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Parent-Reported Quality of Life of Children With Cerebral Palsy in Europe

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ABSTRACT

OBJECTIVE. The goal was to determine whether the type and severity of the child's impairments and the family's psychosocial, social, and economic characteristics influence parent-reported child quality of life across the spectrum of severity of cerebral palsy.

METHODS. Our population-based, cross-sectional survey conducted in 2004 to 2005 involved 818 children with cerebral palsy, 8 to 12 years of age, from 7 countries (9 regions) in Europe. Child quality of life was assessed through parent reports by using the Kidscreen questionnaire, and data were analyzed separately for each of its 10 domains.

RESULTS. The parental response rates were >93% for all domains except one. Gross motor function and IQ level were found to be associated independently with quality of life in most domains. However, greater severity of impairment was not always associated with poorer quality of life; in the moods and emotions, self-perception, social acceptance, and school environment domains, less severely impaired children were more likely to have poor quality of life. Pain was associated with poor quality of life in the physical and psychological well-being and self-perception domains. Parents with higher levels of stress were more likely to report poor quality of life in all domains, which suggests that factors other than the severity of the child's impairment may influence the way in which parents report quality of life.

CONCLUSIONS. The parent-reported quality of life for children with cerebral palsy is associated strongly with impairment. However, depending on the areas of life, the most severely impaired children (in terms of motor functioning or intellectual ability) do not always have the poorest quality of life.

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Key Words

cerebral palsy, child, quality of life, proxy measures, gross motor function classification system, intellectual impairment

Abbreviations

CP—cerebral palsy
QoL—quality of life
GMFCS—gross motor function classification system
SPARCLE—Study of Participation of Children with Cerebral Palsy Living in Europe

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ALTHOUGH QUALITY OF life (QoL) has emerged as an important concept in childhood,¹ little is known about the QoL of children with disabilities, especially at the more severe end of the spectrum. It is now generally accepted that QoL is a subjective concept and therefore should be self-reported by the individual whenever possible.^{2,3} Evidence is accumulating that children can self-report QoL reliably, provided their emotional development, cognitive ability, and reading level are taken into account.⁴ However it may not be possible to obtain reliable information from children with severe intellectual impairments or significant communication problems, and the use of proxies (usually mothers) for the assessment of QoL in such children is necessary.⁵ The QoL of children with cerebral palsy (CP) is one of the main outcomes examined in the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), involving 9 regions across 7 European countries (www.ncl.ac.uk/sparcle). CP is the most common

significant motor impairment in childhood, occurring in 2.5 children per 1000 live births.⁶ Associated disorders such as intellectual impairment, epilepsy, visual and/or hearing impairments, and behavioral problems occur frequently.⁷ The SPARCLE project obtained QoL reports from as many children as possible,⁸ using a standardized assessment of response competence for those with associated intellectual impairment, to determine whether they were able to self-report.⁹ However, because one third of the children were unable to self-report, valid comparisons of QoL across the spectrum of children with CP must be based on proxy reports for the whole population.

Child characteristics such as age, gender, severity of disease, and pain have been shown to influence parent reports of child QoL in various chronic conditions, including CP. Previous studies provided conflicting evidence about the relationship of QoL to severity of motor impairment^{10–12} and suggested that domains related to physical symptoms may be more affected than social or emotional functioning domains.^{13,14} This may be attributable in part to the fact that physical aspects are more easily reported than psychological aspects. However, few studies examined the influence of other impairments in this population. Social contacts and activities with peers are reported to be reduced by chronic pain.^{13,15} Previous studies, mainly from the general population,^{16,17} suggested that children from lower socioeconomic backgrounds have significantly more negative experiences of health and well-being, but there is insufficient evidence to determine whether a similar relationship holds for children with disabilities. Parents' views of their children's QoL may also be affected by the burden of caregiving and their own mental health and well-being.^{18–22} Studies on the QoL of children with CP have focused mainly on small groups of children selected from clinics with homogeneous degrees of impairment severity, rather than the spectrum of impairments, and little is known about the influence of associated impairments in this population, despite the high prevalence of such difficulties. Our population-based study aimed to determine whether the type and severity of the child's motor and associated impairments, as well as the family context (socioeconomic factors and parental stress), influence the child's QoL, as reported by the parents. In particular, we wished to identify the factors associated with the lowest QoL in each domain, because it is important in clinical settings to be able to identify children more likely to have poor QoL. We hypothesized that the influence of impairment would differ according to the dimensions of QoL examined and that the factors associated with QoL would not be the same for different levels of impairment severity. We also expected parental stress to be associated with parent proxy-reports of child QoL.

METHODS

Population

Children with CP and their parents were recruited to the study from population-based CP registers that all belong

to a collaborative group sharing the same definition of CP and classification according to type and severity of impairments.⁶ The participating regions were in Denmark, France (2 regions), Ireland, Italy, Sweden, and the United Kingdom (2 regions). A total of 743 (63%) of 1174 families identified from registers agreed to participate, with families whose disabled children could walk unaided being more likely to decline to participate.²³ For another region in northwest Germany, a sample of 75 children was constructed from referrals by clinicians and statutory and voluntary bodies working with children with CP in a defined geographic area. The children were visited between July 2004 and July 2005 and were 8 to 12 years of age at the time of interview. This age range was chosen because these children are less well studied than preschool-aged children and have not yet entered adolescence, where additional factors may influence QoL. Children and families were visited in each region by researchers trained both to administer questionnaires to parents and to engage children for completion of their questionnaires. Families that were not fluent in the country's official language were excluded. Ethics approval was sought from the appropriate body in each country. Written parental informed consent and child assent were obtained. The detailed protocol is reported elsewhere.²⁴

QoL Measure

QoL was reported by using Kidscreen, a generic, health-related QoL questionnaire for children (8–18 years of age) that was validated psychometrically with 22 110 European children from the general population.²⁵ The instrument has a parent/proxy version with 52 items covering 10 dimensions, namely, physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relation and home life, financial resources, social support and peers, school environment, and social acceptance. Each domain includes 3 to 7 items. Item responses are summed to give a score of 0 to 100 for each domain, with higher scores indicating better QoL. The time required for administration is 15 to 20 minutes.

