

Health-related quality of life in children and adolescents with cerebral palsy with proper cognitive development

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Abstract

Introduction: The assessment of the health-related quality of life (HRQoL) of children and adolescents with cerebral palsy (CP) can help to highlight the most significant problems related to daily functioning.

Aim of the research: Assessment of quality of life in children and adolescents with CP with proper cognitive development and comparison of the assessment of quality of life from the perspective of the child and the parents.

Material and methods: This cross-sectional study involved a group of 64 children and adolescents with CP in the intellectual norm. Subjects presented various stages of functional capacities (Gross Motor Function Classification System-GMFSC; Manual Ability Classification System-MACS), and in daily communication skills (Communication Function Classification System-CFCS). The Kidscreen-27 questionnaire, which was completed by children and 58 parents, was used to assess HRQoL. **Results:** HRQoL is statistically higher in the group of children with CP ($p < 0.05$) compared to the population norm for children in Poland, except for domain IV of Peers & Social Support. Children with CP rated their HRQoL in the domains of Physical Well-Being and Psychological Well-Being significantly better than their parents ($p < 0.05$). At the same time, parents rated their children's HRQoL slightly better in the domain of Autonomy & Parents. Physical disability does not seem to have a significant impact on the level of HRQoL in intellectually normal children and adolescents with CP, making their prospects for good social functioning high.

Conclusions: This knowledge should be the basis of social and educational policies to prevent the marginalization of people with physical disabilities and to enable them to participate as widely as possible in the society.

Introduction

Measuring health-related quality of life (HRQoL) is an important part of the holistic assessment of patients with chronic conditions, particularly those with cerebral palsy (CP) [1]. CP is an umbrella term for a group of permanent motor and postural disorders caused by damage to the developing brain of various origin [2]. These abnormalities are often associated with impairments in cognition, communication and behavior that directly affect overall health, mobility and independence in daily life, increasing the level of disability and handicap [3, 4].

The first studies of HRQoL in children were mainly based on parental opinions, but later self-assessment by the child was included, as recommended by the World Health Organization and the International Association for Child Psychology and Psychiatry [5, 6]. In order to assess HRQoL more accurately, questionnaires have begun to be adapted for CP patients, both general and disease-specific ones [7]. The KIDSCREEN

is a generic questionnaire that includes versions for children/adolescents as well as for parents/carers, and is often used as a tool in studies comparing different aspects of HRQoL between patients and their healthy peers. Little is known about the HRQoL in Polish CP children and adolescents with normal cognitive development. Previously, these measurements were mainly performed in patients with intellectual disabilities [1]. Results of studies carried out so far confirm that both patients and their carers perceive their physical health to be worse than that of their healthy peers. Deficits include poorer ratings of somatic health status (pain, bodily aches and pains, physical fatigue) and poorer physical performance, as manifested by reduced ability to participate in physical activity, sports and difficulties with activities of daily living [8–12]. At the same time, research suggests that there is no direct relationship between objective measures of health status and the individual perceptions of quality of life of the children and their carers; even with similar levels of physical disability, perceptions can vary widely [13–16].

Aim of the research

As there is a lack of information on HRQoL in children and adolescents with CP without intellectual impairment in Poland, we decided to examine this group of patients from the perspective of the child and the parents, and to compare their HRQoL with that of their healthy peers.

Material and methods

This cross-sectional study included 64 children and adolescents with CP aged 8–18 years out of 140 CP patients hospitalized at the Clinical Regional Rehabilitation and Education Centre for Children and Adolescents in Rzeszów between June 2018 and July 2019. The ability to read and understand the questions of the Kidscreen questionnaire was required, as well as written informed consent signed by parents or legal guardians, and for adolescents over the age of 16. Patients with mental retardation were excluded from the study (based on Raven's matrices).

The main research tool was the Kidscreen-27 questionnaire, a generic HRQoL measure for children and adolescents aged 8–18 years. It has five dimensions – I Physical Well-Being (5 items), II Psychological Well-Being (7 items), III Autonomy & Parents (7 items), IV Peers & Social Support (4 items) and V School Environment (4 items).

