

# Quality of life in children and young people with tetraplegic cerebral palsy

## *Jakość życia dzieci i młodzieży z postacią czterokończynową mózgowego porażenia dziecięcego*

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**Słowa kluczowe:** jakość życia, niepełnosprawność intelektualna, tetraplegia, mózgowie porażenie dziecięce.

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### Abstract

**Introduction:** Health-related quality of life (HRQOL) is an important outcome of health interventions for children and youths with cerebral palsy (CP).

**Aim of the research:** To describe HRQOL of children and young people with tetraplegic cerebral palsy from the parents' perspectives, and explore the impact of four factors (severity of CP, intellectual disability, age, and gender) on HRQOL.

**Material and methods:** This is a descriptive study, conducted in educational centres in central and southern Poland. The study encompassed a group of 149 children and youths with tetraplegic cerebral palsy (TCP). The HRQOL study described in this paper was carried out using the PedsQL 4.0 Generic Core and PedsQL 3.0 Cerebral Palsy Module.

**Results:** The lowest subscale score in generic core scales was physical functioning (mean  $\pm$  SD: 11.1  $\pm$  8.5), the highest being emotional functioning (47.1  $\pm$  22.2). The lowest subscale score in CP module was daily activities (3.2  $\pm$  8.5), the highest being pain and hurt (57.1  $\pm$  29.3). PedsQL scores were related to MASC level, GMFCS level, and degree of intellectual disability, but not gender. Age correlated only with the assessment of pain and hurt (Pearson  $r = -0.190$ ;  $p = 0.020$ ). This study showed significant deficits in HRQOL for children with TCP, especially as regards their physical HRQOL.

**Conclusions:** More studies aimed at searching factors related to psychosocial HRQOL are needed. In relation with the increasing life expectancy of persons with TCP, parents and health professionals should pay more attention to appropriate assessment of pain.

### Streszczenie

**Wprowadzenie:** Jakość życia uwarunkowana stanem zdrowia (HRQOL) jest ważnym skutkiem interwencji zdrowotnych u dzieci i młodzieży z mózgowym porażeniem dziecięcym.

**Cel pracy:** Przedstawienie charakterystyki HRQOL dzieci i młodzieży z postacią tetraplegiczną mózgowego porażenia dziecięcego sporządzonej na podstawie oceny rodziców, a także analiza wpływu na nią czterech czynników (stopnia ciężkości porażenia mózgowego, niepełnosprawności intelektualnej, wieku oraz płci).

**Materiał i metody:** Jest to badanie opisowe przeprowadzone w placówkach edukacyjnych zlokalizowanych w środkowej i południowej Polsce. W badaniu udział wzięło 149 osób z postacią tetraplegiczną mózgowego porażenia dziecięcego. Do oceny HRQOL zastosowano PedsQL 4.0 Generic Core i PedsQL 3.0 Cerebral Palsy Module.

**Wyniki:** Najniższą ocenę dla *Generic Core Scales* uzyskano w podskali funkcjonowanie fizyczne (średnia  $\pm$  odchylenie standardowe: 11,1  $\pm$  8,5), a najwyższą dla funkcjonowania emocjonalnego (47,1  $\pm$  22,2). Najniższą ocenę w CP Module uzyskano

dla czynności codziennych ( $3,2 \pm 8,5$ ), natomiast najwyższą dla podskali bólu ( $57,1 \pm 29,3$ ). Wynik PedsQL korelował z poziomem systemów MACS i GMFCS, stopniem niepełnosprawności intelektualnej, ale nie z płcią badanych. Wiek był powiązany jedynie z oceną bólu ( $r = -0,190$ ;  $p = 0,020$ ). W badaniu stwierdzono istotnie niższą jakość życia uwarunkowaną stanem zdrowia osób z postacią tetraplegiczną mózgowego porażenia dziecięcego, zwłaszcza w obszarze funkcjonowania fizycznego.

**Wnioski:** Obszar psychospołeczny HRQOL wymaga badań ukierunkowanych na poszukiwanie czynników modulujących. Ze względu na wydłużający się czas życia osób z mózgowym porażeniem dziecięcym zarówno rodzice, jak i pracownicy opieki zdrowotnej powinni zwrócić uwagę na właściwą ocenę występującego u nich bólu.