Child and Family Characteristics

The following child characteristics were recorded: age, gender, and type of CP (unilateral or bilateral spastic, dyskinetic, or ataxic). The severity of motor impairment was assessed by using the gross motor function classification system (GMFCS)²⁶ and the bimanual fine motor function measure.²⁷ The following associated impairments were also recorded: visual impairments, hearing impairments, seizures, feeding problems, communication problems, and intellectual impairment (based on either a formal IQ assessment, if one had been performed in the past year, or a cognitive description completed by the parents). The assessment of pain was derived from the pain domain of the Child Health Questionnaire,²⁸ with the time frame changed from the past 4 weeks to the past week to be consistent with Kidscreen. Parents were asked about the frequency and

intensity (6-point scales) of their child's pain/discomfort. The 2 items were then combined into an overall score, categorized as none, moderate, or severe pain/discomfort.

Parents provided general information about their family structure, their socioeconomic status (educational qualification, employment status, and occupation), the area of the family domicile, the child's siblings (disabled or not), and the type of school attended. Parental stress was assessed by using the Parenting Stress Index-Short Form, with scores categorized as normal (score: ≤ 71), borderline (score: 72–90), or abnormal (score: >90).²⁹

Statistical Analyses

A validation of the parent version of the Kidscreen questionnaire was conducted with the SPARCLE data. The overall internal consistency for all domains, as measured with Cronbach's α , was $>.70$ (range: .76–.92), except for the self-perception domain ($\alpha = .65$). Convergent and divergent validities were checked by using correlations between and within domains. Confirmatory factor analysis was performed to determine whether the main factors identified in the SPARCLE data were consistent with the domains used. All of the items were correlated most strongly with the factors corresponding to the predicted Kidscreen domains except for 2 items, namely, "Has your child been happy with the way he or she is?" and "Has your child been happy with his or her clothes?" These normally belong to the self-perception domain but were correlated more strongly with psychological well-being and parental relations, respectively.

QoL scores for each domain are reported as median and interquartile range. The proportions of respondents with the minimal (or maximal) possible scores for each domain were calculated, and floor (or ceiling) effects were considered to be present if these proportions were $>15\%$.³⁰ As proposed by the developers, missing items were replaced by the mean of the other items belonging to the same domain if no more than 1 item was missing for that domain.

To determine the factors associated with poor QoL, scores for each domain were dichotomized by using the lowest quartile as a cutoff point. Our clinical decision to focus on the children whose QoL was lowest led to the use of logistic regression rather than linear regression. For each domain, we performed a multivariate, multi-level (clustering the children within the regions), logistic regression analysis.³¹ Children's impairments and pain, family structure, socioeconomic status, and Parenting Stress Index scores were included as covariates in the initial multivariate model if they were related to QoL scores at the 20% significance level in the univariate multilevel analysis. A backward procedure was then used to remove variables from the model (1% significance level). Regression analyses excluded children who had missing values for any of the variables considered in the initial model. We tested for interactions between impairment and other variables in the final model. Models were reanalyzed by excluding the most influential observations to check stability. All analyses

TABLE 1 Characteristics of Children With CP ($n = 818$)

	<i>n</i> (%)
CP type	
Spastic unilateral	279 (34.1)
Spastic bilateral	423 (51.8)
Dyskinetic	86 (10.5)
Ataxic	29 (3.6)
Gross motor function	
Grade I: walks, climbs stairs	257 (31.4)
Grade II: walks inside	164 (20.1)
Grade III: walks with limitation	139 (17.0)
Grade IV: moving limited	113 (13.8)
Grade V: moving severely limited	145 (17.7)
Two-hand motor function	
Grade I: no limitation	281 (34.4)
Grade II: both hands limited in fine skills	205 (25.1)
Grade III: needs help with tasks	131 (16.0)
Grade IV: needs help and adapted equipment	91 (11.1)
Grade V: needs total human assistance	110 (13.4)
Intellectual impairment (IQ)	
>70	385 (47.3)
50–70	186 (22.9)
<50	242 (29.8)
Vision impairment	
Useful vision	759 (92.8)
No useful vision	59 (7.2)
Hearing impairment	
Does not need hearing aids	799 (97.8)
Profound or severe (loss of >70 dB)	18 (2.2)
Seizures	
No seizures in past year	650 (79.6)
Seizures, <1 per mo in past year	63 (7.7)
Seizures, >1 per mo in past year	104 (12.7)
Feeding	
Feeds by mouth without problems	583 (71.4)
Feeds by mouth but with difficulty	176 (21.5)
Partial or complete feeding by tube	58 (7.1)
Communication ability	
Normal communication	463 (56.7)
Problem but communicates with speech	133 (16.3)
Uses alternative formal methods to communicate	98 (12.0)
No formal communication	123 (15.0)
Child's pain/discomfort (parent's view)	
None	228 (28.3)
Moderate	432 (53.6)
Severe	146 (18.1)

were performed by using Stata 9 software (Stata, College Station, TX).

