

Self-reported quality of life of 8–12-year-old children with cerebral palsy: a cross-sectional European study

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Summary

Background Little is known about the quality of life (QoL) of disabled children. We describe self-reported QoL of children with cerebral palsy, factors that influence it, and how it compares with QoL of the general population.

Methods 1174 children aged 8–12 years were randomly selected from eight population-based registers of children with cerebral palsy in six European countries and 743 (63%) agreed to participate; one further region recruited 75 children from multiple sources. Researchers visited these 818 children. 318 (39%) with severe intellectual impairment could not self-report; 500 (61%) reported their QoL using KIDSCREEN, an instrument with scores in ten domains, each with SD=10. Multivariable regression was used to relate QoL to impairments, pain, and sociodemographic characteristics. Comparisons were made with QoL data from the general population.

Findings Impairments were not significantly associated with six KIDSCREEN domains. Comparison of least and most able groups showed that severely limited self-mobility was significantly associated with reduced mean score for physical wellbeing (7·6, 95% CI 2·7–12·4); intellectual impairment with reduced mean for moods and emotions (3·7, 1·5–5·9) and autonomy (3·3, 0·9–5·7); and speech difficulties with reduced mean for relationships with parents (4·5, 1·9–7·1). Pain was common and associated with lower QoL on all domains. Impairments and pain explained up to 3% and 7%, respectively, of variation in QoL. Children with cerebral palsy had similar QoL to children in the general population in all domains except schooling, in which evidence was equivocal, and physical wellbeing, in which comparison was not possible.

Interpretation Parents can be reassured that most children aged 8–12 years with cerebral palsy will have similar QoL to other children. This finding should guide social and educational policy to ensure that disabled children participate fully in society. Because of its association with QoL, children's pain should be carefully assessed.

Introduction

The UN Convention on the Rights of the Child,¹ to which all European Union countries are signatories, states that children's views must be taken into account in all matters concerning them (article 12) and that disabled children are entitled to a “full and decent life” (article 23). Article 7 of the 2006 UN Convention on the Rights of Persons with Disabilities² emphasises the right of disabled children to express their views.

Good quality of life (QoL) is a key outcome for the individual child and is what society wants for all children. QoL is defined by WHO as “an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”.³ QoL is therefore subjective and so must be reported by the individual concerned whenever possible. This is a challenge when assessing children's QoL because they have typically been regarded as unreliable respondents.⁴ Evidence is accumulating that children can self-report QoL reliably if their emotional development, cognitive ability, and reading level are taken into account.⁵

Little is known about QoL of disabled children and previous studies usually included few children,^{6–8} did not use population-based samples,^{9–14} or relied on parental reports.^{9,12,14–17} A further difficulty in some

studies that purport to capture QoL is that the instruments used focus on function and activities,^{18,19} therapeutic consequences,¹² or effect on parents.⁹ Such studies inevitably rate disabled children lower than the general population, but it is misleading to call their outcome measures QoL because children's satisfaction with their lives might not correspond to their ability to undertake certain tasks or activities²⁰ or to the consequences for their family.

Children with cerebral palsy have a range of impairments that are typically present in many disabled children. The objective of this report is to describe the QoL of children with cerebral palsy as reported by the children themselves, to identify factors that affect this QoL, and to compare it with the QoL of children in the general population.

The phrase “disabled child” rather than “child with disability” will be used in this paper, although we recognise that there are arguments for and against each phrase.²¹ In particular, those in agreement with the social model of disability²² will agree with the phrase “child with impairment” but prefer “disabled child” because the child is disabled by society or the environment. The phrase “child with disability”, although laudable for being child centred, nevertheless implies that the disability is something residing in or intrinsic to the child.