Each item is rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much). Some items (1, 9, 10 and 11) were reverse scored. Reverse scoring means that the numerical rating scale runs in the opposite direction. A standardized score was calculated according to a scale from 0 – the worst quality of life to 100 points – the best quality of life (scoring of questions from 0 to 4, total points divided by the maximum for the category and multiplied by 100). The study used a version for children and adolescents and a version for parents and carers, who answered the same questions on behalf of the child [17, 18].

Functional mobility was assessed using the Gross Motor Function Classification System (GMFCS), an objective classification method. It consists of five levels: I (children with minimal or no disability in the area of mobility in the community), II (children are able to move indoors and outdoors with limitations but do not use any equipment), III (children are able to move indoors and outdoors with limitations and use various aids), IV (children use methods of mobility that require physical assistance or powered mobility in most situations), V (children are completely dependent on assistance for mobility) [19, 20].

Manipulative activity in everyday life was assessed using the Manual Ability Classification System (MACS). Assignment of a child to a particular level is based on the activity initiated by the child using objects, and whether the child needs help from another

person or adaptation of equipment to use in everyday activities. The MACS has five levels: I (the child uses objects easily and effectively), II (the child uses most objects but with somewhat limited quality and/or speed of performance), III (the child uses objects with difficulty; requires assistance to perform or modify an activity), IV (the child has limited use of objects that are easy to use and in adapted situations), and V (the child does not use objects and has severely limited ability to perform even simple activities) [21].

Everyday communication skills were assessed using the Communication Function Classification System (CFCFS) for CP patients. All modes of communication (verbal, gestural, behavioral, eye gaze, facial expression, and augmentative and alternative communication) are considered in determining CFCFS levels. The CFCFS has five levels: I (effective sender and receiver for/with known and unknown partners), II (effective but slower sender and/or receiver for/with unknown and/or known partners), III (effective sender and receiver for/with known partners), IV (not effective sender and/or receiver for/with known partners) and V (rarely effective sender and receiver even for/with known partners) [22].

Statistical analysis

Normal distribution was determined using the Shapiro-Wilk test. The ANOVA test was used to compare the distribution of the Kidscreen-27 in the three separate age groups. The independent samples *t*-test was used to assess the significance of differences between the Kidscreen-27 scores of healthy children and those obtained in the group of children with CP. A dependent samples *t*-test was used to assess the significance of differences between the Kidscreen-27 quality of life scores reported by children with CP and those reported by their parents. Spearman's rank correlation coefficient was used to analyze the relationship between the CFCFS/MACS/GMFCS measures and the Kidscreen-27. Calculations were performed using Statistica 12.5 (StatSoft, Inc., Tulsa, OK, USA). A *p*-value less than 0.05 was considered statistically significant.

Results

Characteristics of the study group

A total of 64 children and adolescents with CP who were finally assessed accounted for 46% of those admitted to inpatient rehabilitation during the study period. 39 patients were excluded from the study due to age outside the defined range of 8–18 years, 34 due to inability to read and understand the Kidscreen questionnaire questions, 3 due to lack of written consent.

The 64 patients included 23 (35.9%) girls and 41 (64.1%) boys with a mean age of 12.3 years (SD = 3.0; Me = 12; range: 8–17 years). In order to relate

the results of the study to the Polish norms for the Kidscreen-27 questionnaire, we divided the patients into three age groups: group I (8–11 years, $N = 28$, 43.8%), group II (12–14 years, $N = 17$, 26.6%) and group III (15–18 years, $N = 19$, 29.7%). The clinical presentation of CP was as follows: spastic diplegia (ICD 10 G80.0; $N = 26$, 40.6%), spastic hemiplegia (ICD 10 G80.2; $N = 15$, 23.4%), spastic quadriplegia (G80.1; $n = 14$, 21.9%), mixed (G80.8; $N = 6$, 9.4%) and atactic (G80.4; $N = 3$, 4.7%).

Assessment of HRQoL in the whole population and in separate age groups

Children with CP rated their quality of life as quite high, best in the domain of Psychological Well-Being ($\bar{x} = 75.6$ pts) and worst for Physical Well-Being ($\bar{x} = 62$ pts) (Table 1).

A comparison was also made between the quality of life of children and adolescents with CP and that of healthy children and adolescents (data obtained from published results of a population-based study in Poland [18]). Apart from the domain of Peers & Social Support, self-reported HRQoL is statistically higher in the group of children with CP (Table 2).