## Introduction

Cerebral palsy (CP) is the most common motor disability of childhood. It is an individually specific complex, with unstable clinical picture and functional status, in which (next to movement disorders) the following coexisting disorders may occur: disturbances of sensation, cognition, communication, perception and/or behaviour, and/or a seizure disorder [1]. Their presence and severity depends on the localisation and extent of brain damage. Based on test data, one may say that intellectual disability ( $IQ < 70$ ) occurs in 31–65% patients with CP, whereas epilepsy occurs in 20–46%, vision impairment in 2–19%, hearing impairment in 2–15%, and severely impaired/no speech and feeding problems in 50% [2–5]. Their presence has a fundamental impact on the patients' quality of life, life expectancy, functional status, ability to perform independent activities, and participation.

Most CP cases (approx. 90%) are of spastic form, such as monoplegia, hemiplegia, diplegia, and tetraplegia [4, 6]. Tetraplegic cerebral palsy (TCP) is the most severe type of spastic CP. Its occurrence is assessed at 5.5–35% of cases [7–10]. It is a form of CP in which pareses concern all four limbs. Paresis of the upper limbs is greater than or the same degree as in the lower limbs [11]. The causes of tetraplegia may be of pre-, peri-, and postnatal character. They include: perinatal asphyxia, periventricular leukomalacia (PVL), malformations, infection, and genetic abnormalities [3, 12]. In this clinical form brain injuries are often broad and diffuse, on both cortical and subcortical structures. This results in more frequent, than in other forms, occurrence of epilepsy, intellectual disability, difficulties in communication, difficulties in food intake, and sensory deficits [3, 8, 9, 11–13]. More extensive are also secondary osteoskeletal changes, respiratory disorders, and gastrointestinal disorders, including eating disorders.

Complex consequences of the abovementioned deficits, concerning various spheres of functioning of persons with TCP, may have a negative effect on their quality of life. Quality of life (QoL) is 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 [14]. Health-related quality of life (HRQOL) is a narrower term. These are feelings of an individual on the impact of their health status on various aspects of their own lives. Quality of life and HRQOL are pri-

ority outcomes for health and rehabilitation services [15]. Despite a great deal of interest in HRQOL in children, little information is available regarding the most severe type of CP.

## Aim of the research

The aim of this study was the assessment of HRQOL in children and youths with spastic tetraplegia and intellectual disability.

## Material and methods

The study encompassed a group of 149 children and adolescents with TCP. The tool used in the study was the PedsQL 4.0 Generic Core and PedsQL 3.0 Cerebral Palsy Module. In the study, out of necessity, the possibility of a self-completion questionnaire was abandoned, instead opting for reporting by parents (parent proxy-report). The reasons were communication problems and intellectual disability ( $IQ < 34$ ) occurring in all patients. Parent proxy-report includes ages 2–4 years (toddler), 5–7 years (young child), 8–12 years (child), and 13–18 years (adolescent), and assesses the parent's perception of their child's HRQOL. Both types of evaluation are considered to be important sources of information about the child's quality of life. Parent reports should be treated rather as complementary information [16–18], because the parent's psychological well-being may indirectly affect the assessment of the quality of life of children [19–21]. In the study, in all cases the questionnaires were filled out by the mother or in the case of bereavement (4 cases) by the grandmother of respondents who were affected the most by child care (later referred to as caregivers).

The both scales are reliable and valid measures of HRQOL [22–27]. The 23-item PedsQL 4.0 Generic Core Scales encompass: physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). To create the psychosocial health summary score, the mean is computed as the sum of the items divided by the number of items answered in the emotional, social, and school functioning scales [24]. The 35-item PedsQL 3.0 CP Module encompasses seven scales: daily activities (nine items), school activities (four items), movement and balance (five items), pain and hurt (four items), fatigue (four items), eating activities (five items), and speech and communication (four items). For the parent report for toddlers' form (aged

2–4 years) there are no school activities or speech and communication scales, and the daily activities and eating activities scales are modified to include fewer items (not all items were applicable for toddlers) [27]. The instructions ask how much of a problem each item has been for the past month. A five-point response scale is used (0 – never a problem; 1 – almost never a problem; 2 – sometimes a problem; 3 – often a problem; 4 – almost always a problem). The items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate higher HRQOL [24].

The study was designed in such a way that the age-appropriate questionnaires were handed over to caregivers via the staff of educational institutions the respondents attended. Institutions included in the study were located in central and southern Poland.