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	Measured perceptions of these aspects of life	Groups that reported poorer QoL compared with other children
Physical wellbeing (5)	Physical activity, energy, and fitness	Girls, older children, and children whose parents had a lower employment status
Psychological wellbeing (6)	Positive emotions and satisfaction with life	Older children, children living with one parent, and children whose parents had higher educational qualifications
Moods and emotions (7)	Negative moods, boredom, and stress	Girls and children whose parents had a lower employment status
Self-perception (5)	Self, bodily appearance, and body image	Girls and older children
Autonomy (5)	Freedom of choice and self-determination in leisure time	Children whose parents had higher educational qualifications
Relationships with parents (6)	Interactions and relationships with parents and the socioemotional atmosphere at home	Older children and children whose parents had higher educational qualifications
Social support and peers (6)	Social support available from friends and peers	Boys
School environment (6)	Learning and feelings about school and teachers	Boys, older children, and children living with one parent
Financial resources (3)	Adequacy of pocket money relative to peers	Younger children and children living with one parent
Social acceptance (3)	Social acceptance or rejection by peers, including bullying	Children living with one parent and children whose parents had lower educational qualifications

Number of questions contributing to each domain is shown in parentheses.

Table 1: Description of each KIDSCREEN domain and the associations of QoL in each domain with sociodemographic characteristics for children in the general population

For more on KIDSCREEN see <http://kidscreen.diehauptstadt.de/>

Methods

Participants and procedures

The research is part of the wider Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), which examines how the QoL and participation of children with cerebral palsy relate to their environment, within the conceptual framework of the social model of disability.²² Only aspects relevant to this report are summarised below because the SPARCLE protocol, sampling strategy, participation rates, and potential bias have been reported in detail elsewhere.^{23,24}

Children were eligible for the study if born between July 31, 1991, and April 1, 1997, and on registers of children with cerebral palsy that cover eight regions of six European countries (southeast France, southwest France, southwest Ireland, west Sweden, north England, Northern Ireland, east Denmark, and central Italy). There were 1884 such children. In regions with more than 200 registered children, we sampled so that the number who agreed to participate would be 100–120, and we sought similar numbers of children at each level of severity by grouping children by walking ability and selecting random samples from within strata. In other regions, we approached all eligible children. 1174 eligible families were approached and 743 (63%) agreed to participate.²⁴ A further region in northwest Germany recruited 75 children from multiple sources; the age, sex, and levels of impairment of these children were similar to those of children recorded on the population-based registers.²⁴ Thus, the sample consisted of 818 children.

These children were visited at home in 2004–05 by researchers who administered questionnaires to parents and children, if possible when the children were 8–12 years old. To suit family circumstances, 20 children were interviewed when just under 8 or just over 12. Parents were asked if their child would be able to understand a questionnaire, and if this was unclear their child's understanding was assessed by a test that required the child to order cubes of different sizes.²⁵ 500 (61%) children were capable of reporting their own QoL and experience of pain. Of the 318 who could not self-report, 296 (93%) had an IQ below 70.

Self-reported QoL in the previous week was assessed with KIDSCREEN,²⁶ a modern instrument with excellent psychometric properties, which uses questions derived from focus-group work with children across Europe to assess the QoL of children and young people.^{26–29}

The ten domains of KIDSCREEN are summarised in table 1. Because translations in Danish and Italian were not available from the instrument's developers, these were undertaken according to international guidelines.³⁰ Items are scored on a five-point scale and, within each domain, item scores are summed and transformed to Rasch person parameters by an algorithm that gives children in the reference population a mean score of 50 with an SD of 10.²⁹ The validity of this approach was confirmed for the children with cerebral palsy because all domains fulfilled the assumptions of a Rasch model and displayed no sizeable differential item functioning across disabled and non-disabled children (Erhart M, Robert Koch Institute, personal communication; full details are available on request from the corresponding author). Scores were available for more than 97% of children on all domains except perception of financial resources (89%). The proportions of children scoring maximum and minimum values were similar to those reported for children in the general population.²⁶ All domains had acceptable Cronbach α values³¹ of 0.7 or higher, except self-perception at 0.59.

Frequency and severity of pain were assessed with the two questions about pain from the Child Health Questionnaire,³² with the time period changed from 4 weeks to 1 week for consistency with KIDSCREEN. In the analysis, children who reported pain in response to either question were compared with those who did not.