There were no statistically significant differences in quality of life (Kidscreen-27) between children with CP in the three age groups compared ($p > 0.05$). In the domains of Psychological Well-Being and Autonomy & Parents the best functioning is found in children aged 15–18 years, in the domain of School Environment – children aged 12–14 years, in the domains of Physical Well-Being and Peers & Social Support – children aged 8–11 years a certain downward trend is visible, but it is not statistically significant (Table 3).

Table 1. Distribution of Kidscreen-27 measures in the study group of children with CP ($N = 64$)

Kidscreen-27	$\bar{x}$ (95% CI)	SD	Me	Min.–max.
I Physical Well-Being	62.1 (57.5–66.6)	18.2	64.5	20–100
II Psychological Well-Being	75.6 (72.7–78.5)	11.6	76.0	50–100
III Autonomy & Parents	69.0 (64.4–73.6)	18.4	71.2	4–100
IV Peers & Social Support	68.8 (63.2–74.4)	22.4	69.0	13–100
V School Environment	67.0 (62.5–71.6)	18.3	65.0	19–100

N – number, $\bar{x}$ – mean, % – percent, CI – confidence interval, SD – standard deviation, Me – median, Min. – minimum, Max. – maximum.

Table 2. Distribution of Kidscreen-27 measures in a group of children with CP ($N = 64$) and healthy children ($N = 1718$, normal for the Polish population [18])

Kidscreen-27	Healthy children ($N = 1718$)		Children with CP ($N = 64$)		P -value
	$\bar{x}$ (95% CI)	SD	$\bar{x}$ (95% CI)	SD	
I Physical Well-Being	68.92 (68.07–69.77)	17.98	62.06 (57.53–66.60)	18.16	0.0028**
II Psychological Well-Being	71.32 (70.52–72.12)	16.92	75.55 (72.66–78.45)	11.60	0.0474*
III Autonomy & Parents	64.01 (63.14–64.88)	18.46	69.01 (64.41–73.61)	18.42	0.0335*
IV Peers & Social Support	66.75 (65.77–67.73)	20.70	68.83 (63.22–74.43)	22.45	0.4316
V School Environment	61.16 (60.22–62.09)	19.79	67.04 (62.47–71.62)	18.31	0.0193*

N – number, $\bar{x}$ – mean, % – percent, CI – confidence interval, SD – standard deviation.

Table 3. Distribution of Kidscreen-27 measures in separate age groups of children and adolescents with CP

Kidscreen-27	Age group						<i>P</i> -value
	8–11 years (<i>N</i> = 28)		12–14 years (<i>N</i> = 17)		15–18 years (<i>N</i> = 19)		
	$\bar{x}$ (95% CI)	SD	$\bar{x}$ (95% CI)	SD	$\bar{x}$ (95% CI)	SD	
I Physical Well-Being	64.1 (57.7–70.5)	16.5	58.7 (50.9–66.5)	15.2	62.1 (51.1–73.1)	22.9	0.6374
II Psychological Well-Being	75.7 (71.5–79.9)	10.9	72.6 (66.7–78.6)	11.6	77.9 (71.8–84.0)	12.7	0.3914
III Autonomy & Parents	66.7 (60.7–72.6)	15.3	67.4 (57.9–76.9)	18.5	73.9 (63.2–84.6)	22.2	0.3868
IV Peers & Social Support	72.2 (63.1–81.2)	23.4	67.8 (57.7–77.9)	19.7	64.8 (53.4–76.3)	23.7	0.5427
V School Environment	64.1 (58.3–69.9)	15.0	73.7 (63.0–84.3)	20.7	65.4 (55.8–75.0)	19.9	0.2144

N – number, $\bar{x}$ – mean, % – percent, CI – confidence interval, SD – standard deviation.