RESULTS

A total of 818 children were included in the study. The mean age was 10.4 years, and 59% of the children were boys. The children's characteristics in terms of type of CP, severity of motor impairment, and associated impairments are summarized in Table 1. The child's environment and the family characteristics are presented in Table 2.

The parental response rates were high (93%–97%) for all domains except the financial domain (79%). Table 3 presents descriptive results concerning the Kidscreen domain scores. The median scores were all >75 except for the following domains: autonomy (score: 65), physical well-

TABLE 2 Family Characteristics of Children With CP (n = 818)

	n (%)
Area of family domicile	
Urban	529 (64.9)
Rural	286 (35.1)
Parent educational qualifications	
None/lowest formal qualification	193 (23.8)
Above lowest and below university	505 (62.3)
University degree completed	113 (13.9)
Parental occupation	
≥1 parent working full-time or equivalent	628 (77.2)
Other	186 (22.8)
Family structure	
Married or living with partner	660 (80.9)
Single	156 (19.1)
Siblings	
≥1 sibling (none disabled/ill)	560 (68.6)
≥1 disabled/ill sibling	86 (10.5)
No siblings	171 (21.9)
School type	
Mainstream school	426 (53.0)
Special unit in mainstream school or special school	378 (47.0)
Parenting Stress Index	
Normal (≤71)	255 (32.5)
Borderline (72–90)	266 (33.9)
Abnormally high (>90)	264 (33.6)

being (score: 55), and social support (score: 50). The highest median score (score: 92) was in the social acceptance domain, where a ceiling effect was observed; 40% of the parents reported the maximal score for all 3 items in the domain. A ceiling effect was also observed in the financial domain, with almost 1 of 4 children being rated by the parents as having the maximal score. The results of the univariate multilevel logistic regression analyses are reported in Appendix 1. All of the variables except hearing impairment, area of domicile, and parental employment status were associated significantly ($P < .05$) with ≥1 domain and therefore were tested for inclusion in the corresponding multilevel multivariate models. Table 4 shows the final multivariate models for each domain.

Gross motor function and IQ level were independently associated, positively or negatively, with 4 and 3 QoL domains, respectively. Children with severely impaired motor function were more likely to have poor

QoL in the physical well-being and autonomy domains. Similarly, children with lower IQ were at higher risk of having a poor QoL in the social support domain. However, greater severity of impairment was not always associated with poorer QoL. The risk of poor QoL in terms of social acceptance and school environment decreased with increasing severity of gross motor impairment. Similarly, children with an IQ of <50 were less likely to have poor QoL in the moods and emotions and self-perception domains than were other children. Among the children's associated difficulties, parents tended to perceive children suffering from seizures more than once per month as having significantly poorer QoL in the social support domain. Pain was associated with poor QoL in 3 domains, namely, physical well-being, psychological well-being, and self-perception. Children whose parents had high educational qualifications had increased risk of poor QoL in the parental relations domain, whereas those living in single-parent households had poor QoL in the mood and emotions domain. Parents with higher levels of stress were more likely to report poor QoL for their child in all domains.

DISCUSSION

Although several studies have reported health-related QoL for children with CP,^{12,32–34} few studies^{13,14} have assessed parent-reported QoL across a comprehensive set of subjective domains for a representative series of children with CP covering all levels of severity. We found that the severity of motor and intellectual impairment was associated strongly with poor parent-reported QoL in the domains of physical well-being, autonomy, and social support, indicating that children with severe impairments are less able to create social time or to maintain relationships with other children. In contrast, in domains related to children's feelings or perception in different contexts, such as moods and emotions, self-perception, school environment, and social acceptance, QoL seemed to be better for children with very severe impairments than for their less severely impaired peers. Pain was found to be associated significantly with 3 domains and always worsened QoL. Parents with higher levels of stress were more likely to report poor QoL in all domains.

TABLE 3 Parent-Reported QoL for Children With CP

Domains	No. of Items	Response Rate, n (%)	Nonmissing Scores				Floor Effect, %	Ceiling Effect, %
			Mean	SD	Median	IQR		
Physical well-being	5	790 (97)	55.9	20.1	55	40–70	0.3	2.2
Psychological well-being	6	786 (96)	71.7	15.8	75	63–83	0.1	4.2
Mood and emotions	7	773 (94)	81.5	13.4	82	75–93	0.0	6.0
Self-perception	5	760 (93)	77.9	15.6	80	70–90	0.0	11.7
Autonomy	5	774 (95)	62.4	20.0	65	50–75	0.3	4.0
Parent relations/home life	6	787 (96)	76.9	15.4	79	67–92	0.0	8.6
Financial resources	3	649 (79)	64.5	32.9	75	50–92	11.1	24.4
Social support and peers	6	758 (93)	49.1	23.0	50	33–67	3.3	1.2
School environment	6	778 (95)	72.0	17.9	75	63–83	0.1	5.7
Social acceptance	3	771 (94)	85.9	16.7	92	75–100	0.3	39.8

IQR indicates interquartile range.

