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The quality of life of polish children with cerebral palsy and the impact of the disease on the family functioning

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ABSTRACT

Purpose: Care and upbringing of a child with cerebral palsy (CP) may affect the functioning of parents and the whole family. This study aimed to evaluate the quality of life (QOL) of children with CP in parents' opinion and the impact of disease on family functioning.

Design and methods: This cross-sectional study was conducted among 100 parents of children with CP. Survey instruments used included an Authors-Designed Questionnaire (ADQ) to collect sociodemographic and educational background data as well as four standardized questionnaires for pediatric QOL (PedsQL-GC, PedsQL-CPM, PedsQL-FIM) and for life satisfaction (SWLS).

Results: Teenagers were characterised by a higher QOL compared to other age groups. The lowest scores were observed in the PedsQL-CPM domain of daily and school activities and in the physical functioning domain of the PedsQL. It was shown that family functioning is affected by the children's age and place of residence as well as the level of parental education. It was also shown that men, parents in a relationship, those living in the city and those with vocational education were characterised by a higher level of satisfaction with life than other groups.

Conclusions: The QOL of children with CP is reduced compared to the QOL of healthy children and their condition has a significant impact on family functioning. Therefore, learning about the factors that influence QOL will allow health care providers to properly plan actions aimed at minimising the negative impact of CP on children's QOL and improving the functioning of their families.

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Introduction

Cerebral Palsy (CP) is defined as a non-progressive disorder of motor functions caused by central neuron damage during embryonic, foetal or perinatal development (Rosenbaum et al., 2007). It is an ambiguous disorder in clinical and etiological terms (Abdullahi, Satti, Rayis, Imam, & Adam, 2013; McIntyre et al., 2013). The degree of development and maturity of the central nervous system at the time the damage occurs determines the further clinical picture. Children with CP present various types of spastic paresis of the limbs, involuntary movement, and balance and coordination disturbance. Apart from these motor disabilities, a wide range of sensory and communication problems, as well as secondary musculoskeletal disorders, exist. The incidence of CP varies from 1 to 3 children for every 1000 live newborns, which makes this disorder the most frequent cause of movement disability and, after intellectual

disability (Blair, 2010; Cheshire, Barlow, & Powell, 2010; Dambi et al., 2016; Mohammed, Ali, & Mustafa, 2016), the second most frequent cause of permanent neurodevelopmental disorder among children.

The assessment of the quality of life (QOL) has become an important field, especially in medicine and the social sciences. The results of therapeutic action on QOL is an increasingly studied subject of research, and it has become part of the full clinical evaluation of a patient. The concept of QOL was introduced in the second half of the twentieth century, and although there is no unambiguous definition of it, it is understood as a person's degree of satisfaction with life and with their subjectively assessed self-fulfilment possibilities of future development (Schipper, 1990; "The World Health Organization Quality of Life assessment (WHOQOL)," 1995). But despite the progress of medical knowledge, CP is a disorder that adversely affects the QOL of both children (Albuquerque Frota et al., 2016; Berrin et al., 2007; Livingston, Rosenbaum, Russell, & Palisano, 2007; Maher, Olds, Williams, & Lane, 2008; Michalska, Wendorff, Boksa, & Wiktor, 2012b, 2012a; Varni et al., 2006; Yang, Xiao, & Yan, 2011; Yun et al., 2016) and their guardians (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013; Raina, 2005; Schipper, 1996), interfering in all areas of human functioning.

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Studies into QOL help to assess the legitimacy of medical procedures, their effectiveness and their ability to improve the lives of patients and guardians.

The identification of QOL is important, as satisfaction with life is increasingly taken into account in the assessment of a person's sense of happiness. Satisfaction with life translates into a longer life and depends on the personality traits, life events, moods and cognitive patterns of an individual. Undoubtedly, satisfaction with life can be considered alongside a sense of happiness as an indicator of QOL (Basińska & Wędzińska, 2014). It plays a central role in the functioning of a human being because it is the ultimate goal of personal development; therefore, its evaluation is both a key task and an important scientific challenge (Esnaola, Benito, & Antonio-Agirre, 2017).

