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Health status of children with cerebral palsy living in Europe: a multi-centre study

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Abstract

Aim The aim of this report is to describe the health status of 8–12-year-old children with cerebral palsy (CP) of all severities in Europe using the Child Health Questionnaire (CHQ).

Method A total of 818 children with CP from nine centres in defined geographical areas participated. CP type, gross and fine motor function, additional impairments were classified and family data were obtained. The CHQ was used to measure the parent's perception of their child's physical (PHY) and psychosocial (PSY) health.

Results PHY scores were lower than the reference samples with a median of 46. The severity of gross motor function influenced the CHQ scores significantly in the PHY scale with the lowest scores for children with least gross motor function. There were significant differences between the CP types in PHY with the higher scores for children with unilateral spastic and the lowest scores for children with bilateral spastic and dyskinetic CP type. Fine motor function severity significantly affected both the PHY and PSY scales. The severity of intellectual impairment was significantly associated with CHQ scores in most dimensions with higher scores for higher IQ level in PHY and PSY. Children with seizures during the last year had a significantly lower health compared with children without seizures. The results of the multivariate regression analyses (forward stepwise regression) of CHQ scores on CP subtype, gross and fine motor function, cognitive function, additional impairments, seizures, parental education and employment revealed gross motor function, cognitive level and type of school attended were significant prognostic factors.

Conclusion This report is based on the largest sample to date of children with CP. Health status as measured using the CHQ was affected in all children and was highly variable. Gross motor function level correlates with health from the PHY well-being perspective but the PSY and emotional aspects do not appear to follow the same pattern.

Keywords
child, child health questionnaire, disability, well-being

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Introduction

The relationship between quality of life (QOL), participation, and environment are being studied within a multicentre European study of 8–12-year-old children with cerebral palsy (CP) (SPARCLE, http://www.ncl.ac.uk/sparcle/). CP is the most common cause of significant physical impairment in children and occurs in two per 1000 live births (SCPE 2000, 2002; Himmelmann *et al*. 2005). Every year about 10 000 children in the European Union before its recent expansion are diagnosed with CP, a condition which can take many different forms. In the majority of cases the children's health and well-being are affected.

The health of children with CP depends on several factors, including the severity of CP, the environment, care and interventions. The International Classification of Functioning, Disability and Health is a framework for understanding the bio-psycho-social factors and interactions that can influence the life of children with CP (WHO 2001; Liptak & Accardo 2004). Physical status is the measurement of a child's ability (or capacity) to perform a variety of activities usual for a child in good health. It is often observable standardized activities such as walking, talking, eating, dressing etc. Psychosocial status or well-being is a psychological state and refers to a state of mind that can not be inferred from observable behaviour alone. Personal evaluations reflect the values or preferences of the parent or child, providing an overall summary of health status. Personal evaluations also reflect the impact of specific symptoms and other health states experienced, but not explicitly captured by functional status or well-being measures (Landgraf *et al*. 1996).

The meaning of the concept QOL is debated. A problem with many definitions of QOL and Health-related QOL (HRQOL) is that they often are complex and difficult to operationalize (Eiser & Morse 2001). QOL has been defined by the World Health Organization (WHO) as 'the individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'(WHO 1993). HRQOL refers to an individual's perception of his or her health, which as defined by the WHO consists of physical well-being, mental well-being and social well-being (WHO 1993). In children, HRQOL includes not only concepts of illness, functional status, mental health and comfort, but also parental impact and family functioning.

There are a number of disease-specific and generic measures available with which to assess the impact of CP. The Child Health Questionnaire (CHQ) (Landgraf *et al*. 1996) has been developed as a health questionnaire for children and adolescents. A recent review (McCullough & Parkes 2007) found 13 publications concerning children with CP since 2001. The CHQ demonstrated good psychometric properties for children with CP in an Australian study of health status of children with mild to severe CP (Wake *et al*. 2003). In general, children with CP had lower mean scores and markedly poorer health on every CHQ scale than those in the normative sample. A review and evaluation of the psychometric properties of the CHQ has recently been published (McCullough & Parkes 2007). Children with severe CP had the poorest physical health. In another population-based study of children with moderate to severe CP, the study group scored significantly below the mean on the CHQ for Pain, General Health, Physical Functioning and Impact on Parents (Liptak *et al*. 2001).