TABLE 4 Adjusted Odds Ratio for Covariates Affecting Parents' Reports of Their Children's QoL in Each Domain

Domains	Covariates	Odds Ratio (95% Confidence Interval)	P
Physical well-being (n = 761)	Gross motor function		
	Grade I: walks, climbs stairs	1	<.001
	Grade II: walks inside	2.2 (1.2–4.2)	
	Grade III: walks with limitation	3.4 (1.8–6.5)	
	Grade IV: moving limited	4.7 (2.5–9.0)	
	Grade V: moving severely limited	12.4 (6.5–23.5)	
	Pain/discomfort		
	None	1	<.001
	Moderate	2.5 (1.4–4.3)	
	Severe	5.2 (2.7–9.7)	
Psychological well-being (n = 754)	Parenting Stress Index		
	Normal	1	<.001
	Borderline	1.9 (1.1–3.4)	
	Abnormally high	3.5 (2.1–6.0)	
	Pain/discomfort		
	None	1	<.001
	Moderate	1.6 (1.02–2.4)	
	Severe	2.9 (1.7–4.9)	
	Parenting Stress Index		
	Normal	1	<.001
Mood and emotions (n = 744)	Borderline	2.6 (1.6–4.2)	
	Abnormally high	5.6 (3.6–8.9)	
	IQ		
	>70	1	<.001
	50–70	0.7 (0.4–1.1)	
	<50	0.3 (0.2–0.5)	
	Family structure		
	Married or living with partner	1	.01
	Single	1.6 (1.1–2.4)	
	Parenting Stress Index		
Self-perception (n = 728)	Normal	1	<.001
	Borderline	3.1 (1.9–4.9)	
	Abnormally high	6.9 (4.1–11.4)	
	IQ		
	>70	1	<.001
	50–70	0.6 (0.4–0.9)	
	<50	0.3 (0.2–0.5)	
	Pain/discomfort		
	None	1	<.001
	Moderate	1.8 (1.2–2.7)	
Autonomy (n = 750)	Severe	2.7 (1.6–4.4)	
	Parenting Stress Index		
	Normal	1	<.001
	Borderline	1.8 (1.2–2.6)	
	Abnormally high	2.4 (1.6–3.7)	
	Gross motor function		
	Grade I: walks, climbs stairs	1	<.001
	Grade II: walks inside	0.8 (0.5–1.3)	
	Grade III: walks with limitation	2.1 (1.3–3.3)	
	Grade IV: moving limited	1.6 (0.9–2.6)	
Parent relations/home life (n = 753)	Grade V: moving severely limited	2.6 (1.6–4.3)	
	Parenting Stress Index		
	Normal	1	<.001
	Borderline	1.7 (1.1–2.6)	
	Abnormally high	3.2 (2.1–4.9)	
	Parental qualification		
	None/lowest qualification	1	<.001
	Below university	1.6 (0.99–2.5)	
	University degree	4.1 (2.3–7.4)	
	Parenting Stress Index		
	Normal	1	<.001
	Borderline	3.1 (1.9–5.0)	
	Abnormally high	7.0 (4.3–11.3)	

TABLE 4 Continued

Domains	Covariates	Odds Ratio (95% Confidence Interval)	P
Financial resources (n = 630)	Parenting Stress Index		
	Normal	1	<.001
	Borderline	1.8 (1.1–2.7)	
Social support and peers (n = 728)	Abnormally high	3.3 (2.1–5.4)	
	Seizures		
	No seizures in past year	1	<.01
	Seizures, <1 per mo in past year	1.5 (0.8–2.9)	
	Seizures, >1 per mo in past year	2.3 (1.3–4.1)	
	IQ		
	>70	1	<.001
	50–70	1.7 (1.05–2.8)	
	<50	2.7 (1.6–4.3)	
	Parenting Stress Index		
School environment (n = 751)	Normal	1	<.001
	Borderline	1.9 (1.2–3.2)	
	Abnormally high	3.3 (2.0–5.4)	
	Gross motor function		
	Grade I: walks, climbs stairs	1	<.001
	Grade II: walks inside	0.6 (0.3–0.9)	
	Grade III: walks with limitation	0.4 (0.3–0.7)	
	Grade IV: moving limited	0.3 (0.1–0.5)	
	Grade V: moving severely limited	0.4 (0.2–0.8)	
	Parenting Stress Index		
Social acceptance (bullying) (n = 744)	Normal	1	<.001
	Borderline	2.6 (1.6–4.1)	
	Abnormally high	4.5 (2.8–7.1)	
	Gross motor function		
	Grade I: walks, climbs stairs	1	<.001
	Grade II: walks inside	0.7 (0.5–1.2)	
	Grade III: walks with limitation	0.4 (0.2–0.7)	
	Grade IV: moving limited	0.2 (0.1–0.4)	
	Grade V: moving severely limited	0.1 (0.1–0.2)	
	Parenting Stress Index		
	Normal	1	<.001
	Borderline	1.8 (1.2–2.8)	
	Abnormally high	2.7 (1.7–4.3)	

Multilevel logistic regression analysis explaining QoL scores of <25th percentile was performed.

The SPARCLE group chose to use a generic questionnaire rather than a CP- or disability-specific questionnaire, on the basis of the concept that the same standards for measuring QoL should be used for disabled and non-disabled children. The Kidscreen-52 proxy-rated questionnaire demonstrated good psychometric properties in a large sample of European children with various socioeconomic backgrounds and health conditions.³⁵ However, it had not been used previously in a population of children with CP. Compared with children from the general population,³⁵ the ranges of domain scores were similar in all but 3 domains, namely, autonomy, which “looks at the opportunities to create social and leisure time” (as described by the authors²⁵), physical well-being, which explores the “level of the child’s physical activity, energy and fitness,” and school environment, which corresponds to “the child’s/adolescent’s perceptions of their cognitive capacity, learning and concentration, and their feelings about school.” Our results showed that the lowest median score was in the social support domain. This suggests that, according to their

parents, these children are relatively lonely and have greater difficulty communicating with their peers. Previous studies found that, compared with healthy children, those with a chronic condition have fewer friends.^{36,37} In a sample of 12 adolescents (15–19 years of age) with restricted mobility, Skär³⁸ showed that the teenagers thought that “their disability had always restricted them in making social relations and that their disability was the reason why peers saw them as different.” Their peer-oriented social activities outside school settings were lacking.³⁸ These findings suggest that one possible reason why children have difficulties in building peer relationships may be attributable to both physical and social barriers, as described in the social model of disability.³⁹