Parents provided information about their employment, educational qualifications (table 2), and area of domicile (table 3), and about their child's gross motor function,³³ fine motor function,³⁴ seizures, feeding, communication, intellect, school type, and siblings (table 3). Cerebral palsy type was available from the registers.

Comparative data for children in the general population were available from the developers of KIDSCREEN for children aged 8–12 years in five countries in the SPARCLE study:²⁶ France, Germany, Ireland, Sweden, and the UK. The children's sex and age had been recorded in all five countries; family structure, parental employment, and

educational qualifications had been recorded in all except Sweden and Ireland.

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

Statistical analysis

Stata statistical software (version 9.2) was used for statistical analysis.

Regression models were used to relate each domain of children's QoL to sociodemographic characteristics, pain, and impairments. All models were adjusted for region (children with cerebral palsy) or country (general population). Linear regression was used for all KIDSCREEN domains except for social acceptance; because scores on this domain had a skewed distribution, with 48% of children achieving the maximum, logistic regression was used to compare children in the lowest quartile with the others. Initial models analysed each covariate in turn and excluded children with missing values on any of these covariates; the final multivariable models excluded only children with missing values on the included covariates. All factors were treated as categorical variables.

We first assessed how QoL of children in the general population varied with sociodemographic characteristics. For each KIDSCREEN domain, we used regression to relate QoL to each sociodemographic characteristic (sex and age of the child, family structure, and employment and educational qualifications of the parents) in turn, while adjusting for country. Because family and parental characteristics were not recorded in two countries, we included these characteristics in the models by treating them as interactions with country. All factors identified as significant ($p < 0.05$) were then included in a multivariable model and the least significant factors ($p > 0.05$) were then successively removed. Interactions between main effects of age, sex, and country were included if they were statistically significant ($p < 0.05$). *p* values were derived from the likelihood ratio test statistic.

We next assessed how QoL of children with cerebral palsy varied with impairments and pain. Children were assigned sampling weights to allow for the sampling strategy; therefore, robust SE values and Wald *p* values were used.³⁶ For each KIDSCREEN domain, we used regression to relate QoL to pain, impairments, and the additional sociodemographic characteristics available only for disabled children (type of school, siblings, and area of domicile), considering each factor separately. We adjusted these regressions for the sex and age of the child, family structure, and parental employment and educational qualifications using the relations estimated from the general population (external adjustment using offsets), and we made additional internal adjustment for region. Final multivariable models were developed with the aforementioned backwards stepwise procedure, but to lessen the probability of chance findings due to multiple

	Number from general population (n=3219)	Number with cerebral palsy in countries with general population data (n=379)	Total number with cerebral palsy (n=500)
Country and region			
France:	512 (16%)	85 (22%)	85 (17%)
Southeast	..	38	38
Southwest	..	47	47
Germany: northwest	798 (25%)	45 (12%)	45 (9%)
Ireland: southwest	359 (11%)	67 (18%)	67 (13%)
Sweden: west	406 (13%)	46 (12%)	46 (9%)
UK:	1144 (36%)	136 (36%)	136 (27%)
North England	..	78	78
Northern Ireland	..	58	58
Denmark: east	NA	NA	81 (16%)
Italy: central	NA	NA	40 (8%)
Sex			
Boys	1611 (50%)	219 (58%)	286 (57%)
Girls	1602 (50%)	160 (42%)	214 (43%)
Information not available	6 (0%)	0 (0%)	0 (0%)
Age (years)			
7	0 (0%)	3 (1%)	7 (1%)
8	372 (12%)	73 (19%)	98 (20%)
9	611 (19%)	86 (23%)	105 (21%)
10	717 (22%)	76 (20%)	93 (19%)
11	608 (19%)	81 (21%)	105 (21%)
12	911 (28%)	56 (15%)	79 (16%)
13	0 (0%)	4 (1%)	13 (3%)
Family structure*			
Married or living with partner	1965 (80%)	306 (81%)	408 (82%)
Single	154 (6%)	73 (19%)	92 (18%)
Information not available	335 (14%)	0 (0%)	0 (0%)
Parental employment*			
At least one parent works full time professionally (or equivalent)	959 (39%)	95 (25%)	132 (26%)
Intermediate	965 (39%)	200 (53%)	260 (52%)
One parent works part time or neither parent works	497 (20%)	84 (22%)	106 (21%)
Information not available	33 (1%)	0 (0%)	2 (1%)
Parental educational qualifications*			
Above university entrance	741 (30%)	73 (19%)	126 (25%)
Intermediate	1025 (42%)	204 (54%)	260 (52%)
Lowest formal qualification or none	278 (11%)	99 (26%)	111 (22%)
Information not available	410 (17%)	3 (1%)	3 (1%)