This paper is the fourteenth to be published on the CHQ in children with CP since 2001 but is based on a much larger sample than previous studies. Furthermore, this paper is based on children in Europe whereas previous work relates to the US or Western Australia (McCullough *et al*). Therefore, this report can offer some definitive answers on the health status of children with CP in Western Europe.

The aim of this report is to describe the health status of children with CP of all severities in Europe using the CHQ.

Subjects

The population of children with CP in the study came from eight population-based registers of children in a defined geographical area: north England, west Sweden, Northern Ireland, southeast France, southwest France, southwest Ireland, east Denmark and central Italy. A further region in northwest Germany recruited children from multiple sources; the age, gender and levels of impairment were similar to those of children on the population-based registers.

Each child classified for impairment by type and severity. These registers make every effort to be comprehensive and share the same definition of CP (SCPE 2000). Full details of the sample and potential for bias are published (Dickinson *et al*. 2006).

The age group studied was 8–12 years with dates of birth 31/7/1991 and 01/4/1997 inclusive (i.e. between 12 years 11 months and 7 years 3 months on 1st July 2004). In order to maximize numbers in the smaller centres, the youngest in the cohort were not approached until reaching age 8 years and the oldest approached before they became 13. Because milder CP makes up the majority of CP, in centres with sufficient overall number of cases (Northern Ireland, east Denmark, west Sweden, north England) stratification according to walking

Table 1. CHQ domains, number of parent respondents, median and inter-quartile range

CHQ domain	No. items	Description	*n*	Median	IQR
Physical Functioning	6	Presence and extent of physical limitations because of health-related problems	778	89	(50–100)
Role/Social Limitations – Emotional Behavioural	3	Captures limitations to school life and activities with friends because of emotional or behavioural difficulties	785	100	(67–100)
Role/Social Limitations – Physical	2	Captures limitations to school work and activities with friends because of physical health	791	100	(67–100)
Bodily Pain	2	Used as an indicator of physical health	806	70	(50–100)
Behaviour	6	Measures the frequency of behaviour problems and ability to get along with others, and as well as a global rating of child's behaviour overall	792	73	(64–83)
Mental Health	5	Captures anxiety, depression and positive effect	800	75	(65–85)
Self-esteem	6	Captures satisfaction with school, athletic ability, appearance, ability to get along with others and life overall	783	75	(65–88)
General Health	6	Assessment of overall health and illness	809	64	(46–77)
Parental Impact – Emotional	3	Capture amount of distress experienced by parent in respect of aspects to do with the child	807	75	(50–83)
Parental Impact – Time (PT)	3	Capture amount of limitation in personal time experienced by parent in respect of aspects to do with child	803	89	(56–100)
Family Activities	6	Assesses the frequency of disruption in usual family activities because of the child's general health and well-being	805	79	(58–96)
Physical summary scale			737	46	(33–54)
Psychosocial summary scale			737	50	(43–56)

CHQ, Child Health Questionnaire; INR, Inter-quartile range.

ability was carried out before randomization to ensure that children with all severity of CP were represented in sufficient numbers. The eligible sample in those centres was all children in the relevant age group after stratification and randomization. In the other centres the eligible sample was all those children on the registers in the relevant age group.