CP causes parents to adapt to a new situation, and introduces changes into their system of family functioning. The daily care of people suffering from CP is difficult, due to their mobility problems and developmental delays, as well as a wide range of necessary medical intervention and rehabilitation. The main challenges faced by parents are the effective management of a child's health issues and the fulfilment of the requirements of guardians (Basińska & Wędzińska, 2014; Wędzińska, 2013). Unfortunately, taking care of a sick child often releases a spectrum of emotions in parents, such as fear, sadness, anger, helplessness and hurt, that affect the functioning of the parents and the whole family (Glinac, 2017; Parchomiuk, 2007; Rosińczuk, Kołtuniuk, Księżyc, & Wolniak, 2013; Zuurmond et al., 2018; Zuurmond, Mahmud, Polack, & Evans, 2015). Therefore, as healthcare representatives perform their therapeutic activities, they should focus not only on providing technical guidance but also on providing care and psychological support to all family members of a child with CP (Raina, 2005). This is supported by the feedback of parents. Those who participated in support group meetings assessed the functioning of their family higher than those who did not participate in support group meetings (Zuurmond et al., 2018). It should be remembered that proper family functioning increases the chance of a child suffering from CP to optimise their development (Glinac, 2017).

The purpose of this study was to determine the influence of selected sociometric variables on the QOL of children with CP and the impact of a child's state of health on both family functioning and satisfaction with life.

Methods

Design and sample

The investigators used a cross-sectional, descriptive correlational study design with purposive sampling and a survey method of data collection and measurement. The study was conducted from December 2016 to February 2017.

The study sample consisted of 100 participants who were parents of children with CP (92 women and 8 men). All participants were recruited from families of children receiving specialist services in regional rehabilitation centres and associations for families of children with CP. Researchers approached all eligible individuals in person at their children's visits to these facilities during the 3-month study period to introduce the study and obtain written informed consent from those agreeing to participate.

The research project was approved by the Bioethics Committee of a Medical University in Poland. The study was conducted in accordance with the Helsinki Declaration (World Medical Association, 2013).

Participant recruitment

The inclusion criteria were: being the biological parent of a child, having a permanent residence with a child, a lack of diagnosed mental illness, written consent for participation in the study, ability to read and write in Polish, and a child with diagnosed CP in accordance with

ICD-10 criteria. In the rest of this paper, study participants are referred to as parents. The exclusion criteria were: the age of the child being under 2 years or an incomplete survey.

Measures

Data collection and measurement tools used in this study included the following survey instruments: an Authors-Designed Questionnaire (ADQ) to collect sociodemographic and educational background data and four standardized questionnaires. The four standardized questionnaires were the Pediatric Quality of Life 4.0 Generic Core (PedsQL-GC) (Varni, Burwinkle, Seid, & Skarr, 2003; Varni, Limbers, & Burwinkle, 2007b, 2007a; Varni, Seid, & Kurtin, 2001), PedsQL 3.0 Cerebral Palsy Module (PedsQL-CPM) (Varni et al., 2006; Yang et al., 2011; Yun et al., 2016), PedsQL Family Impact Module (PedsQL-FIM) (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004) and the Satisfaction with Life Scale (Juczyński, 2001). The PedsQL psychometric properties are commonly accepted among authors conducting research in the field of QOL and is a widely used instrument for measuring pediatric QOL that covers physical, emotional, social and school functioning domains. The SWLS is recognized as a valid and reliable measure of life satisfaction.

Questionnaires were administered by pencil-and-paper in a packet completed at one time over 15 to 30 min during a clinic appointment. Participant anonymity was ensured by storing completed questionnaires separately from the informed consent documents.