A strength of this study is that it examined separately the influence of the severity of impairment on each domain. As described previously,⁴⁰ we found a strong positive trend between GMFCS results and the physical domain, with the most severely affected children being more likely to have poor QoL. However, an important

finding in our study was the relationship between physical ability and social functioning. Our results showed a lower risk of having poor QoL in the school environment and social acceptance domains among children with more severely impaired gross motor function. A possible explanation is that these children are less often in mainstream schools and thus less frequently in contact with their nondisabled peers. Children with disabilities were reported to be restricted in their involvement in community socialization activities,⁴¹ but type and degree of disability were not found to be correlated strongly with participation, especially in a school environment.⁴² Wake et al¹⁴ analyzed Child Health Questionnaire scores according to the severity of the physical disability. Scores on the behavior scale were significantly poorer for children who could walk independently (GMFCS level I/II) than for those who were wheelchair dependent (GMFCS grade IV/V), whereas scores on the role/social-emotional scale (exploring limitations in schoolwork or activities with friends as a result of emotional or behavioral problems) were similar across the spectrum of CP severity. In our study, parents' perception of children's QoL was also associated with intellectual impairment. Previous studies yielded conflicting conclusions. Two studies of parent-reported QoL that used the Child Health Questionnaire found similar scores for children with CP with or without intellectual impairment, one defining intellectual impairment as mild, moderate, or severe¹⁴ and the other as having an IQ of <70.⁴³ In contrast, Sabaz et al⁴⁴ found a specific relationship between health-related QoL and cognition in children with refractory epilepsy. Children with epilepsy and intellectual disability (IQ of <70) had significantly lower levels of emotional well-being, social functioning, and behavior, compared with intellectually normal children with epilepsy.

For children with CP, pain may result from impairments, from invasive medical, surgical, and rehabilitative procedures,⁴⁵ and from the common headaches and abdominal pain that all children experience.⁴⁶ Although some studies showed that parents could not estimate reliably the intensity of their children's pain,⁴⁷ we used parent reports in the analyses to perform valid comparisons across the whole population of children. As reported by the parents, >70% of children experienced some pain. This is consistent with previous research with adults with CP⁴⁸ and some studies with children with CP.^{33,49,50} However, Kennes et al¹³ reported a low prevalence of pain in a population-based sample of 408 children with CP; 90% were not restricted in activities by their level of pain, and 86% of those children were free of pain and discomfort all of the time. The impact of pain on children's QoL and participation were reported previously.^{15,51} In a study involving 198 children with moderate to severe CP (GMFCS level III–V), Houlihan et al¹⁵ found that pain was associated with educational and social consequences. This relationship was also reported in the general population, where restrictions in maintaining social contacts and activities with same-age friends were found to be associated with chronic and recurrent pain conditions.⁵²

The factor associated most consistently with lower

QoL was parental stress, with high levels of parental stress increasing significantly the risk of being in the lowest quartile of QoL in all domains. This is consistent with previous evidence that mothers^{19,22,53} or both parents^{20,54} who report their own health or well-being as poor tend to rate their children's QoL or emotional well-being more poorly. Because the study was cross-sectional, however, we are unable to establish the causal nature and direction of the relationship between parental stress and child QoL. These findings support the need to adjust for parental stress in models of parent-reported child QoL. From a clinical point of view, they emphasize the importance of considering stress management as a part of intervention programs that involve parents of children with special needs.⁵⁵

Another implication of these findings is that parent reports of child QoL should not be considered as equivalent to child self-reports but as reflecting different perspectives.^{18,56,57} In the SPARCLE project, however, most of the children with severe physical and intellectual impairment were unable to self-report, leading to the importance of using the parent's responses to report on the QoL of all children with CP, across the entire spectrum of disabilities.

Previous studies of children in the general population^{16,17,58,59} or with specific conditions such as obesity⁶⁰ tended to show that children have significantly higher QoL scores if their families have higher incomes, their parents have higher educational levels and are employed, or they live with both parents. In our study, socioeconomic determinants were associated weakly with QoL, as reported by the parents. We found that the risk of being in the lower quartile of QoL in the parental relations domain increased with higher levels of parental education. This could seem to contradict previous findings in the general population, but a possible explanation may be that parents with higher levels of education tend to have higher expectations for their child and the difference between those expectations and reality influences their assessment of their child's QoL negatively.

CONCLUSIONS

There is increasing interest in the QoL of children with CP. The spectrum of physical, cognitive, and communication impairments for these children is so broad that our results can be generalized to many disabled children. Our findings show the importance of asking families about different aspects of their child's QoL, especially when the child has associated severe intellectual disabilities. Because our results support the hypothesis that there are factors other than the severity of the child's impairment that influence how parents report their child's QoL, pediatricians should pay attention to the parents' well-being when they are concerned about the child's QoL and should be aware that there are important differences according to the domains examined. Additional population-based studies with a longitudinal design are required to enhance our understanding of the relationships between impairments, parental background, and child QoL.