Methods

Cerebral palsy subtype was divided into spastic unilateral, spastic bilateral, dyskinetic and ataxic as defined by a European collaboration (SCPE 2000). Gross motor function was classified according to the Gross Motor Function Classification System five-level grading (GMFCS) (Palisano *et al.* 1997). The focus is on the child's self-initiated movements. For hand function the Bimaual Fine Motor Function (BFMF) five-level grading system was applied (Beckung & Hagberg 2002). The focus is on grasping and holding. Cognitive level was divided into IQ > 70, IQ 70–50 and IQ < 50; vision as normal versus blind or no useful vision (0.3 corrected on the best eye or blindness); hearing as normal versus severe hearing impairment (loss > 70 dB); seizures in last year yes or no. The study protocol has been described in detail (Colver 2006).

Child Health Questionnaire

The CHQ is a measure of the physical and psychosocial health of children 5 years of age and older. The conceptual framework of the CHQ is that health is constructed from two unique yet complementary dimensions of physical and psychosocial (emotional, behavioural and social) well-being and deficits in either dimension. It measures the concepts shown in Table 1.

Parent-perceived health status was assessed using the CHQ PF50 50-item questionnaire. The CHQ assesses physical functioning, behaviour, mental health, general health, social and family functioning, family cohesion, self-esteem, pain and the impact of health issues on parental time and emotions. It comprises 13 single- and multi-item child health scales and was developed for children in the general population (for which normative data are available), and for children with chronic conditions (Landgraf *et al.* 1996). There are also two summary measures – Physical health and Psychosocial health. Scoring of the Physical and Psychosocial summary measures involves three steps. First, the 10 domain scales are standardized using means and standard deviations (SD) from the combined general US population and six clinical samples (Landgraf *et al.* 1996). Second, the scales are aggregated using

weights (factor score coefficients) from the same normative and clinical datasets. Finally, the aggregate scores are standardized using a linear T-score transformation (mean of 50 and a SD of 10).

Where appropriate, the time reference is 4-week recall. The multi-item scales are transformed to a range of 0–100, with 0 indicating poor health and 100 indicating excellent health. The CHQ is a reliable, valid and acceptable generic questionnaire for use in children with CP (Wake *et al*. 2003; Morales *et al*. 2006; McCullough & Parkes 2007). It has been used in many childhood diseases and has been translated into many languages. We were concerned that questions from the Physical Functioning scale (limitations in walking a distance of one block, playing soccer and riding a bike) might be inappropriate to families with children with very severely impaired mobility skills. We, therefore, explained that in advance for the parents. The researcher was present when the parent filled out the questionnaire and could answer any questions about the meaning of any item.

Statistical analyses were performed with Stata software (version 9.2) and the gllamm program (Rabe-Hesketh). As the domain scores were not normally distributed, medians and inter-quartile ranges were reported and the Kruskal–Wallis non-parametric test was used to test for significant associations with impairment variables. Because of the large number of tests, a significance level of 1% was used. Multilevel multivariable logistic regression analyses of the lowest quartile of HRQoL were carried out in each of the two summary scale scores (Physical and Psychosocial). The factors studied were entered into the models as independent variables provided they were associated in the univariate analysis (with $P < 0.20$). Forward stepwise procedures were used to construct the models (significance level for entry or removal was 5%). Final multivariable models excluded only observations with missing values on the included covariates. Multilevel modelling was used as observations within a centre might be more similar than observations in different centres. Goodness-of-fit was assessed using the Bayesian Information Criterion and models were rerun excluding influential observations to check stability.

Ethics

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.

Table 2. Child characteristics of sample ($n = 818$)

Child characteristics	Value
Age mean (SD), y, Range, y	10.4 years, (1.5), and 7.7–13.6
Sex M/F	483/334 (59%/41%)
Cerebral Palsy type	
Unilateral spastic	279 (34%)
Bilateral spastic	423 (52%)
Dyskinetic	86 (11%)
Ataxic	29 (4%)
GMFCS	
I	257 (31%)
II	164 (20%)
III	139 (17%)
IV	113 (14%)
V	145 (18%)
BFMF	
I	281 (34%)
II	205 (25%)
III	131 (16%)
IV	91 (11%)
V	110 (13%)
IQ	
50–70	186 (23%)
<50	242 (30%)
Vision	
Blind or no useful vision	59 (7%)
Hearing	
Impairment > 70 db in better ear	18 (2%)
Seizures last year	
Yes	167 (21%)
Feeding	
By mouth with difficulties	176 (22%)
By tube	58 (7%)
Communication	
Problems, but speech	133 (16%)
Alternative formal	98 (11%)
No formal communication	123 (15%)
Schooling	
Mainstream school	290 (58%)
Mainstream school, visits to special unit	65 (13%)
Special unit in mainstream school	46 (9%)
Special school	97 (19%)