The Pediatric Quality of Life Generic Core (PedsQL-GC): The 23-item PedsQL™ encompass four dimensions: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items) and School Functioning (5 items). Parent proxy-report includes ages 2–4 (toddler), 5–7 (young child), 8–12 (child), and 13–18 (adolescent), and assesses parent's perceptions of their child's QOL. The questionnaire for children aged 2–4 consist of 21 items, and do not assess School Functioning or Communication. Participants responses are measured on a 5-point Likert scale from 0 (Never a problem) to 4 (always a problem). Items are reverse scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). The total scale score is obtained by summing the average scores from each of the dimensions. The lower the score, the lower the QOL.

The PedsQL Cerebral Palsy Module (PedsQL-CPM): The 35-item PedsQL™ 3.0 CP Module encompasses seven dimensions: (1) Daily Activities (9 items), (2) School Activities (4 items); (3) Movement and Maintaining balance (5 items); (4) Pain (4 item); (5) Fatigue (4 items); (6) Eating Activities (5 items); and (7) Speech and Communication (4 items). Parent proxy-report includes ages 2 to 4 years (toddler), 5 to 7 years (young child), 8 to 12 years (child), and 13 to 18 years (adolescent) and assesses parent's perception of their child's QOL. For the parent report for toddlers from (aged 2–4 y), there are no School Activities or Speech and Communication scales. Participants responses are measured on a 5-point Likert scale from 0 (Never a problem) to 4 (always a problem). Items are reverse scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). There is no total score. Higher scores in each dimension indicate better QOL (fewer symptoms or problems).

The PedsQL Family Impact Module (PedsQL-FIM): The 36-item PedsQL™ Family Impact Module is a parent-report instrument designed to assess the impact of pediatric health conditions on parents and the family. It includes 8 dimensions measuring parents' self-reported functioning: (1) Physical Functioning (6 items); (2) Emotional functioning (5 items); (3) Social Functioning (4 items); (4) Cognitive Functioning (5 items); (5) Communication (3 items); (6) Worry (5 items); (7) Daily Activities (3 items); and (8) Family Relations (5 items). Participants responses are measured on a 5-point Likert scale from 0 (Never a problem) to 4 (always a problem). Items are reverse scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). A higher score in each dimension means better functioning (less

negative impact). The total scale score is calculated as the sum of the 36 item scores divided by the number of items answered.

The Satisfaction with Life Scale (SWLS): The SWLS Scale includes 5 statements about satisfaction with life. Participants respond by rating their level of agreement with each statement on a 7-point Likert-type scale, where 1 is “1 = Strongly disagree” to “7 = Strongly agree”. The total raw score is calculated by adding together the scores of the 5 individual statements responses (minimum total score of 5 and maximum total score of 35). The total raw score is then converted to a sten score which classifies the results into 3 groups, and determines the level of satisfaction with life: 1–4 is low, 5–6 is average and 7–10 is high.

An Authors-Designed Questionnaire (ADQ): The ADQ included 6 questions: 2 open ended, regarding the age and sex of each child and parent, and 4 closed ended, regarding each guardian's sex, education (vocational, secondary, higher), place of residence (village or city) and marital status (single or in a relationship).

Operational definitions:

Vocational Education – There are two types of vocational schools, basic vocational schools (BVS) and technical upper secondary schools. Students go to vocational school or technical upper secondary school after graduating from lower secondary school at approximately 15 years of age. The BVS is 3 years while technical upper secondary school is 4 years. Completion of technical upper secondary school allows students to obtain the technician title and high-school certificate.

Secondary education – The most common secondary school is a liceum, a typical high school lasting 4 years, that ends with an exam for a secondary school certificate or matriculation certificate (referred to as a “matura”) at approximately 18 years of age. This may be followed by several forms of upper education leading to a Bachelor's, Master's or doctoral degree.

