Special school	127	(62)
Missing	11	(5)	*Missing*	9	(5)

Values are n (%) except for age. GMFCS, Gross Motor Function Classification System; BFMF, Bimanual Fine Motor Function.

parent QoL reports available) groups were comparable (no significant difference) in terms of age, sex, the main impairment variables (IQ, gross and fine motor function, communication) and pain, though there was a tendency for more severity in associated impairments in the participant group (no useful vision [P: 22% NP: 9%]) and fed using gastrostomy (P: 22% vs NP: 11%). Surprisingly, considering the above, significantly more children in the non-participant group attended special units or special schools (NP: 88% vs P: 70%). Also, the parents in the non-participant group reported higher levels of parenting stress than those in the participant group (NP: 54% vs P: 44%).

Response rates to the KIDSCREEN questionnaire were very good except for the Finances domain score which was missing in over half of the parent-professional pairs; as most of the non-missing scores were extreme (0 or 100), we excluded this domain from our study. The proportion of complete parent-professional response pairs was more than 70% in eight out of nine domains and the reliability of the reports was good (Cronbach's $\alpha \geq 0.60$) in most domains (Table II). Parents and professionals reported a very high QoL for the child in the Social acceptance domain (means 92.4 and 92.6 respectively), which asks whether the child is bullied or made fun of. On the contrary, they rated child QoL as very low in the Social support domain (means 37.8 and 44.4 respectively), which concerns the child's relationships with peers, and in the Physical well-being domain (means 47.6 and 46.7 respectively).

Only two significant differences were found between the mean parent and professional domain scores (Social support and Psychological; Table II). The average rate of disagreement over all domains was 62%. Rates of agreement ranged between 25% (Psychological) and 49% (Physical; Fig. 1). Correlations (Pearson and ICC) were below 0.41 in all domains (Table SI; supplementary material, published online).

Table III shows the univariate multilevel models explaining respectively 'parent>professional disagreement' and 'parent<professional disagreement'. Two variables were found to be significantly associated with greater odds of disagreement: child pain (as reported by the professional) and parental stress. When professionals reported severe child pain, they were more likely to rate the child's QoL as significantly lower than the parents (Physical and Parental relations domains), whereas the odds of parents rating QoL significantly lower increased with increasing parental stress (Emotions and Self-perception domains). All the other significantly associated variables reduced the odds of parent-professional disagreement in either direction. Increasing severity of intellectual impairment was associated with decreasing odds of both 'parent<professional' and 'parent>professional' disagreement in the Psychological domain. Similarly, parents and professionals were more likely to agree concerning the QoL of children with severe physical impairments, with less 'parent>professional' disagreement in the Self-perception domain concerning children with poor gross motor function and less 'parent<professional' disagreement in the Physical domain concerning those with more severe feeding impairment. Age was also significantly associated with parent-professional agreement, with reduced disagreement in either direction for older children in the Social support domain and less 'parent>professional' disagreement in the Social acceptance domain.

In two domains (Autonomy and School), none of the variables tested were associated with either type of disagreement. Six variables (child sex [female/male], fine motor function, communication impairment, parent-reported child pain, parental qualifications, and type of employment) were not significantly associated with either type of disagreement in any domain.

Table SII (supplementary material, published online) presents the variables independently associated with low child QoL in the parent proxy-reports (bold print) and professional proxy-reports (normal print) and shows that parent and professional reports of child QoL are not associated with the same variables (except for one association in the Parental relations domain).

High parental stress is significantly associated with low parent-reported child QoL in seven domains. Parents of children with severe physical impairment are significantly more likely to report poor QoL for their child (Physical, Social support and Autonomy domains). Child pain (parent-reported) is associated with higher odds of low child QoL in the parent reports in the Physical and Psychological domains. Parents with a university degree were significantly more likely to report lower QoL for their child in the Parental relations domain. None of the variables tested was significantly associated with parent-reported child QoL in the Social acceptance domain.