BFMF, Bimaual Fine Motor Function; GMFCS, Gross Motor Function Classification System.

Results

A total of 818 families agreed to participate. The details of the characteristics of the population are given in Table 2. The median CHQ scores ranged from 64 to 100 with the lowest score for General Health and the highest for Role/Social Limitations – Emotional/Behavioural and Role/Social Limitations(Physical) (Table 1). The Physical summary scale was lower than the reference samples with a median of 46. Because of the significant ceiling effect in Role/Social Limitations – Emotional Behavioural and Role/Social Limitations – Physical (respectively 59%

and 60%) we did not include these domains in the subsequent analyses. There were significant differences between the CP types in Physical Functioning, Bodily Pain, General Health , Parental impact-Time, Physical Health with the higher scores predominantly for children with unilateral spastic (Physical Functioning, Bodily Pain, Parental impact-Time, Physical health) and the lowest scores predominantly for children with bilateral spastic and dyskinetic CP type (Table 3). The severity of gross motor function influenced the CHQ scores significantly in Physical Functioning, Bodily Pain, Behaviour, General Health, Parental impact-Time, Family Activities and Physical Health with the lowest scores for children in GMFCS level V. Fine motor function severity was significantly affecting the same CHQ dimension and in addition also Self-Esteem and Psychosocial health (Table 3). The severity of intellectual impairment was significantly associated with CHQ scores in most dimensions with higher scores for higher IQ level in Physical Functioning, Bodily Pain, Behaviour, General Health, Parental impact-Time, Family Activities, Physical health and Psychosocial health which was also the case for children with normal feeding (Table 4). Children with seizures during the last year had a significantly lower health compared with children without seizures in the following domains: Bodily Pain, Self-esteem, General Health, Parental impact-Emotional, Parental impact-Time, Family Activities and Physical health (Table 4).

The results of the multivariate regression analyses (forward stepwise regression) of CHQ scores on CP subtype, GMFCS, BFMF, cognitive function, additional impairments, seizures, parental education and employment are shown in Table 5. Gross motor function, cognitive level and type of school attended were significant prognostic factors (Table 5, Figs 1 & 2).

Table 3. Univariate analysis of association between the domain scores and type of Cerebral Palsy (CP), gross motor function (GMFCS) and fine motor function (BFMF)

	CP type					GMFCS						BFMF					
CHQ dimension	**Spastic unilateral**	**Spastic bilateral**	**Dys-kinetic**	**Ataxic**	***P****	**I**	**II**	**III**	**IV**	**V**	***P***	**I**	**II**	**III**	**IV**	**V**	***P***
Physical Functioning	94	83	89	83	0.002	94	94	100	78	46	0.0001	94	89	89	81	47	0.0001
Bodily Pain	80	60	70	70	0.01	80	70	70	60	60	0.0001	80	70	70	70	50	0.0001
Behaviour	73	76	77	73	0.11	73	73	73	77	79	0.002	75	68	68	77	79	0.0001
Mental Health	75	75	75	80	0.67	75	75	75	75	75	0.96	75	75	75	75	70	0.07
Self-esteem	75	75	75	71	0.71	75	75	75	79	75	0.74	79	75	77	79	75	0.009
General Health	67	60	60	73	0.003	68	64	64	63	47	0.0001	68	64	64	59	43	0.0001
Parental Impact – Emotional	75	75	75	67	0.77	75	75	71	75	67	0.95	75	67	67	75	67	0.02
Parental Impact – Time	89	78	78	89	0.006	94	89	78	89	78	0.0001	100	78	78	78	78	0.0001
Family Activities	83	75	75	83	0.02	88	79	75	75	71	0.0001	88	75	75	71	71	0.0001
Physical summary scale	50	44	43	44	0.0001	51	47	49	41	32	0.0001	51	45	43	41	34	0.0001
Psychosocial summary scale	49	51	50	49	0.40	49	49	50	52	52	0.04	52	48	48	53	50	0.0003

*Significance level of the Kruskal–Wallis test.