Higher education – The Higher Education Institutions (HEIs) in Poland are classified as either state (public) and private (non-public) institutions. The two main categories of HEIs are university-type and non-university-type. Both types offer first- and second-cycle programmes as well as long-cycle Master's degree programmes, but only university-type HEIs can offer third-cycle programs (doctoral studies) and are authorized to award doctoral degrees. First-cycle programs last 3 years and lead to the Bachelor's or Engineer's degree. Second-cycle programs last up to an additional 2 years and lead to a Master's degree. Master's degrees allow students to continue their education while applying for PhD studies or to begin to work on a second type of degree.

City – A city, as defined for Poland, is a contiguous developed and inhabited area featuring closely-spaced multi-family units housing most of its population and a mean population density of 2600 inhabitants per square kilometre.

Village – A village is defined as developed and undeveloped inhabited area featuring non-uniformly dispersed single-family units housing most of the population and a mean population density of 100 inhabitants per square kilometre.

Data analysis

The statistical analysis was carried out using the Calc application from OpenOffice 3.4.1. The analysis of ordinal variables was performed by calculating the mean (M), standard deviation (SD), median (Me), minimum (Min) and maximum (Max).

The analysis of categorical variables was performed by calculating the number (n) and percentage of occurrences (%) of each value. The normality of the variable distribution was verified using the Shapiro-Wilk test. The comparison of ordinal variables was calculated using

the Kruskal-Wallis test, as the compared groups were not parallel or normally distributed. The *p*-value for statistical significance was set for $\alpha = 0.05$.

Correlations between 2 ordinal variables were analysed using the Spearman coefficient. The strength of the dependencies was interpreted according to a scheme (Hinkle, Wiersma, & Jurs, 2003) where $|r| \geq 0.9$ is a very strong correlation, $0.7 \leq |r| < 0.9$ is a strong correlation, $0.5 \leq |r| < 0.7$ is a medium correlation, $0.3 \leq |r| < 0.5$ is a weak correlation and $|r| < 0.3$ is a very weak correlation.

Results

The average age of the 100 parents who participated in the study was 33.86 ± 14.5 . The youngest woman taking part in the study was 24 years old, the youngest man was 30 years old and the maximum age was 66 years in both sexes. Table 1 shows the characteristics of guardians according to sociodemographic variables.

The participants' children (62% boys and 38% girls) were all diagnosed with CP between birth and 2 years of age. The average age of these children at the time the study took place was 9.72 ± 6.85 years.

Analysis of QOL in the PedsQL-GC

The surveyed parents assessed the overall QOL of their children at 35.53 points (SD = 17.14), with the highest score in the emotional dimension (total score = 44.15, SD = 21.23) and the lowest score in the physical dimension (total score = 24.25, SD = 19.82). A statistically significant ($p < 0.05$) relationship was observed between the PedsQL-GC score and the age of the children assessed in both emotional ($p = 0.00$) and social ($p = 0.044$) dimensions. Children aged 13–18 received significantly higher scores than those in other age groups. However, there was no significant relationship between a child's sex and parental perception of QOL. Table 2 presents detailed results.

A statistically significant ($p < 0.05$) relationship was observed between the ages of both children and parents and the children's QOL. Children of parents aged 40–50 were characterised by a higher QOL in the emotional dimension ($p = 0.00$) than children of parents in other age groups. There was no statistically significant relationship between place of residence ($p = 0.698$), sex ($p = 0.606$), education ($p = 0.891$) or parent's marital status ($p = 0.31$) in the dimensions of the PedsQL-GC.

Table 1
Sociodemographic characteristics of the parents.

Sociodemographic data	Women <i>n</i> = 92 (%)	Men <i>n</i> = 8 (%)
Age (years)		
18–29	20 (21.74%)	0 (0.00%)
30–39	34 (36.95%)	1 (12.5%)
40–49	25 (27.17%)	4 (50%)
50+	4 (4.34%)	1 (12.5%)
Place of residence		
City	68 (73.91%)	8 (100%)
Village	24 (26.08%)	0 (0.00%)
Marital status		
In relationship	73 (79.35%)	6 (75%)
Single	19 (20.65%)	2 (25%)
Education		
Vocational	14 (15.22%)	3 (37.5%)
Secondary	35 (38.04%)	1 (12.5%)
Higher	43 (46.74%)	4 (50%)

Table 2
Children's age and QOL in PedsQL-GC.