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APPENDIX Univariate Multilevel (Grouping Children Within Centers) Models Explaining QoL Scores of <25th Percentile

Unadjusted Odds Ratio (95% Confidence Interval)										
	Physical Well-being	Psychological Well-being	Moods and Emotions	Self-perception	Autonomy	Parent Relations/ Home Life	Financial Resources	Social Support and Peers	School Environment	Social Acceptance
Gender										
Boys	1	1	1	1	1	1	1	1	1	1
Girls	1.2 (0.8–1.6)	1.4 (0.99–1.9)	1.0 (0.7–1.4)	1.4 (1.01–1.9) ^a	0.9 (0.7–1.2)	1.0 (0.7–1.3)	0.8 (0.6–1.2)	0.8 (0.5–1.1)	1.0 (0.7–1.4)	1.0 (0.7–1.4)
Age										
≤9 y	1	1	1	1	1	1	1	1	1	1
10 y	1.3 (0.8–2.0)	1.8 (1.2–2.7) ^a	1.5 (1.01–2.3) ^a	1.1 (0.7–1.6)	1.0 (0.7–1.6)	1.3 (0.8–2.0)	1.4 (0.9–2.3)	1.4 (0.9–2.2)	1.8 (1.1–2.7) ^a	1.2 (0.8–1.8)
≥11 y	1.3 (0.9–1.9)	1.8 (1.2–2.5) ^a	1.3 (0.9–1.8)	1.5 (1.1–2.1) ^a	1.5 (1.02–2.0) ^a	1.5 (1.03–2.1) ^a	0.8 (0.5–1.2)	1.1 (0.7–1.6)	1.6 (1.1–2.2) ^a	1.6 (1.1–2.2) ^a
GMFCS										
Grade I: walks, climbs stairs	1	1	1	1	1	1	1	1	1	1
Grade II: walks inside	2.7 (1.5–4.9) ^a	0.9 (0.6–1.5)	0.8 (0.5–1.2)	1.2 (0.8–1.9)	0.9 (0.5–1.4)	0.9 (0.5–1.3)	0.7 (0.5–1.2)	1.1 (0.7–1.9)	0.7 (0.4–1.1)	0.8 (0.5–1.2)
Grade III: walks with limitations	4.2 (2.3–7.7) ^a	0.8 (0.5–1.3)	0.9 (0.6–1.5)	1.2 (0.8–1.8)	2.2 (1.4–3.6) ^a	0.7 (0.4–1.1)	0.6 (0.4–1.1)	0.9 (0.5–1.7)	0.6 (0.3–0.9) ^a	0.4 (0.3–0.7) ^a
Grade IV: moving limited	6.0 (3.2–11.0) ^a	1.3 (0.8–2.1)	0.7 (0.4–1.2)	0.9 (0.5–1.4)	1.8 (1.1–3.0) ^a	0.6 (0.4–1.1)	1.0 (0.6–1.8)	2.7 (1.6–4.7) ^a	0.4 (0.2–0.7) ^a	0.3 (0.2–0.5) ^a
Grade V: moving severely limited	18.3 (10.1–33.1) ^a	1.3 (0.8–2.1)	0.6 (0.4–1.02)	0.5 (0.3–0.8) ^a	3.0 (1.8–4.8) ^a	0.9 (0.6–1.5)	1.1 (0.6–2.0)	2.7 (1.6–4.5) ^a	0.6 (0.4–1.01)	0.2 (0.1–0.3) ^a
Bimanual fine motor function										
Grade I: no limitation	1	1	1	1	1	1	1	1	1	1
Grade II: both hands limited in fine skills	1.5 (0.9–2.4)	0.8 (0.6–1.3)	0.9 (0.6–1.3)	0.9 (0.6–1.4)	1.1 (0.7–1.6)	1.0 (0.7–1.5)	1.1 (0.7–1.7)	1.1 (0.7–1.8)	1.0 (0.7–1.5)	0.8 (0.5–1.2)
Grade III: needs help with tasks	2.4 (1.4–4.1) ^a	0.9 (0.6–1.4)	0.9 (0.6–1.5)	1.1 (0.7–1.7)	2.0 (1.2–3.1) ^a	0.9 (0.6–1.5)	1.1 (0.6–1.8)	1.0 (0.6–1.8)	0.6 (0.3–0.9) ^a	0.8 (0.5–1.3)