**Table 1.** Characteristics of the study population

Characteristics	N (%)
Gender:	
Male	85 (57)
Female	64 (43)
Age [years]:	
2–4	8 (5.4)
5–7	14 (9.4)
8–13	53 (35.5)
> 13	74 (49.7)
Degree of intellectual disability:	
IQ < 20 (profound)	88 (61)
IQ 20–34 (severe)	57 (39)
GMFCS (level):	
II	2 (1.3)
III	5 (3.4)
IV	54 (36.2)
V	88 (59.1)
MACS (level):	
II	3 (2.0)
III	19 (12.8)
IV	55 (36.9)
V	72 (48.3)
Accompanied diseases and dysfunctions:	
Epilepsy	92 (61.7)
Visual impairments	60 (40.3)
Hearing impairments	12 (8.1)
No diseases or dysfunctions	36 (24.3)

After filling in the questionnaire it was returned to the facility, where it was checked for the correctness of filling in and topped with a functional classification using the Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) by a physiotherapist. The GMFCS and MACS were used to determine the severity of CP (Levels I through V, with V as the most severe impairment). The inclusion criterion was diagnosis of TCP confirmed by medical history.

The study was approved by the Ethics Committee at the Health Sciences Faculty at the Jan Kochanowski University in Kielce.

### Statistical analysis

Means, standard deviation, median, min, and max were calculated for continuous data. For group comparisons of continuous variables, ANOVA was used. The Pearson correlation was used to examine the relationship between the age and the PedsQL scales. The Spearman rank correlation was used to examine the relationship between ranked variables and the PedsQL scales. A significance level of 0.05 was used throughout.

### Results

The caregivers evaluating the quality of life were persons with secondary education (46%) or primary and vocational education (39%), rarely higher education (15%). Most of them (78%) gave up paid work to care for the child. The average age of the evaluators was  $40 \pm 7.0$  years (min. 22, max. 57). Subjects with TCP were mostly teenagers (almost 50% of respondents over 13 years of age), often classified into levels IV (36.2%) and V (59.1%) of GMFCS and levels IV (36.9%) and V (48.3%) of MACS. They were characterised by the presence of intellectual disability of severe and profound degree (61% IQ < 20). The most common coexisting disorder was epilepsy, occurring in 61.7% of patients. During the study all persons attended special educational institutions. Table 1 shows the general characteristics of the study group.

Table 2 presents results of the Generic Core Scales and CP Module. The lowest assessed subscale of Generic Core Scales was physical functioning ( $11.1 \pm 8.5$ ), and the highest was emotional functioning ( $47.1 \pm 22.2$ ). The PedsQL Module CP subscale analysis revealed lower scores of daily activities and school activities, speech, and eating activities.

No significant correlations between HRQOL scores and gender of the studied group were found (data not shown). Age correlated only with the assessment of pain (Pearson  $r = -0.190$ ,  $p = 0.020$ ). Statistically significant difference in the pain subscale between groups 2–4 years old and groups of more than 8 years of age was noted (2–4 years:

**Table 2.** PedsQL Generic Core Scales and Cerebral Palsy Module scores

PedsQL scales	N	Mean	SD	Min.	Me	Max.
Generic Core Scales						
Physical functioning	149	11.1	8.5	0	12.5	37.5
Emotional functioning	149	47.1	22.2	0	50	100
Social functioning	149	36.7	26.1	0	35	100
School functioning	149	34.7	21.7	0	35	100
Psychosocial functioning	149	40.1	18.7	0	41.7	86.7
Overall score	149	29.1	13.6	0	30.4	68.5
CP Module						
Pain and hurt	149	57.1	29.3	0	56.3	100
Fatigue	149	43.7	21.2	0	43.8	100
Eating activities	149	16.9	20.0	0	10	85.0
Speech	141	18.2	27.7	0	0	100
Daily activities	149	3.2	8.5	0	0	47.2
School activities	141	5.6	13.3	0	0	75
Movement and balance	149	26.5	26.3	0	20	100

81.25 ±25.44 vs. 8–13 years: 52.99 ±29.04,  $p = 0.006$ ; 2–4 years: 81.25 ±25.44 vs. > 13 years: 54.81 ±27.19,  $p = 0.008$ ). The level of MACS correlated with all areas of the generic and specific scale. The level of GMFCS and degree of intellectual disability of the studied groups correlated with some areas of both scales (Table 3). Children in Level V of GMFCS and MACS, i.e. judged to be most severely affected, had the lowest HRQOL scores in all domains of the PedsQL Generic Core Scale and CP Module (Tables 4, 5). Subjects with TCP and severe mental retardation (IQ 34–20) scored higher in both PedsQL scales than respondents with profound mental retardation (IQ < 20). These differences were statistically significant for all items, except for social functioning and movement and balance (data not shown).