Children's age	M	Me	SD	Min	Max	P-value*
PedsQL-GC						
2–4	37.57	35.71	15.06	20.24	83.33	$p = 0.103$
5–7	39.33	42.39	13.29	17.39	60.87	
8–12	38.86	35.32	10.78	28.26	67.93	
13–18	43.41	42.39	8.15	27.17	70.65	
Physical functioning						
2–4	27.26	21.87	18.52	6.25	90.62	$p = 0.652$
5–7	27.27	25.00	21.61	0.00	65.62	
8–12	30.20	26.65	21.17	9.37	78.112	
13–18	26.04	18.75	18.44	0.00	71.87	
Emotional functioning						
2–4	40.97	35.00	15.44	15.00	90.00	$p = 0.00$
5–7	50.90	50.00	10.91	30.00	65.00	
8–12	51.25	50.00	10.90	40.00	80.00	
13–18	58.83	60.00	12.30	35.00	90.00	
Social functioning						
2–4	42.92	35.00	19.21	20.00	100.00	$p = 0.044$
5–7	44.54	55.00	24.02	0.00	70.00	
8–12	32.92	35.50	12.87	15.00	55.00	
13–18	48.83	50.00	15.35	25.00	80.00	
School functioning						
2–4	50.46	41.67	23.74	16.67	100.0	$p = 0.193$
5–7	41.81	40.00	16.92	15.00	75.0	
8–12	46.25	47.50	5.28	40.00	55.0	
13–18	50.33	50.0	9.28	35.00	70.0	

Notes: *the Kruskal-Wallis test; P-value in bold type denotes a significant difference. Abbreviations: PedsQL-GC, the Pediatric Quality of Life Generic Core; M, mean; Me, median; min, minimum; max, maximum; SD, standard deviation.

Analysis of QOL in the PedsQL-CPM

General results analysis of the PedsQL-CPM revealed that pain was the highest dimension and daily and school activities were the lowest dimensions. Table 3 presents detailed results.

There were statistically significant differences between the PedsQL-CPM scores and the marital status of the parents in the pain dimension ($p = 0.035$), the education of the parents in the fatigue dimension ($p = 0.025$) and the age of the child in the dimension of school activities ($p = 0.00$), fatigue ($p = 0.046$) and speech ($p = 0.00$). Children of single parents received higher scores in the pain dimension than children of parents in relationships indicating that single parents in this study sample perceived their children as having less pain and a higher quality of life than other parents. In the fatigue dimension, children of parents with a vocational education achieved a higher score than children of parents with a secondary or higher education. In the school activities and speech and communication dimensions, children aged 8–12 achieved a significantly higher score than other respondents. There was no relationship between the place of residence, the sex of the parents or children and the dimensions of the PedsQL-CPM.

Table 3
The average scores in PedsQL-CPM.

PedsQL-CPM ($n = 100$)	M	SD	Me	Min	Max
Daily activities	16.92	21.37	5.56	0.00	75.00
School activities	12.81	22.88	0.00	0.00	81.25
Movement and balance	22.30	21.17	20.00	0.00	100.00
Pain and hurt	54.69	29.28	56.25	0.00	100.00
Fatigue	44.94	21.44	50.00	0.00	87.50
Eating activities	35.78	28.41	36.25	0.00	100.00
Speech and communication	22.56	34.31	0.00	0.00	100.00

Abbreviations: PedsQL-CPM, the Pediatric Quality of Life Cerebral Palsy Module; M, mean; Me, median; min, minimum; max, maximum; SD, standard deviation.

Table 4
The average scores in PedsQL-FIM.