Table 4. Quality of life of children with CP according to Kidscreen-27 in relation to norms [18] in the age group 8–11 years

Kidscreen-27	Age group 8–11 years – total						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	566	74.68	16.22	28	64.07	16.53	0.0008***
Psychological Well-Being	566	77.78	14.15	28	75.71	10.87	0.4459
Autonomy & Parents	566	69.33	16.97	28	66.67	15.33	0.4165
Peers & Social Support	566	71.69	19.66	28	72.15	23.42	0.9047
School Environment	566	70.37	18.34	28	64.11	14.99	0.0762
Kidscreen-27	Age group 8–11 years – girls						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	302	73.12	16.52	10	63.60	13.72	0.0727
Psychological Well-Being	302	77.3	15.46	10	74.20	15.74	0.5334
Autonomy & Parents	302	68.76	17.96	10	66.80	9.50	0.7317
Peers & Social Support	302	71.74	20.61	10	76.70	23.73	0.4567
School Environment	302	72.44	17.66	10	62.50	17.34	0.0808
Kidscreen-27	Age group 8–11 years – boys						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	264	76.48	15.72	18	64.33	18.28	0.0019**
Psychological Well-Being	264	78.32	12.48	18	76.56	7.38	0.5552
Autonomy & Parents	264	69.98	15.76	18	66.61	18.05	0.3853
Peers & Social Support	264	71.63	18.55	18	69.63	23.54	0.6642
School Environment	264	68.01	18.83	18	65.01	13.98	0.5078

N – number, $\bar{x}$ – mean, CI – confidence interval, SD – standard deviation, CP – cerebral palsy.

Assessment of HRQoL in relation to Polish population norms for healthy children and adolescents [18]

In the age group 8–11 years, the quality of life of children with CP is significantly lower in the domain of Physical Well-Being (for the whole population as well as for the subgroup of boys, while for girls the results are close to statistical significance). In addition, in the area of School Environment, the results obtained to the detriment of children with CP are also at a level close to statistical significance (Table 4).

Children with CP in the 12–14 age group have a significantly lower quality of life in the domain of Physical Well-Being (the whole group/the subgroup of boys/for girls the results are close to statistical significance). In contrast, children with CP (boys and the whole group) have a significantly higher quality of life in the domain of School Environment compared to healthy children. However a noticeable change in attitude towards school is observed among healthy children aged 12–14 (whole group) compared to younger

children – the scores are 9.8 points lower than in the entire group of children aged 8–11, and even 11.63 points lower when comparing the subgroups of boys within the same age ranges (Tables 4 and 5).

In the 15–18 age group, adolescents with CP show significantly better quality of life in the areas of Psychological Well-Being, Autonomy & Parents and School Environment. In the healthy adolescents, a decrease in quality of life scores is observed compared to the younger 12–14 age group, whereas no such decrease is observed in the group of peers with CP. In the domain of Psychological Well-Being, the healthy adolescents showed a deterioration of 6.34 points, while their peers with CP showed an improvement of 5.34 points, as well as in the domain of Autonomy & Parents – a deterioration of 6.45 points and an improvement of 6.54 points, respectively. In the domain of School Environment, a decrease in quality of life was observed in both groups, a deterioration of 7.72 and 8.26 points, respectively, although adolescents with CP functioned significantly better in this domain (Tables 5 and 6).

Table 5. Quality of life in children with CP according to Kidscreen-27 in relation to norms [18] in the age group 12–14 years

Kidscreen-27	Age group 12–14 years – total						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	528	70.21	17.35	17	58.71	15.16	0.0072**
Psychological Well-Being	528	71.58	16.14	17	72.61	11.58	0.7943
Autonomy & Parents	528	64.89	17.77	17	67.38	18.48	0.5703
Peers & Social Support	528	67.68	21.52	17	67.79	19.67	0.9834
School Environment	528	60.57	19.51	17	73.68	20.73	0.0067**
Kidscreen-27	Age group 12–14 – girls						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	291	68.75	17.54	5	54.80	20.86	0.0797
Psychological Well-Being	291	71.16	16.75	5	78.40	16.56	0.3386
Autonomy & Parents	291	64.51	17.66	5	76.60	26.81	0.1335
Peers & Social Support	291	68.92	21.67	5	65.80	29.63	0.7512
School Environment	291	63.97	18.55	5	72.00	30.54	0.3435
Kidscreen-27	Age group 12–14 – boys						P-value
	Healthy children			Children with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	237	71.98	16.99	12	60.33	12.89	0.0201*
Psychological Well-Being	237	72.11	15.39	12	70.20	8.59	0.6705
Autonomy & Parents	237	65.37	17.93	12	63.53	13.44	0.7264
Peers & Social Support	237	66.14	21.27	12	68.63	15.53	0.6896
School Environment	237	56.38	19.89	12	74.38	16.86	0.0023**

N – number $\bar{x}$ – mean, SD – standard deviation, CP – cerebral palsy.