Discussion

This report offers some definitive answers on the health status of children with CP in Europe based on a large sample. We asked parents of children with CP living in Europe about their perception of their child's health using the CHQ PF-50, a 50-item parent-reported heath status measure. Generic measures such as the CHQ have been shown to be useful in establishing a profile of the child health across multiple health domains that align with the WHO definition of health (Waters *et al.* 2000a,b; Wake *et al.* 2003). Many researchers have used the CHQ to measure QOL in children with CP (Houlihan *et al* 2001; Liptak *et al.* 2001; Schneider *et al.* 2001; Vitale *et al.* 2001; McCarthy *et al.* 2002; Wake *et al.* 2003; Vargus-Adams 2005; Majnemer *et al.* 2007).

Table 4. Univariate analysis of association between the domain scores and intellectual impairment, feeding and seizures

	IQ				Feeding†				Seizures in last year		
CHQ dimension	**>70**	**50–70**	**<50**	***P****	**1**	**2**	**3**	***P***	**NO**	**YES**	***P***
Physical Functioning	94	89	72	0.0001	94	78	50	0.0001	89	78	0.03
Bodily Pain	70	80	60	0.0001	70	60	50	0.0001	70	60	0.0001
Behaviour	77	73	73	0.0001	73	73	81	0.0001	73	73	0.09
Mental Health	75	75	75	0.03	75	75	78	0.20	75	70	0.02
Self-esteem	79	75	75	0.31	75	75	75	0.89	79	75	0.01
General Health	70	64	49	0.0001	68	56	35	0.0001	67	51	0.0001
Parental Impact – Emotional	75	67	67	0.08	75	67	67	0.38	75	67	0.006
Parental Impact – Time	89	78	67	0.0001	89	78	78	0.0001	89	78	0.0009
Family Activities	88	75	67	0.0001	83	67	71	0.0001	79	67	0.0001
Physical summary scale	50	46	39	0.0001	49	41	32	0.0001	48	39	0.0001
Psychosocial summary scale	51	47	49	0.002	50	48	53	0.09	51	47	0.02

*Significance level of the Kruskal–Wallis test.
†Feeding codes 1, 2, 3.

Table 5. Final multilevel multivariate logistic regression model of the lowest quartile of health status for the two summary scores: Physical and Psychosocial

Variables		**OR**	**95% CI**
Physical summary score ($n = 728$)			
GMFCS	Walks, climbs stairs	1	
	Walks inside	2.1	1.1–3.7
	Walks with lim.	2.3	1.3–4.4
	Moving limited	4.7	2.4–9.0
	Moving severely lim.	7.4	3.7–14.5
School	Mainstream school	1	
	Mainstream school and visits special unit	1.9	0.9–4.1
	Special unit in mainstream school	2.0	0.97–4.0
	Special school	2.1	1.2–3.4
Psychosocial summary score ($n = 734$)			
IQ	>70	1	
	50–70	2.6	1.6–4.0
	<50	2.8	1.7–4.7
GMFCS	Walks, climbs stairs	1	
	Walks inside	1.2	0.7–1.9
	Walks with lim.	0.8	0.5–1.4
	Moving limited	0.4	0.2–0.8
	Moving severely lim.	0.4	0.2–0.7

GMFCS, Gross Motor Function Classification System.