NA=general population data not available for Denmark and Italy. ..=not applicable because general population data were from a national sample. *Excluding general population in Sweden and Ireland.

Table 2: Distribution of sociodemographic characteristics of children in the general population and children with cerebral palsy

hypothesis testing, the *p* value for removal of factors from the multivariable model was set at $p > 0.01$. For factors with several ordinal categories, *p* values for trend were assessed. Models were checked for interactions, influence and sensitivity analyses were undertaken, and plots of residuals were examined. To investigate whether pain mediated a relation between impairments and QoL, we used logistic regression to relate pain to impairments, adjusting for region.

	Number (%)
Impairment	
Gross motor function	
I Walks and climbs stairs, without limitation	218 (44%)
II Walks with limitations	118 (24%)
III Walks with assistive devices	93 (19%)
IV Unable to walk, limited self-mobility	49 (10%)
V Unable to walk, severely limited self-mobility	22 (4%)
Bimanual fine motor function	
I Few restrictions	241 (48%)
II&III Moderate restrictions	219 (44%)
IV&V Severe restrictions	40 (8%)
Seizures	
No seizures (either with or without medication)	456 (91%)
Seizures	44 (9%)
Feeding	
No problems	446 (89%)
Feeds orally with difficulty, or by tube	54 (11%)
Communication	
Normal	409 (82%)
Difficulty but uses speech	66 (13%)
Uses non-speech for formal communication	25 (5%)
No formal communication	0 (0%)
Intellectual impairment	
None or mild (IQ >70)	363 (73%)
Moderate or severe (IQ ≤70)	134 (27%)
Information not available	3 (1%)
Cerebral palsy subtype	
Unilateral spastic	220 (44%)
Bilateral spastic	235 (47%)
Dyskinetic or ataxic	44 (9%)
Information not available	1 (0%)
Pain	
Reported no pain during previous week	217 (43%)
Reported pain during previous week	272 (54%)
Information not available	11 (2%)
Sociodemographic characteristics	
Schooling	
Mainstream school	290 (58%)
Mainstream school and visits special unit	65 (13%)
Special unit in mainstream school	46 (9%)
Special school	97 (19%)
Information not available	2 (0%)
Siblings	
None	86 (17%)
One or more, none disabled	347 (69%)
One or more, one or more disabled	58 (12%)
Information not available	9 (2%)
Area of domicile	
City	79 (16%)
Town or suburbs	244 (49%)
Village or countryside	175 (35%)
Information not available	2 (0%)

Table 3: Children with cerebral palsy (n=500): distribution of impairment, pain, and additional sociodemographic characteristics available only for these children

Finally, we compared QoL of children with cerebral palsy with that of children in the general population of the five countries in SPARCLE for which general population data were available. For each KIDSCREEN domain (except for physical wellbeing, which needed a minor amendment to one item to make it more suitable for children with cerebral palsy), multivariable regression was used to compare QoL in children with cerebral palsy with that in the general population, both unadjusted and adjusted for country and for sociodemographic characteristics that were significant in the general population.

Role of the funding source

The funding source and sponsor, the European Commission, had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

The general population sample consisted of 3219 children whose sociodemographic characteristics are shown in table 2. The final multivariable models, adjusted for country, are summarised in the right-hand column of table 1. QoL on all domains varied with sociodemographic factors—in particular sex, age, parental employment status, parental educational qualifications, and whether the child lived with one or two parents. However, these models explained only 4–13% of the variation in QoL. There were no significant interactions between age, sex, and country.