Table II: Mean and reliability of parent and professional reports

	Complete pairs	*Parent reports*			*Professional reports*		
	n (%)	*Mean (SD)*	*Reliability*[a]	*(95%CI)*[b]	*Mean (SD)*	*Reliability*[a]	*(95%CI)*[b]
Physical	173 (82)	47.6 (19.9)	0.75	(0.69)	46.7 (18.9)	0.80	(0.75)
Autonomy	155 (74)	57.3 (21.0)	0.75	(0.69)	55.7 (21.2)	0.82	(0.78)
Psychological	172 (82)	71.1[c] (16.3)	0.89	(0.87)	67.2 (15.8)	0.89	(0.87)
Emotions	149 (71)	83.0 (13.0)	0.81	(0.77)	81.3 (13.1)	0.84	(0.80)
Self-perception	135 (64)	82.8 (14.4)	0.58	(0.47)	81.8 (13.9)	0.56	(0.46)
Parent relations	157 (75)	79.0 (13.6)	0.63	(0.55)	80.5 (18.2)	0.82	(0.78)
Social support	153 (73)	37.8[d] (21.2)	0.84	(0.81)	44.4 (22.2)	0.85	(0.82)
School	170 (81)	74.2 (17.8)	0.87	(0.85)	71.5 (16.8)	0.89	(0.87)
Social acceptance	162 (77)	92.4 (10.8)	0.55	(0.44)	92.6 (9.7)	0.66	(0.57)

[a]Cronbach's alpha; [b]one-sided 95% confidence interval (CI; lower bound); [c]two-sided paired t-test between parent and professional mean scores: p=0.009; [d]two-sided paired t-test between parent and professional mean scores: p=0.002.

In the professionals' proxy-reports, the severity of the child's physical impairment was associated with lower child QoL in the Physical, Autonomy and Psychological domains. Professionals were less likely to report a low QoL for children with more severe communication impairment (School domain), children in special units or schools (Self-perception and Social acceptance domains), children with parents with higher educational qualifications (Psychological domain) and males (Emotions domain).

Discussion

To our knowledge, this is the first study on a large international population of children with motor and intellectual impairments which compares parent and professional reports of child QoL. The large population size allowed examination of whether child and family characteristics explained disagreement between parent and professional reports. However, the number of tests undertaken is fairly large compared with the size of the sample and caution is required in the interpretation of our results. Also, we did not have sufficient numbers to enable comparison of the different types of professional respondents (teachers, carers, and therapists) and this should be addressed in future research. A further issue, which could not be explored in this cross-sectional study and should be the subject of future longitudinal studies, is the probable change over time in parent/professional/child relationships, which is likely to influence their agreement on child QoL.

The relatively high level of non-response in our study is to be expected in a population of children with such severe impairment, where parents can feel that responding places too much of an extra burden on them. The study of the characteristics of the children in both populations (participants/non-participants) shows that they were broadly comparable. However, there is a difference in reported level of parental stress between both groups. As we found that higher levels of parental stress were associated with more disagreement between parents and professionals concerning child QoL, it is likely that we underestimated disagreement and would have found higher levels had we been able to include all parents.

Our definition of agreement takes the variability of the respondents' scores into account. By using the SD of the respondents with the largest variability, there is a risk of underestimating disagreement. However our concern was that by using too narrow a definition of agreement, one might classify as disagreement a difference which may simply be the result of measurement error.

Table III: Univariate multilevel logistic regression models explaining 'parent>professional' and 'parent<professional' disagreement (parent and professional ratings differ by more than half a standard deviation) versus agreement for each domain[a]

Parent>professional disagreement	*QoL domain OR 95%CI*					
Age, y	Social support			Social acceptance		
7–8	1			1		
9–10	0.1	0.03	0.4	0.3	0.1	0.9
11–13	0.3	0.1	1.1	0.2	0.1	0.6
			$p=0.004$			$p=0.01$
IQ	Psychological					
50-70	1					
<50	0.2	0.1	0.8			
			$p=0.01$			
Feeding	Social support					
By mouth without difficulty	1					
By mouth with difficulty	1.0	0.40	2.5			
By tube (gastrostomy)	0.2	0.03	0.9			
			$p=0.03$			
Child pain (professional report)	Physical			Parental relations		
No pain	1			1		
Moderate pain	2.6	0.8	8.4	6.0	1.3	28.3
Severe pain	7.5	2.0	28.6	6.3	1.2	34.0
			$p=0.005$			$p=0.02$
Gross motor function	Self-perception					
Walks, climbs stairs	1					
Walks inside	0.6	0.1	3.1			
Walks with limitations	2.5	0.4	14.6			
Moving limited	0.9	0.2	3.7			
Moving severely limited	0.2	0.1	0.9			
			$p=0.007$			

Parent<professional disagreement	*QoL domain OR 95%CI*					
Age, y	Social support					
7–8	1					
9–10	0.3	0.1	0.9			
11–13	0.9	0.3	3.2			
			$p=0.01$			
IQ	Psychological					
50–70	1					
<50	0.2	0.04	0.7			
			$p=0.005$			
Feeding	Physical					
By mouth without difficulty	1					
By mouth with difficulty	0.4	0.1	0.8			
By tube (gastrostomy)	0.3	0.1	0.8			
			$p=0.02$			
Parental stress	Emotions			Self-perception		
Normal	1			1		
Borderline	2.5	0.7	9.2	5.3	1.4	19.6
Abnormally high	6.2	1.5	25.0	2.2	0.6	7.8
			$p=0.02$			$p=0.02$

[a] Only those domains which are significantly associated with a studied variable are presented. QoL, quality of life; OR, odds ratio; CI, confidence interval.