## Discussion

The HRQOL of children and adolescents with CP is a topic often discussed in the literature, although usually research focuses on milder forms of CP. The results confirm that the HRQOL of people with CP is lower than that of healthy children [28–37]. Only Dickinson *et al.* [38] reported no differences between the two groups. The quality of life of people with CP is comparable to patients treated for cancer and rheumatic diseases [39], patients with myelomeningocele [40], or with neuromuscular diseases [41]. The health-related quality of life in TCP patients is significantly lower compared with other types of CP [27, 28, 42].

The Generic Core of the PedsQL 4.0 and CP Module scores presented in Table 2 demonstrated significantly lower health-related quality of life compared with two literature-based groups with TCP [27, 28]. Significant differences were found for physical functioning score (11.1 ±8.5 vs. 31.04 ±27.92 and 33.78 ±29.07), and similar results for psychosocial functioning score (40.1 ±18.7 vs. 51.72 ±15.56 and 49.96 ±15.63). As in other studies [27, 28, 43, 44] physical functioning score was lower than psychosocial health score. Varni *et al.* [28] claim that children with TCP have diminished physical (but not psychosocial) well-being when compared with those with other spasticity types. This raises the question of whether parents of children with TCP are not too optimistic about their emotional and social functioning, and whether they can assess it objectively. This applies particularly to such elements of the PedsQL questionnaire as the feeling of fear, sadness, anger, or establishing relationships with peers. Although most interventions aim to improve physical independence, a lot more could be done in the wider society to improve social inclusion and participation of children with CP [45].

The PedsQL CP Module showed that patients had the greatest difficulties with daily and school activities, and the least with pain and hurt, and fatigue, which is comparable with the results obtained by Varni *et al.* [27].

The PedsQL scores of patients with TCP were related to their GMFCS level, MACS level, and degree of intellectual disability, but not age and gender. Severe disability and the presence of numerous coexistent

**Table 3.** Correlation between PedsQL scores and degree of intellectual disability, GMFCS level, and MACS level

PedsQL scales	N	Degree of intellectual disability		GMFCS level		MACS level	
		r	p	r	p	r	p
Generic Core Scales							
Physical functioning	149	0.239	0.004	-0.347	< 0.001	-0.474	< 0.001
Emotional functioning	149	0.204	0.014	-0.316	< 0.001	-0.402	< 0.001
Social functioning	149	0.137	0.102	-0.024	0.772	-0.227	0.005
School functioning	149	0.252	0.003	-0.116	0.183	-0.271	0.002
Psychosocial functioning	149	0.241	0.003	-0.159	0.053	-0.350	< 0.001
Overall score	149	0.304	< 0.001	-0.218	0.008	-0.406	< 0.001
CP Module							
Pain and hurt	149	0.202	0.015	-0.290	< 0.001	-0.378	< 0.001
Fatigue	149	0.193	0.020	-0.193	0.018	-0.376	< 0.001
Eating activities	149	0.362	< 0.001	-0.427	< 0.001	-0.477	< 0.001
Speech	141	0.443	< 0.001	-0.161	0.057	-0.386	< 0.001
Daily activities	149	0.265	< 0.001	-0.200	0.014	-0.287	< 0.001
School activities	141	0.548	< 0.001	-0.282	< 0.001	-0.431	< 0.001
Movement and balance	149	0.154	0.064	-0.543	< 0.001	-0.496	< 0.001

r – Spearman rank correlation coefficient.