Self-assessment of the HRQoL (Kidscreen-27) in relation to parents' assessment

The analysis includes a group of 58 children and young people with CP and 58 parents who completed the Kidscreen-27 questionnaire designed for carers (90.6%). A statistically significant difference is observed between the children's level of assessment of their perceived quality of life and that of their parents in two areas: Physical Well-Being and Psychological Well-Being. Children rate their quality of life better in these domains than their parents. At the same time, parents rate their children's quality of life better in the Autonomy & Parents domain, although these differences are not statistically significant (Table 7).

Assessment of the relationship between communication skills (CFCS), manual skills (MACS), level of functional mobility (GMFCS) and HRQoL (Kidscreen-27)

Table 8 shows the distribution of CFCS, MACS and GMFCS values in the study group. The majority

of children ranked at Level I and II in the measures analyzed.

With the exception of a weak but statistically significant correlation between quality of life in the Physical Well-Being domain of the GMFCS ($r_s = -0.32$), no correlation between the analyzed measures and quality of life is observed (Table 9).

Discussion

A meta-analysis of studies assessing the HRQoL of children with CP indicates that perceptions of HRQoL domains beyond Physical Well-Being are dependent on the type of HRQoL questionnaire used. The pattern of assessment in mental health and social functioning is not consistent across studies. Differences are evident particularly in mental health: CHQ/PedsQL – reduced self-esteem, poor mental health, CPQOL/KIDSCREEN/TACQOL/YQOL – non-significant differences in the frequency of negative emotions, feelings and moods experienced by children and adolescents with CP and peers.

Table 6. Quality of life in adolescents with CP according to Kidscreen-27 in relation to norms [18] in the age group 15–18 years

Kidscreen-27	Age group 15–18 years – total						P-value
	Healthy adolescents			Adolescents with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	624	62.60	18.05	19	62.11	22.088	0.9080
Psychological Well-Being	624	65.24	17.66	19	77.95	12.65	0.0019**
Autonomy & Parents	624	58.44	18.81	19	73.92	22.24	0.0005***
Peers & Social Support	624	61.47	19.69	19	64.84	23.70	0.4654
School Environment	624	53.30	17.68	19	65.42	19.91	0.0035**
Kidscreen-27	Age group 15–18 years – girls						P-value
	Healthy adolescents			Adolescents with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	348	59.13	18.09	8	59.38	20.00	0.9656
Psychological Well-Being	348	62.32	18.24	8	77.13	14.38	0.0233*
Autonomy & Parents	348	56.22	18.89	8	80.38	16.03	0.0004***
Peers & Social Support	348	62.79	20.17	8	67.38	22.33	0.5259
School Environment	348	54.59	17.87	8	64.88	23.42	0.1107
Kidscreen-27	Age group 15–18 years – boys						P-value
	Healthy adolescents			Adolescents with CP			
	N	$\bar{x}$	SD	N	$\bar{x}$	SD	
Physical Well-Being	276	66.92	17.06	11	64.09	25.53	0.5978
Psychological Well-Being	276	68.89	16.21	11	78.55	11.94	0.0517
Autonomy & Parents	276	61.26	18.36	11	69.22	25.55	0.1664
Peers & Social Support	276	59.82	18.98	11	63.00	25.55	0.5915
School Environment	276	51.64	1.34	11	65.82	18.15	0.0084**

N – number, $\bar{x}$ – mean, SD – standard deviation, CP – cerebral palsy.

Table 7. Level of self-assessment of quality of life in children with CP compared to their parents' perception of quality of life

Kidscreen-27	Children's opinion (N = 58)		Parents' opinion (N = 58)		P-value
	$\bar{x}$ (95% CI)	SD	$\bar{x}$ (95% CI)	SD	
Physical Well-Being	63.5 (59.1; 67.8)	16.5	57.9 (53.8; 62.0)	15.5	0.0040**
Psychological Well-Being	75.2 (72.3; 78.1)	11.0	71.1 (68.5; 73.8)	10.1	0.0041**
Autonomy & Parents	68.1 (63.4; 72.8)	17.9	70.4 (66.2; 74.5)	15.7	0.3368
Peers & Social Support	68.8 (62.9; 74.6)	22.2	67.3 (61.8; 72.7)	20.6	0.6041
School Environment	67.0 (62.3; 71.7)	17.8	67.2 (62.8; 71.5)	16.5	0.9467

N – number, $\bar{x}$ – mean, SD – standard deviation, CI – confidence interval. *Bold characters indicate statistically significant values ($p < 0.05$).