The average parent-professional disagreement rate was high (62%), similar to the disagreement rate found between children and their parents (64%) in the self-reporting group of the SPARCLE project.[1] It concurs with previous evidence[3] of greater agreement between proxies for observable dimensions of a child's life compared with more subjective domains. We found approximately equal proportions of parents rating higher and parents rating lower than professionals in most domains, except for the Psychological domain (parents mostly rated higher) and the Social support domain (parents mostly rated lower). This is consistent with evidence that physicians report more emotional and psychological problems for children than parents do.[24]

We found that parents and professionals were more likely to agree about the QoL of children with severe impairments (in the Psychological domain for severe intellectual impairment, and in the Physical and Self-perception domains for physical impairment). As hypothesized, the factors increasing the odds of parent-professional disagreement were not the same depending on the direction of disagreement. Professionals were more likely to report lower child QoL than the parents in the Physical well-being and Parental relations domains when the child experienced severe pain. Unfortunately, the basic assessment of pain in our study does not enable us to be more specific as to the localization and supposed cause of the children's pain. Previous studies (with one exception[32]) have shown that professionals regarded child pain as more frequent than families[25,26] and a study concerning end-of-life child care found that, for physicians, the main determinant of the quality of their care was the amount of pain the child experienced, whereas for parents communication determined the quality of care.[27] We also found that parents reporting high levels of parenting stress were more likely to rate their child's QoL as lower than the rating given by professionals. These results are consistent with evidence that parents (and, in particular, mothers) who report their own health or well-being as poor tend to rate their child's QoL as worse than the ratings given by parents in good health.[12] Interestingly, this replicates what we found concerning child-parent disagreement in the group of less severely impaired children,[1] where parenting stress negatively affected parent reports while children self-reported significantly higher QoL, and children who reported pain rated significantly lower QoL than their parents.

Similar patterns emerged for both parents and professionals concerning physical impairment and pain, with increasing severity yielding increased odds of low child QoL. Other studies concerning parent reports of QoL for children with CP also found that the more severely physically impaired children had lower QoL in areas of physical functioning[8,11] and those experiencing pain had lower QoL and less social interaction.[28]

In all domains except two, high parental stress was significantly associated with low child QoL, as has previously been shown.[12] Several studies reported statistically significant associations between parents' own QoL and their proxy reports of child QoL (e.g.[29]), and a recent study found that parent QoL explained 62% of variability in child disease-specific QoL.[30] Parents of children with CP frequently experience high stress levels and negative health consequences due to the burden of care-giving.[31] Our cross-sectional study cannot establish whether the association between parental stress and child QoL is causal or not; however it has been suggested that when a parent feels overwhelmed by the stress associated with caring for their child with a disability, there can be negative implications for the child, the parent, and the family as a whole.[32] There is also evidence that heightened parental stress is associated with coercive parent-child interactions.[33] This is also consistent with our finding that, in professional reports, parental stress was only significantly associated with low child QoL in the Parental relations domain. However, it is equally possible that the relationship between child QoL and parental stress is bidirectional, with low child QoL also contributing to heighten stress in parents. Professionals reported low QoL for children in special schools less frequently than they did for children in mainstream schools. This may be because children with very severe impairments have less opportunity of negative interaction with non-disabled peers (Social acceptance), and those with very low intellectual abilities may not be sufficiently aware of themselves to care about the way they look or compare themselves to others (Self-perception).

Three main recommendations arise from this study. Professionals involved in the care of children with disabilities should pay special attention to the assessment and management of child pain (through detailed questions concerning localization and supposed cause) and direct their efforts towards helping parents cope with the burden of care-giving. Clinicians and researchers should be aware that parents and professionals have different perspectives on child QoL and that child pain and parental well-being are particularly important factors to take into account when assessing children's well-being. Future research should continue to include evaluation of child QoL from multiple sources and explore the relationship between proxy-reports.

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Supplementary material

The following supplementary material is available for this article online:

Table SI: Correlation and agreement in parent and professional reports

Table SII: Factors associated with low child QoL according to **parent proxy-reports (bold print)** and professional proxy-reports (normal print) (separate multivariate multilevel logistic regressions for each type of respondent and in each domain*).

This material is available as part of the online article from http://www.blackwell-synergy.com/doi/abs/10.1111/j.1469-8749.2008.03026.x (this will link you to the article abstract).

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