Our findings reveal associations between function and some aspects of health in that the CHQ dimensions of Physical Functioning, Bodily Pain, Behaviour, Mental Health Self-esteem, General Health, Parental impact-Emotional, Parental impact-Time, Family Activities, Physical health and Psychosocial health were clearly affected in all children with the lowest scores in children with bilateral spastic and dyskinetic CP and the highest scores for children with unilateral spastic CP type.

However, the Physical Functioning score in this study indicated better health compared with scores reported for American and Australian children with CP by McCarthy and colleagues 2002; Wake and colleagues 2003; Vargus-Adams 2005. Another positive finding was that limitations in school and friend-related activities as a consequence of physical health Role/Social Limitations–Physical and emotional-behavioural problems Role/Social Limitations–Emotional Behavioural had a high median score of 100. Parents also scored their emotional impact higher than in previous reports from CP populations and the time impact almost at the same level as scores obtained in normative samples (Landgraf *et al.* 1996; Waters *et al.* 2000a).

Similarly to McCarthy and colleges and Vargus-Adams, we found that children with CP had lower scores on the physical summary scores than the normative population but the differences for the psychosocial summary scores were small (McCarthy *et al.* 2002; Vargus-Adams 2005).

Interestingly, the risk of poor psychosocial summary scores in this European study decreased with increasing GMFCS levels, suggesting that the parents of the children with severe motor and cognitive difficulties were more optimistic about the social-emotional health of their children.

The prevalence of poor health was most pronounced in the domains of Physical health, General Health and Bodily Pain. Significantly lower CHQ scores were found associated with higher GMFCS levels, and with the presence of cognitive impairment, feeding difficulties and seizures. Fung *et al* also reported feeding difficulties to be related to poor health (Fung *et al.* 2002). Liptak and colleagues (2001) also found poor CHQ scores in Physical Functioning, Bodily Pain, General Health and Parental impact-Time for the children on GMFCS levels III, IV and V. Pain was related to CP type, severity of gross and fine motor function, cognitive impairments, feeding difficulties and seizures. Similar results are reported by Houlihan and colleagues (2001).