PedsQL-FIM	M	SD	Me	Min	Max
Physical functioning	43.84	20.36	45.83	4.17	95.83
Emotional functioning	49.20	19.76	45.00	15.00	100.0
Social functioning	44.76	21.57	40.63	6.25	100.0
Cognitive functioning	55.45	21.77	50.00	10.00	100.0
Communication	46.80	22.99	50.00	0.00	100.0
Worries	34.16	18.00	35.00	0.00	80.0
Daily activities	34.38	21.36	33.33	0.00	83.33
Family relations	55.55	23.10	55.00	5.00	100.0
General score	46.04	16.10	42.71	14.58	86.81

Abbreviations: PedsQL-FIM, the Pediatric Quality of Life Family Impact Module; M, mean; Me, median; min, minimum; max, maximum; SD, standard deviation.

Family Functioning in PedsQL-FIM

According to the PedsQL-FIM, the average transformed score of the level of family functioning was 46.04 (SD = 16.10), with the highest in the family relations dimension (total score = 55.55, SD = 23.10) and the cognitive dimension (total score = 55.45, SD = 21.77) and the lowest in the daily activities dimension (total score = 34.38, SD = 21.36) and worries dimension (total score = 34.16, SD = 18.00). Table 4 presents detailed results.

There was a statistically significant ($p = 0.040$) difference between the results of the PedsQL-FIM and the place of residence in the physical dimension, with parents living in cities functioning better than parents living in villages. In the cognitive dimension, education had a significant impact on the level of family functioning, with parents with a higher education achieving statistically significant ($p = 0.032$) higher scores than parents with a vocational or secondary education. In addition, children's age significantly correlated with the level of family functioning in the physical dimension ($p = 0.026$). Among children aged 8–12, the PedsQL-FIM dimensions were higher than in other age groups. The parents' sex ($p = 0.509$), marital status ($p = 0.722$) and age ($p = 0.937$) were not significantly correlated with the level of family functioning.

The SWLS Questionnaire

The average score obtained in the SWLS questionnaire for the overall assessment of satisfaction with life was 6.02 on the sten scale. This means that 42% rated their level of satisfaction with life as average (5–6), 40% as high (7–10) and 18% as low (1–4).

Analysis of the results showed that 37.5% of men and 42.39% of women assessed their satisfaction with life as average, while 62.5% of men and 38.04% of women assessed their level of satisfaction with life as high. Over 40% of parents in a relationship assessed their level of satisfaction with life as high. Similarly, slightly <37% of single parents also assessed their level of satisfaction with life as high. There was no correlation between marital status, education, nor place of residence and the level of satisfaction with life. The age of parents correlated with the results of the SWLS questionnaire ($p = 0.028$). Parents aged 40–50 assessed their satisfaction with life at a higher level than the parents in other age groups.

In addition, data analyses revealed relationships between the PedsQL-GC dimensions and the level of parents' satisfaction with life ($p < 0.05$ for all domains). Higher parental perceptions of a child's QOL in the physical and school dimensions were positively correlated with parental satisfaction with life while higher parental perceptions of a child's QOL in the social and emotional dimensions were negatively correlated with parental satisfaction with life. Table 5 presents detailed results.

Similarly, to the PedsQL-GC, the QOL of a child in each domain of the PedsQL-CPM is associated ($p < 0.05$) with the level of satisfaction of life of the parent. It has been shown that a higher QOL of a child in some of those domains also correlates with a lower satisfaction with life of the parent. Table 5 presents detailed results.

Table 5
Correlations between children's QOL and parental satisfaction with life.

	Correlation with SWLS	
	Correlation coefficient	P-value
PedsQL-GC		
Physical functioning	0.086	<0.05
Emotional functioning	−0.050	<0.05
Social functioning	−0.004	<0.05
School functioning	0.124	<0.05
General score	−0.032	<0.05
PedsQL - CPM		
Daily activities	−0.252	<0.05
School activities	−0.216	<0.05
Movement and balance	−0.171	<0.05
Pain and hurt	−0.302	<0.05
Fatigue	−0.064	<0.05
Eating activities	−0.130	<0.05
Speech and communication	−0.204	<0.05

Notes: P-value in bold type denotes a significant difference.