500 (61%) of the 818 children in the SPARCLE study self-reported their QoL. Tables 2 and 3 summarise the number of children with cerebral palsy who were recruited in each geographical area and the type and severity of impairments, experience of pain, and sociodemographic characteristics of these children. More than half reported pain in the previous week but logistic regression indicated that pain was not significantly associated with any impairments: for example, the odds ratio comparing reporting of pain by children who were unable to walk with that of children who walked “without limitation” (ie, gross motor function classifications IV and V vs I) was 1.0 (95% CI 0.5–1.7).

We then examined how QoL on each KIDSCREEN domain varied with impairments, pain, type of school, siblings, and area of domicile, analysing each of these factors separately but adjusting for region and for the relations between QoL and sociodemographic characteristics that were significant in the general population (detailed results of regression models are available from the corresponding author on request). Impairments were not significantly associated with QoL on six domains: psychological wellbeing, self-perception, social support and peers, school environment, financial resources, and social acceptance (all $p > 0.01$). Children who reported pain in the previous week tended to report a lower QoL on

all ten domains, although the association was statistically significant for only five.

The relation of QoL with impairments and pain differed little between the aforementioned models—which included each type of impairment separately—and the final multivariable models (table 4), indicating the absence of association between these factors. Specific impairments were associated with poorer QoL for only four domains: poorer walking ability was associated with poorer physical wellbeing; intellectual impairment was associated with poorer moods and emotions and with less autonomy; and speech difficulty was associated with poorer relationships with parents. Pain was significantly associated with poorer QoL for these four domains and also for the self-perception and school domains.

These associations were confirmed by sensitivity analysis with weights that allowed for non-response. Although poorer walking ability was significantly associated with better QoL on the school domain in the primary analysis, this trend was not significant in the sensitivity analysis and so was omitted from the final model. Further sensitivity analysis, with internal adjustment for all sociodemographic characteristics, yielded similar results. There were no significant interactions between the main effects in the final models. Exclusion of children with the largest residuals changed the estimates little. Plots of residuals showed no systematic pattern, but the variance of QoL was generally lower for extreme values, so significant findings should be interpreted cautiously.

In the final multivariable model, impairments, pain, and region together accounted for up to 17% of the variation in QoL; in univariable models, they accounted for up to 3%, 7%, and 8%, respectively (table 5).

Finally, we compared the QoL of the 379 children with cerebral palsy in France, Germany, Ireland, Sweden, and the UK with that of children in the general population in these countries. The children with cerebral palsy were more likely than children in the general population to be boys and children under 12 years, to live with a single parent, and to have parents with lower employment status and lower educational qualifications (table 2). The QoL of the two groups is summarised in the figure.

Physical wellbeing was not formally analysed because the questions in this domain had required slight modification for children with cerebral palsy. Multivariable regression indicated that the QoL of the children with cerebral palsy was similar to that of children in the general population in all other domains except for the school environment, where children with cerebral palsy had significantly better QoL ($p \leq 0.001$), both unadjusted and after adjustment for country; further adjustment for all relevant sociodemographic characteristics gave similar results. However, in Northern Ireland, which had a high non-response rate (51%), children with cerebral palsy had a higher QoL for all domains than did other children in the UK (both those with cerebral palsy in north England and those in the general population of the UK). Sensitivity