The CHQ equates QoL with physical health. Consequently, CHQ items relating to activity limitations and difficulties caused by illness will elicit reduced QoL when applied to people with pronounced motor disabilities (as in the case of CP) [23]. A similar situation applies to social wellbeing and school functioning. Children and adolescents with CP did not feel

supported or accepted by their peers and reported significantly lower academic achievement (CPQOL, PedsQL/TACQOL/YQOL) in contrast to those tested with the KIDSCREEN, where both children's and parents' HRQoL scores were significantly higher in terms of relationships with parents/home life/and learning in the school environment. It is difficult to assess

Table 8. Distribution of CFCS, MACS and GMFCS values in the study group

CFCS	N	%
I Effective sender and recipient for known and unknown partners	37	57.8
II Efficient but slower sender and/or receiver for unknown and/or known partners	26	40.6
III Successful sender and recipient for known partners	1	1.6
IV Non-permanent/Not effective sender and/or recipient for known partners	0	0
V Rarely effective sender and receiver even for known partners	0	0
MACS	N	%
I The child handles objects easily and effectively	22	34.4
II The child handles most objects but with somewhat limited quality and/or speed of execution	34	53.1
III The child handles objects with difficulty; requires assistance to undertake or modify an activity	6	9.4
IV The child has limited use of objects that are easy to use and in adapted situations	2	3.1
V The child does not use objects and has severely limited ability to perform even simple tasks	0	0
GMFCS	N	%
I Children with minimal or no disability in the field of mobility in the community	23	35.9
II Children are able to go inside and outside with restrictions, but do not use devices	33	51.6
III Children are able to go inside and outside with restrictions and use various aids	1	1.6
IV Children use methods of mobility that require physical assistance or powered mobility in most settings	7	10.9
V Children totally dependent on assistance in mobility	0	0

N – number, % – percent, CFCS – the Communication Function Classification System for Individuals with Cerebral Palsy, MACS – the Manual Ability Classification System, GMFCS – the Gross Motor Function Classification System.

Table 9. Correlations between the quality of life of children with CP (Kidscreen-27) and the skills of the communication (CFCS), manual dexterity (MACS) and level of functional mobility (GMFCS)

Tools	Kidscreen-27				
	Physical Well-Being	Psychological Well-Being	Autonomy & Parents	Peers & Social Support	School Environment
CFCS	–0.15 (0.2508)	0.21 (0.1020)	–0.10 (0.4403)	–0.12 (0.3614)	0.03 (0.8358)
MACS	–0.10 (0.4296)	0.14 (0.2688)	0.14 (0.2639)	–0.08 (0.5535)	0.13 (0.3234)
GMFCS	–0.32 (0.0106*)	0.03 (0.8297)	0.09 (0.4688)	–0.15 (0.2383)	0.11 (0.3915)

CFCS – the Communication Function Classification System for Individuals with Cerebral Palsy, MACS – the Manual Ability Classification System; GMFCS – the Gross Motor Function Classification System. *Bold characters indicate statistically significant values ($p < 0.05$).

which of these assessment tools are the most appropriate when assessing QoL in children with CP [23].

The children and adolescents with CP we studied rated their HRQoL (KIDSCREEN) globally as quite high; they function best in the mental health domain, worst in the physical health domain. The self-rated quality of life of children with CP compared to their healthy peers is statistically significantly higher in all domains except peer contacts (Peers & Social Support). The level of HRQoL of children with CP is similar regardless of age, although some differences can be observed: children aged 8–11 years function best in the domains of Physical Well-Being and Peers & Social Support, children aged 12–14 years in the domain

of School Environment, while adolescents aged 15–18 years in the domains of Psychological Well-Being and Autonomy & Parents.