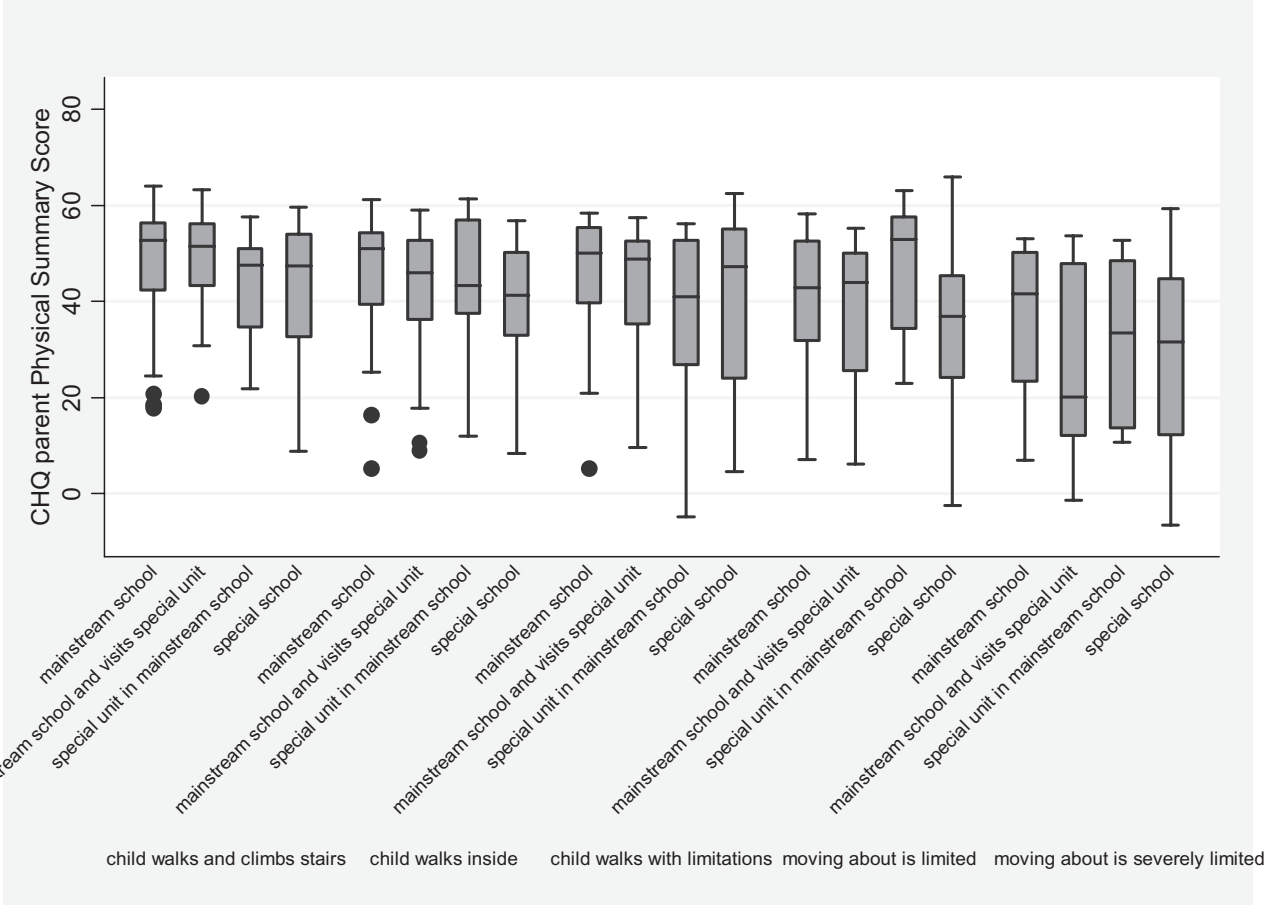

Figure 1. Physical summary score according to Gross Motor Function Classification System level and type of school attended. CHQ, Child Health Questionnaire.

Another prognostic factor for poor health was an environmental factor: attending a special school. This has also been reported in a group of Canadian children with CP (Majnemer *et al.* 2007).

Parental education and employment were not significantly associated with poor child HRQoL in this study.

We found the mean CHQ scores to be higher in all dimensions compared with the Australian study of children with mild to severe CP of almost similar mean age (Wake *et al.* 2003). In the Australian study, health status did not vary by cognitive status or epilepsy as it did in our study. However, the severity of gross motor function affected the scores in the same dimensions in Europe and Australia. This is also in accordance with the results of Vargus-Adams (2005) in American children, concluding that the degree of reduced health status is related to the severity of CP. However, our results reveal higher mean CHQ scores in all dimensions than those presented by Vargus-Adams (2005). Compared with the results of McCarthy *et al* there were similarities but our scores were lower in Bodily Pain, Mental Health and Self-esteem.

Mental Health, Self-esteem and Parental impact-Emotional were the CHQ dimensions least affected by CP type, motor function and additional impairments in this study. Mental Health, Self-esteem and Behaviour were the dimensions that were also scored on average in a sample of children with moderate to severe CP (Liptak *et al.* 2001).

Population-based studies have shown that the GMFCS levels correlates with cognitive level, additional impairments and the presence of seizures and thus can be a indicator of the total disability load for children with CP (Himmelmann *et al.* 2006). The present study indicates that this is true concerning health from the physical well-being perspective but the psychosocial and emotional aspects do not follow the same pattern.