	b* (95% CI)	p
Physical wellbeing (n=481)		
Gross motor function		
I Walks and climbs stairs, without limitation	0.0	NA
II Walks with limitations	-0.7 (-3.5 to 2.2)	0.65
III Walks with assistive devices	-1.8 (-5.1 to 1.5)	0.28
IV Unable to walk, limited self-mobility	-4.0 (-7.7 to -0.4)	0.03
V Unable to walk, severely limited self-mobility	-7.6 (-12.4 to -2.7)	0.002
p for trend		0.005
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-6.4 (-8.9 to -4.0)	<0.0001
Psychological wellbeing	Not significantly associated with any of the factors considered	
Moods and emotions (n=473)		
Intellectual impairment		
None or mild (IQ>70)	0.0	NA
Moderate or severe (IQ≤70)	-3.7 (-5.9 to -1.5)	0.001
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-3.5 (-5.4 to -1.6)	0.0003
Self-perception (n=482)		
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-3.0 (-5.2 to -0.9)	0.005
Autonomy (n=481)		
Intellectual impairment		
None or mild (IQ>70)	0.0	NA
Moderate or severe (IQ≤70)	-3.3 (-5.7 to -0.9)	0.006
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-4.7 (-6.8 to -2.6)	<0.0001
Relationships with parents (n=480)		
Communication		
Normal speech	0.0	NA
Difficulty with speech or no speech	-4.5 (-7.1 to -1.9)	0.001
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-3.1 (-5.3 to -0.8)	0.007
Social support and peers	Not significantly associated with any of the factors considered	
School environment (n=485)		
Pain		
Reported no pain during previous week	0.0	NA
Reported pain during previous week	-4.8 (-7.2 to -2.4)	<0.0001
Financial resources	Not significantly associated with any of the factors considered	
Social acceptance	Not significantly associated with any of the factors considered	

Regression models are adjusted for region and for sociodemographic characteristics. n=number of children included in model. NA=not applicable. *b-coefficients indicate the difference in QoL between the relevant category and the reference category; b-coefficients <0 indicate a lower QoL in the corresponding category.

Table 4: Multivariable linear regression models relating KIDSCREEN domains to impairment and pain in children with cerebral palsy

analysis that excluded this group showed no significant difference between the QoL of disabled children and the

general population in the school domain ($p=0.23$) but autonomy was significantly lower ($p=0.004$) in the children with cerebral palsy.

Discussion

For children with cerebral palsy, type and severity of impairments were not associated with QoL for six KIDSCREEN domains: psychological wellbeing, self-perception, social support, school environment, financial resources, and social acceptance. Specific impairments were associated with poorer QoL in the four other domains: children with poorer walking ability had poorer physical wellbeing; those with intellectual impairment had lower moods and emotions and less autonomy; and those with speech difficulty had poorer relationships with their parents. Despite these associations, impairments explained little of the variation in the QoL of children with cerebral palsy. Average differences in QoL between children with

gross motor function levels I and V were less than 1 SD of the QoL in the general population.²⁶ Differences between children with and without intellectual and communication impairment were of similar magnitude to the combined effect of social factors such as parental education, parental employment, and family structure.

Pain was associated with poorer QoL for all domains but explained little of the variation in QoL. It was not significantly associated with impairments.

The QoL of children with cerebral palsy was, on average, similar to that of children of the same age in the general population in all domains except for the school environment, in which it was better. However, sensitivity analysis indicated that there might be little difference in the school domain, and that autonomy might be lower in the disabled children than in the general population.

This study has several strengths: participants were sampled from children with cerebral palsy in nine defined geographic areas, eight of which had population-based registers; QoL was captured with a new European questionnaire (KIDSCREEN) that has strong psychometric validity, was developed by eliciting the views of children,^{26,27} and is based on a sound theoretical framework that emphasised perception of psychosocial aspects of wellbeing rather than functioning or symptoms; QoL was reported by children themselves rather than by parents or other proxies; and all children who self-reported were included, irrespective of their impairments. However, some children with intellectual impairment cannot self-report and interpretation of their parent-reported QoL presents special problems,³⁷ which we are examining and will report separately.

Although 37% of families of children with cerebral palsy were non-responders, we have previously investigated the potential for non-response bias,²⁴ and in the present report we allowed for different levels of non-response in different groups in a sensitivity analysis. Nevertheless, the QoL of non-responders might have been systematically different from that of responders, and so additional bias could be present. Such potential bias might explain the apparently better QoL at school of the children with cerebral palsy compared with the general population. Furthermore, these samples came from separate studies,²⁶ and regional samples of disabled children were compared with national samples of the general population. Ideally, children with cerebral palsy would have been compared with concurrent samples from non-disabled children, but the additional cost of visiting even one control for each child with cerebral palsy would have been prohibitive. Use of the KIDSCREEN general population data, which were obtained only 2 years previously from a large sample in European countries covered by our study, was a reasonable compromise.