A large cross-sectional study of quality of life SPARCLE1 with the KIDSCREEN52 questionnaire (818 children aged 8–12 years) conducted in nine European countries between 2004 and 2006 showed that in six domains out of ten surveyed, the quality of life reported by children did not differ from the norm (Psychological well-being, Self-perception, Social support, School environment, Financial resources, Social acceptance). Specific conditions were associated with poorer HRQoL in the four remaining domains: severely reduced physical self-efficacy was significantly

associated with reduced mean physical well-being scores, mental impairment with reduced scores in moods and emotions and autonomy, speech difficulties with reduced quality in relationships with their parents [24]. Most children aged 8–12 years with CP had a similar QoL to their healthy peers. A follow-up of the SPARCLE2 study of 355 adolescents aged 13–17 years between 2014 and 2016 found that severity of physical disability was significantly associated with reduced HRQoL of adolescents in only three domains (Mood & Emotions, Autonomy, and Social Support & Peers). Young people with CP had significantly lower HRQoL than young people in the general population in only one domain – Social Support & Peers. Additionally, HRQoL in childhood was found to be a consistent predictor of HRQoL in adolescence. It appeared that children's psychological problems and parental stress in childhood or their worsening between childhood and adolescence predicted only a small reduction in HRQoL in adolescence [25]. Such correlations are characteristic of countries with high economic status, where children have access to rehabilitation and psychological care and a developed school support system. Children with CP from low- and middle-income countries had significantly worse HRQoL in all domains compared to an age-matched control group. Irrespective of the economic status of the country, physical well-being was always the worst dimension of HRQoL and was associated with impaired motor function, while material status was important for functioning in other dimensions of quality of life [15].

Regarding the HRQoL self-assessment of the children with CP we studied, it was observed that their quality of life did not deteriorate with age and, in the adolescent group, was not worse than that of their healthy peers in any of the areas studied; in fact, it turned out to be statistically significantly higher in the domains of school environment, mood and feelings, and family relationships and sense of autonomy (Psychological Well-Being, Parents & Autonomy, School Environment). It is also noteworthy that the children with CP we studied have a higher HRQoL in the domain of School Environment in all age groups, and the self-assessment of the level of school functioning does not decrease with age in contrast to healthy peers. This may indicate a better adaptation of children with CP, most likely triggered by the favorable and supportive behavior of teachers and caregivers, as well as the long duration of the disability and the need to cope with it from an early age. The importance of adapting to disability from birth is shown by the results of a study on the HRQoL of children after mild to moderate cranio-cerebral trauma. These children divide their lives into 'pre- and post-injury' periods, compare their current abilities to those before the injury, and report even minor inconveniences, unnoticeable to those around them. The level of HRQoL in the self-assessment with the KIDSCREEN-27 in this group of patients was

significantly reduced in all domains studied except Family & Peer relationships [26]. Adolescents with CP additionally appear to have a lower susceptibility to rebellious behavior characteristic of adolescence, which is not insignificant for the formation of cooperation with teachers. The process of psychological and social changes associated with adolescence is accompanied by a decrease in the perception of HRQoL by healthy children precisely in the domain of school and environment, and to a lesser extent in psychological and physical well-being and family relationships, as described in the current report of the Children's Rights Ombudsman on the QoL of children and adolescents in Poland based on self-assessment with the Kid-screen-27 [27]. The sense of psychological well-being of children with CP seems to be mainly related to good family relationships. The impact of adolescence on the needs for autonomy and separateness in the CP group is probably not as intense as in their healthy peers because of the strong caring relationships with parents, mainly the mother. Parents often display an overprotective attitude towards their disabled children, which shapes the high level of insecurity associated with the family. Children and adolescents with CP feel very secure in their home environment, which can lead them to feel less need and expectation for autonomy and separateness. This sense of psychological well-being, however, is often disrupted in young adults with CP, as indicated by research findings suggesting lower levels of global sense of resourcefulness and meaningfulness in life, as well as coping with stress [28]. Among young adults, there is also an apparent trend towards lower levels of perceived psychological well-being compared to childhood [29]. This is certainly contributed to by the increasing importance of the peer environment with age, which, as the results of the study indicate, is not very conducive to children with disabilities [25]. The activity levels of children and adolescents with CP related to social and recreational activities and satisfaction with participation in them are lower than in the population of healthy children [25, 30, 31]. Children with CP also spend less time with friends and experience less social support from friends, and are at increased risk of bullying and harassment at school [32, 33]. Peer friendships have been proven to play an important role in shaping children's mental well-being and contribute to reducing the risk of developing mental disorders. Making friends is also important for good development and psychosocial functioning in adulthood [34]. This is particularly important for children with CP, who are at higher risk of developing anxiety and behavioral problems, and difficulties in making friends are a factor that exacerbates this risk [35].