Grade IV: needs help and adapted equipment	4.9 (2.7–8.8) ^a	1.0 (0.6–1.8)	0.6 (0.3–1.1)	0.4 (0.2–0.7) ^a	1.8 (1.02–3.1) ^a	1.1 (0.6–1.9)	1.1 (0.6–2.2)	1.6 (0.8–2.9)	0.5 (0.3–0.96) ^a	0.3 (0.2–0.6) ^a
Grade V: needs total human assistance	10.6 (6.1–18.9) ^a	1.6 (0.99–2.7)	0.8 (0.4–1.3)	0.6 (0.3–0.97) ^a	3.3 (2.0–5.6) ^a	1.1 (0.7–1.9)	1.7 (0.9–3.3)	5.2 (3.0–9.3) ^a	0.9 (0.5–1.5)	0.2 (0.1–0.4) ^a
Vision										
Normal vision	1	1	1	1	1	1	1	1	1	1
No useful vision	4.4 (2.4–8.2) ^a	1.2 (0.7–2.3)	1.1 (0.6–2.1)	0.3 (0.1–0.8) ^a	1.9 (0.97–3.6)	1.0 (0.5–1.8)	2.5 (1.1–5.8) ^a	5.7 (2.9–11.4) ^a	1.3 (0.7–2.5)	0.3 (0.1–0.8) ^a
Hearing										
Normal hearing	1	1	1	1	1	1	1	1	1	1
Needs hearing aids	0.9 (0.3–3.0)	1.1 (0.4–3.1)	1.2 (0.4–3.5)	2.1 (0.7–5.8)	1.0 (0.3–3.0)	1.2 (0.4–3.6)	2.5 (0.7–8.9)	1.2 (0.3–3.9)	0.8 (0.2–2.8)	1.3 (0.4–4.0)
Seizures										
No seizures in past year	1	1	1	1	1	1	1	1	1	1
Seizures, <1 per mo in past year	2.5 (1.4–4.4) ^a	1.5 (0.9–2.6)	1.3 (0.7–2.2)	0.9 (0.5–1.6)	1.6 (0.9–2.8)	1.3 (0.8–2.4)	2.3 (1.2–4.3) ^a	2.3 (1.3–4.3) ^a	1.0 (0.6–1.8)	1.4 (0.8–2.5)
Seizures, >1 per mo in past year	3.4 (2.1–5.5) ^a	1.5 (0.9–2.4)	1.2 (0.7–1.9)	0.6 (0.4–1.1)	1.1 (0.7–1.9)	0.7 (0.4–1.3)	1.7 (0.9–3.1)	4.2 (2.5–7.1) ^a	1.1 (0.6–1.8)	0.8 (0.5–1.4)
Feeding										
By mouth with no problems	1	1	1	1	1	1	1	1	1	1
By mouth with difficulty	2.8 (1.9–4.2) ^a	1.1 (0.7–1.6)	0.7 (0.5–1.03)	0.5 (0.4–0.8) ^a	1.4 (0.9–2.1)	0.9 (0.6–1.4)	1.5 (0.9–2.3)	2.2 (1.4–3.4) ^a	0.8 (0.5–1.2)	0.4 (0.2–0.6) ^a
Tube feeding	11.9 (6.2–22.9) ^a	1.7 (0.9–3.1)	0.7 (0.3–1.3)	0.3 (0.1–0.7) ^a	4.3 (2.3–8.1) ^a	1.1 (0.6–2.2)	2.0 (0.9–4.3)	3.1 (1.6–6.0) ^a	0.9 (0.5–1.9)	0.3 (0.1–0.7) ^a
Communication										
Normal	1	1	1	1	1	1	1	1	1	1
Speech problems	1.6 (0.96–2.5)	0.8 (0.5–1.3)	1.1 (0.7–1.7)	0.6 (0.4–0.9) ^a	1.6 (1.04–2.5) ^a	1.0 (0.6–1.6)	1.8 (1.1–2.9) ^a	2.4 (1.5–4.0) ^a	0.7 (0.4–1.1)	0.8 (0.5–1.2)
Alternative forms	2.4 (1.5–4.1) ^a	1.1 (0.7–1.8)	0.7 (0.4–1.1)	0.5 (0.3–0.9) ^a	1.5 (0.9–2.4)	0.8 (0.5–1.3)	1.4 (0.8–2.6)	2.3 (1.3–4.1) ^a	0.5 (0.3–0.9) ^a	0.4 (0.2–0.8) ^a
No formal communication	7.0 (4.3–11.3) ^a	1.2 (0.8–1.9)	0.7 (0.4–1.2)	0.3 (0.2–0.6) ^a	3.3 (2.0–5.3) ^a	1.3 (0.8–2.0)	1.9 (1.02–3.4) ^a	5.2 (3.1–8.7) ^a	0.8 (0.5–1.3)	0.2 (0.1–0.4) ^a