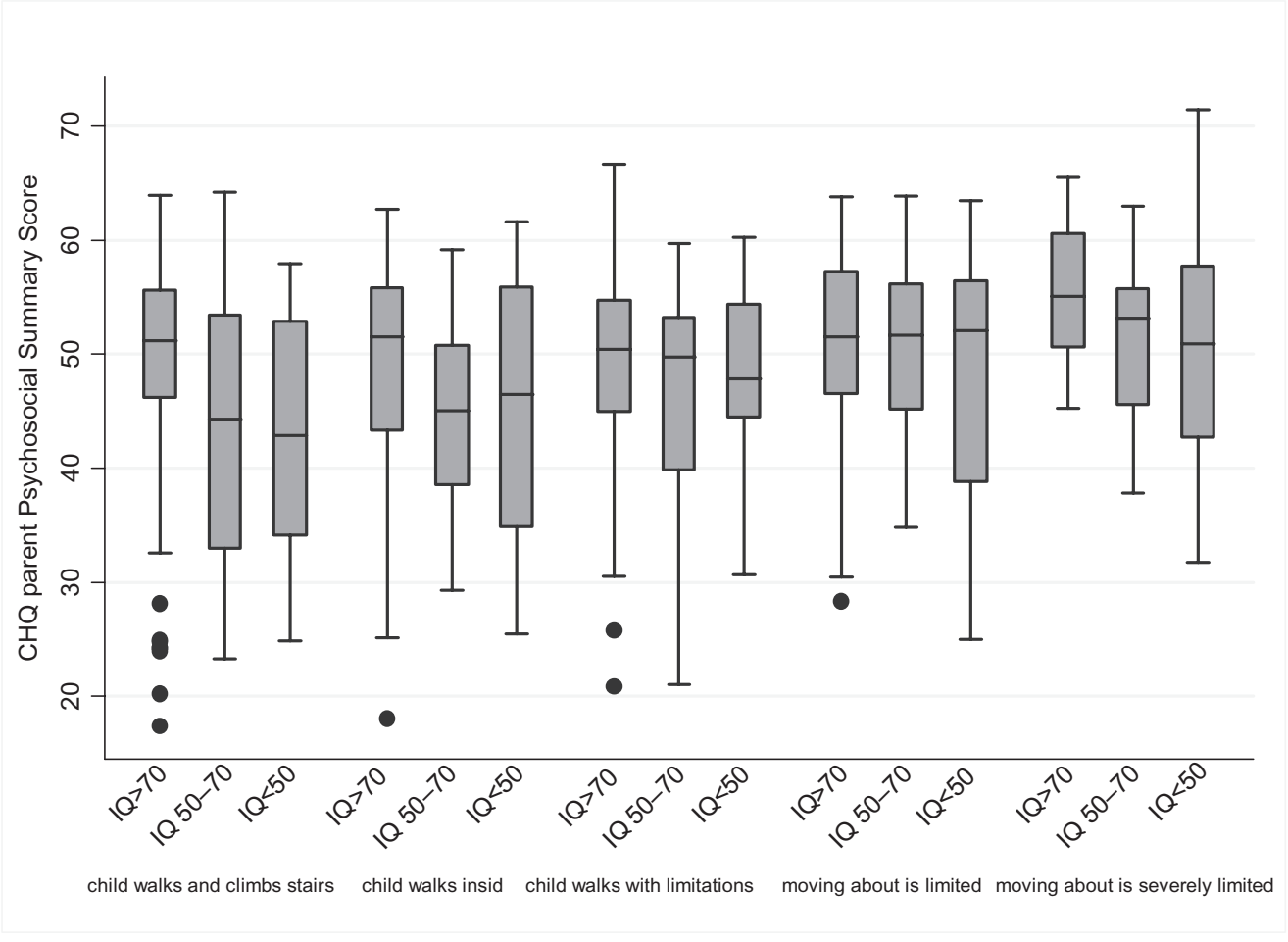

Figure 2. Physical summary score according to Gross Motor Function Classification System level and level intellectual impairment. CHQ, Child Health Questionnaire.

Key messages

- This study indicates that health was clearly affected in all children and that health status as measured by the CHQ is highly variable in children with CP.
- Gross motor function, cognitive level and type of school attended were the significant prognostic factors.
- The present study indicates that gross motor functional level correlates with good health from the physical well-being perspective but the psychosocial and emotional aspects do not follow the same pattern.

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