**Table 4.** Generic Core Scales and CP Module mean subscale scores stratified by GMFCS

PedsQL scales	GMFCS II		GMFCS III		GMFCS IV		GMFCS V		ANOVA P-value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Generic Core Scales									
Physical functioning	20.31	6.63	16.87	11.61	14.35	9.45	8.63	6.77	< 0.001 <sup>1</sup>
Emotional functioning	60.00	0.00	66.00	13.87	53.43	20.11	41.78	22.53	0.003 <sup>2</sup>
Social functioning	25.00	35.36	38.00	16.05	37.71	26.27	36.31	26.65	0.918
School functioning	40.00	14.14	37.50	11.90	36.70	21.26	33.05	22.66	0.792
Psychosocial functioning	41.67	16.50	48.40	8.34	43.41	17.88	37.64	19.41	0.240
Overall score	34.24	13.06	35.64	6.83	32.21	13.37	26.79	13.71	0.077
CP Module									
Pain and hurt	100.00	0.00	75.00	23.39	64.39	29.16	50.69	27.96	0.003 <sup>3</sup>
Fatigue	84.38	4.42	53.75	14.39	47.30	20.65	40.02	20.66	0.004 <sup>4</sup>
Eating activities	30.00	42.43	49.50	31.74	25.60	22.65	9.49	11.45	< 0.001 <sup>5</sup>
Speech	0.00	0.00	50.00	48.14	22.62	29.43	14.62	24.79	0.030 <sup>6</sup>
Daily activities	0.00	0.00	16.11	22.60	5.14	10.41	1.33	4.10	0.000 <sup>7</sup>
School activities	0.00	0.00	26.56	33.22	8.55	15.50	3.13	9.09	0.001 <sup>8</sup>
Movement and balance	92.50	10.61	66.00	18.51	39.63	26.60	14.77	17.10	< 0.001 <sup>9</sup>

<sup>1</sup>II vs. V,  $p = 0.001$ ; <sup>2</sup>III vs. V,  $p = 0.009$ ; <sup>3</sup>II vs. IV,  $p = 0.047$ ; II vs. V,  $p = 0.007$ ; <sup>4</sup>II vs. III,  $p = 0.013$ ; II vs. IV,  $p = 0.004$ ; II vs. V,  $p < 0.001$ ; <sup>5</sup>III vs. IV,  $p = 0.031$ ; III vs. V,  $p < 0.001$ ; <sup>6</sup>II vs. III,  $p = 0.006$ ; II vs. V,  $p = 0.047$ ; <sup>7</sup>II vs. II,  $p = 0.002$ ; III vs. IV,  $p = 0.023$ ; III vs. V,  $p = 0.003$ ; <sup>8</sup>II vs. III,  $p = 0.001$ ; III vs. IV,  $p = 0.02$ ; III vs. V,  $p = 0.004$ ; <sup>9</sup>II vs. III,  $p = 0.037$ ; II vs. IV,  $p < 0.001$ ; II vs. V,  $p < 0.001$ ; III vs. IV,  $p = 0.038$ ; III vs. V,  $p < 0.001$ .



**Table 5.** Generic Core Scales and CP Module mean subscale scores stratified by MACS

PedsQL scales	MACS II		MACS III		MACS IV		MACS V		ANOVA P-value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Generic Core Scales									
Physical functioning	28.12	13.62	15.95	9.65	13.81	7.99	7.12	5.80	< 0.001 <sup>1</sup>
Emotional functioning	68.33	12.58	59.34	16.66	53.36	17.13	38.11	23.68	< 0.001 <sup>2</sup>
Social functioning	45.00	13.23	43.93	24.56	41.20	26.25	31.05	25.99	0.079
School functioning	41.67	15.28	37.76	17.58	41.60	20.97	28.32	22.14	0.011 <sup>3</sup>
Psychosocial functioning	54.31	5.67	47.10	13.03	45.99	15.79	33.25	19.98	< 0.001 <sup>4</sup>
Overall score	44.68	3.77	35.70	9.77	33.50	11.64	23.45	13.78	< 0.001 <sup>5</sup>
CP Module									
Pain and hurt	64.58	13.01	75.99	20.76	64.28	26.39	46.38	29.85	< 0.001 <sup>6</sup>
Fatigue	72.92	23.66	55.59	16.91	48.48	17.54	35.72	21.33	< 0.001 <sup>7</sup>
Eating activities	56.67	15.28	35.00	29.06	20.82	18.85	7.57	9.23	< 0.001 <sup>8</sup>
Speech	92.36	8.42	25.99	33.61	25.16	30.05	8.27	15.87	< 0.001 <sup>9</sup>
Daily activities	13.89	19.45	10.23	15.90	3.03	6.99	1.00	3.82	< 0.001 <sup>10</sup>
School activities	37.50	28.64	16.12	22.47	5.99	11.40	1.23	4.31	< 0.001 <sup>11</sup>
Movement and balance	45.00	17.32	58.68	29.19	29.45	23.49	15.07	19.15	< 0.001 <sup>12</sup>