	Physical Well-being	Psychological Well-being	Moods and Emotions	Self-perception	Autonomy	Parent Relations/Home Life	Financial Resources	Social Support and Peers	School Environment	Social Acceptance
IQ										
>70	1	1	1	1	1	1	1	1	1	1
50–70	1.8 (1.2–2.8) ^a	1.0 (0.7–1.5)	1.0 (0.7–1.5)	0.7 (0.5–1.1)	1.7 (1.2–2.6) ^a	1.0 (0.6–1.4)	1.4 (0.9–2.2)	2.2 (1.4–3.5) ^a	1.0 (0.6–1.5)	0.9 (0.6–1.3)
<50	4.1 (2.8–6.1) ^a	1.1 (0.7–1.5)	0.6 (0.4–0.8) ^a	0.4 (0.3–0.6) ^a	2.2 (1.5–3.2) ^a	1.0 (0.7–1.5)	2.5 (1.6–3.9) ^a	4.6 (3.0–7.1) ^a	0.8 (0.5–1.2)	0.4 (0.2–0.5) ^a
CP type										
Spastic unilateral	1	1	1	1	1	1	1	1	1	1
Spastic bilateral	2.6 (1.7–3.9) ^a	1.0 (0.7–1.4)	0.8 (0.5–1.1)	0.8 (0.6–1.2)	1.8 (1.3–2.6) ^a	0.9 (0.6–1.2)	1.2 (0.8–1.7)	1.4 (0.9–2.0)	0.6 (0.4–0.9) ^a	0.5 (0.3–0.7) ^a
Dyskinetic	4.0 (2.2–7.3) ^a	0.7 (0.4–1.2)	0.6 (0.4–1.1)	0.4 (0.3–0.8) ^a	2.5 (1.5–4.3) ^a	0.5 (0.3–0.9) ^a	1.6 (0.8–3.0)	2.0 (1.1–3.6) ^a	0.5 (0.3–0.9) ^a	0.2 (0.1–0.5) ^a
Ataxic	1.0 (0.4–2.9)	0.5 (0.2–1.3)	0.6 (0.2–1.7)	0.2 (0.1–0.7) ^a	0.9 (0.3–2.2)	0.4 (0.2–1.2)	1.5 (0.5–4.2)	2.0 (0.8–5.0)	1.4 (0.6–3.2)	0.7 (0.3–1.6)
Child pain/discomfort										
None	1	1	1	1	1	1	1	1	1	1
Moderate	2.3 (1.4–3.7) ^a	1.8 (1.2–2.6) ^a	1.5 (0.99–2.1)	1.8 (1.2–2.6)	1.4 (0.96–2.1)	1.6 (1.1–2.4) ^a	1.2 (0.8–1.8)	1.1 (0.7–1.6)	1.3 (0.9–1.9)	1.1 (0.8–1.7)
Severe	7.6 (4.4–13.0) ^a	4.1 (2.5–6.6) ^a	2.1 (1.3–3.4) ^a	2.6 (1.6–4.2) ^a	2.2 (1.4–3.6) ^a	2.0 (1.2–3.2) ^a	1.2 (0.7–2.0)	1.2 (0.7–2.1) ^a	1.8 (1.1–2.9) ^a	1.3 (0.8–2.1)
Area of family domicile										
Urban	1	1	1	1	1	1	1	1	1	1
Rural	1.1 (0.8–1.5)	0.8 (0.5–1.1)	0.8 (0.6–1.1)	0.8 (0.6–1.2)	1.0 (0.7–1.4)	0.9 (0.6–1.3)	1.0 (0.7–1.4)	0.9 (0.6–1.3)	0.9 (0.6–1.3)	0.9 (0.7–1.3)
Parental qualifications										
None/lowest formal qualification	1	1	1	1	1	1	1	1	1	1
Below university	0.7 (0.5–1.1)	0.9 (0.6–1.3)	1.0 (0.7–1.5)	1.0 (0.7–1.5)	1.2 (0.8–1.7)	1.4 (0.9–2.1)	0.7 (0.5–1.1)	0.8 (0.5–1.2)	1.0 (0.7–1.5)	0.9 (0.6–1.4)
University degree	0.6 (0.3–1.1)	1.0 (0.6–1.7)	0.9 (0.5–1.6)	0.9 (0.7–1.5)	1.6 (0.96–2.7)	3.5 (2.0–6.1) ^a	0.7 (0.4–1.4)	0.8 (0.5–1.5)	0.9 (0.5–1.5)	1.1 (0.7–2.0)
Parental occupation										
≥ 1 parent working full-time or equivalent	1	1	1	1	1	1	1	1	1	1
Other	1.1 (0.8–1.7)	1.2 (0.8–1.8)	1.5 (1.1–2.2) ^a	1.0 (0.7–1.4)	1.1 (0.7–1.5)	0.8 (0.5–1.2)	1.3 (0.9–2.1)	1.0 (0.6–1.5)	1.1 (0.7–1.6)	1.1 (0.8–1.6)
Family structure										
Married or living with partner	1	1	1	1	1	1	1	1	1	1
Single	0.9 (0.6–1.4)	1.6 (1.1–2.3) ^a	1.7 (1.2–2.5) ^a	1.2 (0.8–1.7)	1.0 (0.7–1.5)	0.9 (0.6–1.3)	1.3 (0.9–2.1)	0.9 (0.6–1.5)	1.6 (1.1–2.4) ^a	1.1 (0.8–1.7)
Siblings										
≥ 1 healthy sibling	0.9 (0.6–1.3)	0.7 (0.5–1.1)	0.8 (0.5–1.1)	1.0 (0.7–1.5)	0.7 (0.4–1.3)	1.6 (1.1–2.5) ^a	1.6 (0.8–3.3)	1.1 (0.6–2.1)	0.9 (0.5–1.7)	1.3 (0.7–2.4)
≥ 1 disabled/ill sibling	1.1 (0.6–2.1)	0.7 (0.4–1.3)	0.8 (0.4–1.5)	1.0 (0.6–1.8)	0.9 (0.6–1.4)	1.7 (0.9–3.2)	1.1 (0.7–1.8)	1.1 (0.7–1.7)	1.0 (0.6–1.5)	1.4 (0.9–2.1)
No siblings	1	1	1	1	1	1	1	1	1	1
School type										
Mainstream	1	1	1	1	1	1	1	1	1	1
Special unit/special school	3.4 (2.3–5.0) ^a	0.9 (0.7–1.3)	0.8 (0.6–1.1)	0.5 (0.4–0.8) ^a	2.1 (1.5–2.9) ^a	1.0 (0.7–1.4)	1.5 (1.03–2.3) ^a	2.7 (1.8–4.0) ^a	0.8 (0.5–1.1)	0.6 (0.4–0.9) ^a
Parenting Stress Index										
Normal	1	1	1	1	1	1	1	1	1	1
Borderline	2.2 (1.4–3.6) ^a	2.5 (1.6–4.0) ^a	2.7 (1.7–4.1) ^a	1.5 (1.1–2.3) ^a	1.9 (1.3–3.0) ^a	3.2 (2.0–5.1) ^a	1.8 (1.1–2.9) ^a	2.0 (1.3–3.3) ^a	2.2 (1.4–3.5) ^a	1.4 (0.9–2.2)
Abnormally high	4.5 (2.9–7.2) ^a	6.1 (3.9–9.7) ^a	4.8 (3.1–7.4) ^a	1.8 (1.2–2.7) ^a	3.6 (2.4–5.5) ^a	6.8 (4.2–10.9) ^a	3.3 (2.1–5.4) ^a	4.3 (2.7–7.0) ^a	3.6 (2.3–5.6) ^a	2.0 (1.3–3.0) ^a

^a Significant odds ratio ($P < .05$).

Parent-Reported Quality of Life of Children With Cerebral Palsy in Europe

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