In children with disabilities, there is a need to continuously develop resilience and skills for effective coping strategies for independent living by developing self-confidence and self-esteem, problem-solving

skills, adaptability to adversity, promoting integration with peers, making lasting friendships, finding benefits and satisfaction in life despite disabilities [36, 37].

The convergence of HRQoL ratings made by children with CP and their carers is generally not very high. The children we studied statistically significantly better assessed their HRQoL in the domains of Physical functioning and Mental health compared to their parents' assessment of their QoL, while being aware of poorer functioning in these domains relative to their healthy peers. This corresponds with findings from other studies on the QoL of children with chronic diseases. Parents tend to underestimate their child's ability to adapt [38]. A study of the level of quality of life of children with CP based on the KIDSCREEN-52 among 500 children from seven European countries aged 8–12 years found that children rated their QoL significantly higher in 8 out of 10 domains studied, as did parents in the domain concerning mood and emotion ratings, and lower only in the domain concerning family finances [39]. Concordance between children's and parents' ratings is generally low to moderate in both childhood and adolescence in all HRQoL domains. In the domains of Mood & Emotions, Self-esteem, Relationship with parents and Social support & Peer relationships, the extent of discrepancy increases significantly between childhood and adolescence [40]. It follows that children with CP are able to adapt to the activity limitations that have existed since early childhood and can have a satisfactory quality of life, despite even significant motor deficits. A good sense of social acceptance and self-esteem plays a large role in reducing the likelihood of anxiety and depression. Unfortunately, the chronicity of the disease generates a tendency in parents to underestimate their child's ability to adapt and accept the diagnosis. Younger parents (especially mothers) and those with lower social competence and higher emotionality rate their children worse [38, 41]. Parents' lower assessments of the level of quality of life for their children with CP may also be due to the fact that they are more able to consciously and objectively assess the negative prospects of the impact of disability on their children's quality of life across the lifespan, which is undoubtedly associated with a high level of concern about their level of quality of life in adulthood. There is ample evidence that high levels of parental stress are a major factor influencing negative assessments of their children's health-related quality of life levels [39, 42–45]. Research findings suggest that negativity and anxiety about the future of parents of children with CP do not correlate with perceptions of their level of quality of life in adulthood. The results of studies on the level of quality of life of young adults with CP indicate that there is no relationship between psychological well-being and body structure and large motor function, lower self-reported physical health scores of young adults with CP did not translate into a sense of poorer quality of life in terms of social and environ-

mental functioning. Physical aspects such as reduced motor function and pain are factors that reduce global quality of life, but for young adults with CP the psychological and emotional spheres, communication, skills, level of social interaction and sense of success in fulfilling daily social roles appear to be more important. An important component of children and adolescents' assessment of QoL is the ability to learn and function in a peer group [46, 47]. Currently, a multifaceted approach to collecting information about the level of QoL of children and young people with CP has become the gold standard, taking into account simultaneous assessments on QoL questionnaires by children and their parents, as well as observations by clinicians and teachers caring for them on a daily basis. Taking into account the perspectives of the child and parents, as well as the professionals caring for the child (clinicians/therapists/teachers), provides an important opportunity to provide a comprehensive assessment of the level of QoL, as it includes the child's behavior in different contexts of daily functioning [42, 44]. In a holistic assessment, the child's own perspective should always be taken into account, the viewpoints of the children and their caregivers should be treated complementarily in order to gain a better knowledge of the HRQoL of children and young people with CP [40].

Conclusions

Physical disability does not appear to have a significant impact on the level of HRQoL in intellectually normal children and young people with CP, making their prospects for good social functioning high. This knowledge should be the basis of social and educational policies to prevent the marginalization of people with physical disabilities and to enable them to participate as widely as possible in the society.

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Ethical approval

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Conflict of interest

The authors declare no conflict of interest.

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