<sup>1</sup>II vs. III,  $p < 0.001$ ; II vs. IV,  $p < 0.001$ ; II vs. V,  $p < 0.001$ ; III vs. V,  $p = 0.012$ ; IV vs. V,  $p = 0.047$ ; <sup>2</sup>II vs. V,  $p = 0.002$ ; III vs. V,  $p = 0.031$ ; <sup>3</sup>IV vs. V,  $p = 0.012$ ; <sup>4</sup>II vs. V,  $p = 0.014$ ; <sup>5</sup>II vs. V,  $p < 0.001$ ; III vs. V,  $p = 0.041$ ; <sup>6</sup>II vs. V,  $p = 0.029$ ; <sup>7</sup>II vs. IV,  $p = 0.008$ ; II vs. V,  $p < 0.001$ ; III vs. V,  $p = 0.034$ ; <sup>8</sup>II vs. III,  $p = 0.005$ ; II vs. IV,  $p < 0.001$ ; II vs. V,  $p < 0.001$ ; III vs. V,  $p < 0.001$ ; <sup>9</sup>II vs. III,  $p = 0.005$ ; II vs. IV,  $p < 0.001$ ; II vs. V,  $p < 0.001$ ; <sup>10</sup>II vs. IV,  $p = 0.003$ ; II vs. V,  $p < 0.001$ ; III vs. IV,  $p = 0.045$ ; III vs. V,  $p = 0.014$ ; <sup>11</sup>II vs. III,  $p < 0.001$ ; II vs. IV,  $p < 0.001$ ; II vs. V,  $p < 0.001$ ; III vs. V,  $p = 0.005$ ; <sup>12</sup>II vs. V,  $p = 0.005$ ; III vs. IV,  $p = 0.006$ ; III vs. V,  $p < 0.001$ .

disorders in persons with TCP may result in secondary musculoskeletal problems and health problems increasing with age, including chronic pain. Among population-based studies of CP, males have been found to have higher prevalence of CP than females. It was suspected that gender may influence the motor outcome and cognitive development in children with CP. In our study, similarly as in others [32, 43, 44, 46], no impact of demographic factors on HRQOL was noticed. The results indicate that gender and age may be less important factors of well-being. More detailed longitudinal studies are required, especially in the case of adults. According to Usuba *et al.* [47], deteriorations in the HRQOL were most evident in adults with CP in their late 20s and 30s.

In the CP Module the top-rated feature was pain and hurt. In the study group a statistically significant difference in the subscale between a group of 2–4-year-olds and a group of over-8-year-olds was revealed, which indicates an increase in discomfort connected with pain. Significant differences were also

noticed at the II and IV and II and V level of GMFCS. Children with TCP self-reported greater pain severity than children with hemiplegia or diplegia [27]. The same pattern was found for parent proxy-reports of children's pain [27, 42].

Our study showed that higher gross motor functioning (lower GMFCS level) and higher fine motor functioning (lower MACS level) were associated with higher PedsQL CP Module scores. These results are concordant with other papers concerning the GMFCS system [29, 32, 36, 42, 43, 48] and MACS system [42, 48]. The level of MACS correlated with all elements of Generic Core of the PedsQL 4.0 and CP Module. For contrast, social functioning was not associated with level of GMFCS and degree of intellectual disability. The lack of correlation between the GMFCS level and psychosocial HRQOL has been noticed before [32, 43, 46, 49].

The present study has its strengths and limitations. The major strength is the size of the sample included in the survey. To our knowledge, this is the first study in Poland on a large population of children

with TCP, who were recruited from southern and central Poland. The major limitation is basing the study on parent-proxy reporting. It is, however, the only possibility of assessing HRQOL in severe cases of CP.

## Conclusions

Cerebral palsy is the most common motor disability during childhood, and it is associated with other conditions. The severity of symptoms varies between individuals, and the same may be said about health-related quality of life. Increasing life expectancy of persons with severe CP may result in a decline in their medical and functional status. In such a case the HRQOL evaluation is of special importance because it may be useful for identifying and prioritising health problems. This study showed significant deficits in HRQOL for children with TCP, especially as regards physical HRQOL. Future studies will be needed to search for variables that could influence psychosocial HRQOL. In the case of children with limited cognitive or communication abilities, special attention should be paid to possibilities and ways of assessing emotional state, as well as pain and fatigue, i.e. domains particularly relevant to aging.

## Conflict of interest

The authors declare no conflict of interest.

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