Previous studies of children with cerebral palsy provide conflicting evidence about the relation of QoL to motor impairment, and few examine other impairments. Varni and colleagues¹¹ used the PedsQL instrument on a convenience sample of 69 children aged 5–18 years; in this study, QoL was significantly poorer for the four domains of

	r^2 impairment*	r^2 pain*	r^2 region*	R^2 total†
Physical wellbeing	2%	7%	8%	17%
Moods and emotions	3%	4%	3%	9%
Self-perception	NA	3%	6%	8%
Autonomy	2%	6%	8%	14%
Relationships with parents	3%	3%	6%	11%
School environment	NA	6%	8%	11%

NA=not applicable because QoL on this domain was not significantly associated with impairment. * r^2 is % variance explained by impairment, pain, and region in separate univariable models. † R^2 is % variance explained jointly by impairment, pain, and region in multivariable models.

Table 5: Percentage of variation explained by univariable and multivariable linear regression models relating KIDSCREEN domains to impairment and pain in children with cerebral palsy

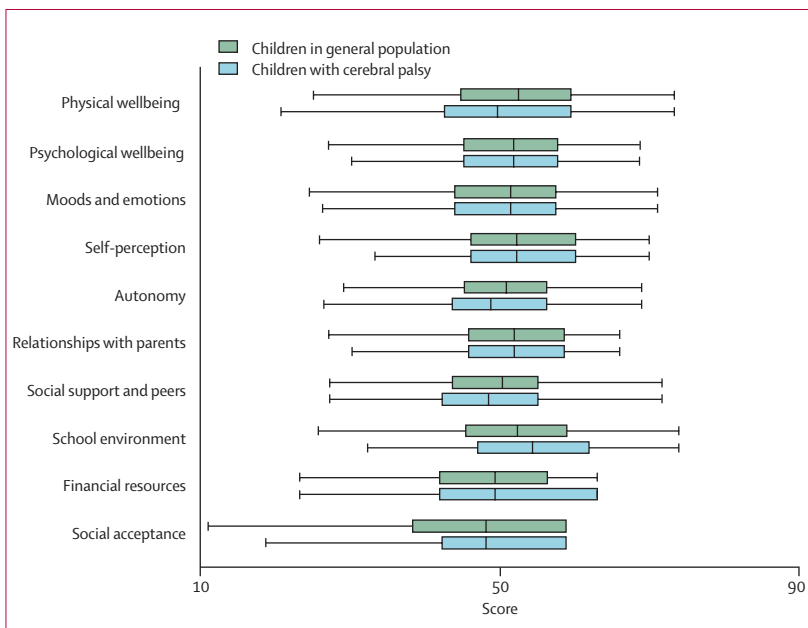


Figure: Box and whisker plots of KIDSCREEN quality of life scores by domain for children with cerebral palsy and children in the general population
The scales for each domain have mean=50 and SD=10 in the reference population.²⁶

PedsQL—physical, emotional, social, and school function—in children with bilateral spastic cerebral palsy than in those with unilateral cerebral palsy, whereas we identified no significant associations between QoL and laterality. However, the social and school domains used by Varni and colleagues included questions about function and participation, whereas KIDSCREEN focuses entirely on subjective perceptions. Two studies^{9,14} used parental reports from the Child Health Questionnaire; this questionnaire captures aspects of function, physical health, and effect on family,³² but only two of its domains—psychological wellbeing and self-esteem—overlap with KIDSCREEN. In the first study, QoL was poorer in more impaired children;⁹ in the second, epilepsy was associated with poorer self-esteem, but neither intellectual nor motor impairment was associated with self-esteem or psychological wellbeing.¹⁴ A population-based study of parental reports for children aged 5–13 years reported, as we did, no association between severity of motor impairment and emotional wellbeing.¹⁵ Studies in disabled children without cerebral palsy had contrasting findings: for example, in children with mobility impairment³⁸ or spina bifida¹⁷ severity of impairment was not related to QoL, but in children with arthritis it was.³⁹

Few studies have compared self-reported QoL of children aged 8–12 years who have cerebral palsy with that of the general population of the same age. In their study of children aged 5–18 years, Varni and colleagues¹¹ reported that QoL was lower than in the general population but they did not report scores by age group. A recent systematic review⁸ of self-concept in children with cerebral palsy covered six of the KIDSCREEN domains but included only six suitable studies, the largest of which assessed only 64 children; there was insufficient evidence to establish whether self-concept was lower in the disabled children than in those without cerebral palsy. Studies of children with spina bifida,⁴⁰ rheumatoid arthritis,⁷ physical impairments,^{6,13,41} and behaviour and learning difficulties¹⁰ provide conflicting evidence about how the QoL of these children compares with that of the general population. It is difficult to compare these studies with each other or with our study because of the small numbers,^{6,7,40,41} non-representative samples,^{6,7,10,41} and different age ranges.^{6,7,10,13,40,41}

The lack of association between pain and impairments in our study could be because we excluded children who could not self-report, reducing statistical power in the group of children with severe intellectual impairment who are more likely to have severe motor and other impairments. However, our finding is supported by a population study¹⁵ that elicited parents' reports of their children's pain.

Our finding that pain was associated with poorer QoL on all domains is confirmed by studies of children with cerebral palsy,^{15,16} mobility impairment,³⁸ and arthritis.^{42,43} In our sample, 54% had experienced pain in the previous week, a higher prevalence than in the general population.^{44–46} However, we did not study the source of the pain, which could

be similar to the general pains that all children experience. Furthermore, children with poor QoL might perceive pain differently or report emotional distress as pain.

We think our robust study design, with large numbers of children from several countries, sampling from population registers, and an instrument for self-reporting directed at the subjective, allows our conclusions to resolve apparent conflicts in previous results.

Whereas specific domains of QoL of children with cerebral palsy are associated with specific impairments, QoL on most aspects of life is not associated with impairments and is therefore likely to be determined largely by social and environmental factors, although these might differ between children with cerebral palsy and those with no disability.

Our cross-sectional design cannot attribute causality, but improvement in physical function might plausibly enhance physical wellbeing, and improvement in speech and communication might plausibly improve a child's perception of relationships with parents and home life. Every effort should be made to ask about and treat pain because it is common in children with cerebral palsy and is associated with reduced QoL across all domains. The effectiveness of such interventions should be assessed in randomised controlled trials.

Is it surprising that subjective QoL of children with cerebral palsy is similar to that of the general population? Possibly, from the perspective of a non-disabled adult imagining what it would be like to be disabled,⁴⁷ but probably not from the perspective of a child whose sense of self from birth incorporates their impairment and who embraces growth, development, and living with the same excitement as most children. Many parents are upset when their child is diagnosed with cerebral palsy, but they can now be reassured that most children with cerebral palsy who can provide information when 8–12 years old experience similar QoL to that of other children of their age.

There is widespread acceptance of the need for disabled children to be integrated fully into society.^{1,2} The change now needed concerns attitudes. Pity and sorrow should not be directed to disabled children because our findings indicate that they experience most of life as do non-disabled children. Therefore, maximum effort is needed to support social and educational policies that recognise the similarity between the lives of disabled children and those of other children, and that ensure their right as citizens, rather than as disabled children, to participate fully in society.

Contributors

AFC, GS, UT, CA, EB, JF, VM, SIM, and JP participated in the planning of the study. AFC coordinated the study and took overall responsibility for the delivery of the work. GS, UT, CA, EB, JF, VM, SIM, and JP had responsibility for data collection. UR-S provided full information about the KIDSCREEN instrument, coordinated the collection of general population data, and assisted with its validation for the disabled children in this study. HOD did the statistical analysis. KNP was responsible for the day-to-day administration of the study and data collection in one centre. AFC, HOD, and KNP participated in writing the paper. All authors have seen and approved the final version.

Conflict of interest statement

We declare that we have no conflict of interest.

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