Abbreviations: PedsQL-GC, the Pediatric Quality of Life Generic Core; PedsQL-CPM, the Pediatric Quality of Life Cerebral Palsy Module; SWLS, Satisfaction with Life Scale.

Correlation testing between the level of family functioning (PedsQL-FIM), parental perception of child's general QOL (PedsQL-GC), and parental satisfaction with life (SWLS) revealed a positive correlation between family functioning across all dimensions and both parental perception of child's QOL and parental satisfaction with life ($p < 0.05$). Tables 6 and 7 presents detailed results.

Discussion

Research into the QOL among children with CP is important, not only because of its contribution to reliable evaluations, but also for the provision of better treatment and rehabilitation (Kulak & Topór, 2010). Consideration is given to whether the QOL of individuals with CP is more determined by their personality, situational factors or other predictors, such as sociometrics. Whether QOL depends on character traits and attitudes toward life depends on what meaning the condition has, both to those affected and to their parents (Basińska & Wędzińska, 2014). The most desirable reaction is an attitude of acceptance, in which parents accept their children's lives and feel the need to provide them with rational help and support. Unfortunately, there is no single or universal approach for families to take when faced with a child with a disability. Each family's approach is related to many factors, including QOL before the birth of the child, the degree of disability, age and sex of the child, and individual styles of coping with difficult situations (Basińska &

Table 6
Correlations between children's QOL and the family functioning.

	Correlation with PedsQL-FIM	
	Correlation coefficient	P-value
PedsQL-GC		
Physical functioning	0.330	<0.05
Emotional functioning	0.286	<0.05
Social functioning	0.245	<0.05
School functioning	0.070	<0.05
PedsQL-CPM		
Daily activities	0.013	<0.05
School activities	0.045	<0.05
Movement and balance	0.129	<0.05
Pain and hurt	0.098	<0.05
Fatigue	0.084	<0.05
Eating activities	0.011	<0.05
Speech and communication	0.117	<0.05

Notes: P-value in bold type denotes a significant difference.

Abbreviations: PedsQL-GC, the Pediatric Quality of Life Generic Core; PedsQL-CPM, the Pediatric Quality of Life Cerebral Palsy Module; PedsQL-FIM, the Pediatric Quality of Life Family Impact Module.

Table 7
Correlations between the family functioning and parental satisfaction with life.

PedsQL-FIM	Correlation with SWLS	
	Correlation coefficient	P-value
Physical functioning	0.079	<0.05
Emotional functioning	0.184	<0.05
Social functioning	0.117	<0.05
Cognitive functioning	0.090	<0.05
Communication	0.044	<0.05
Worries	0.114	<0.05
Daily activities	0.077	<0.05
Family relations	0.029	<0.05
General score	0.120	<0.05

Notes: P-value in bold type denotes a significant difference.

Abbreviations: PedsQL-FIM, the Pediatric Quality of Life Family Impact Module; SWLS, Satisfaction with Life Scale.

Wędzińska, 2014). The following discussion focuses on comparing and contrasting the results of our study with those of other researchers to confirm areas of disease management and identify new factors affecting QOL that require increased attention in the clinical setting to improve the lives of children with CP and their families.

Many authors (Livingston et al., 2007; Michalska et al., 2012b; Varni et al., 2006; Varni, Limbers, & Burwinkle, 2007; Yang et al., 2011) indicate that the QOL of children with CP is significantly reduced compared to the QOL of healthy children. This is confirmed by the analyses of our own study, in which respondents assessed the overall QOL at a low level (total score of 35.53). Interestingly, however, our results are contradictory to the European survey carried out in 2007 by Dickinson et al. (2007). Those studies have shown that children with CP have similar QOL to children in the general population in all dimensions, with the exception of the school dimension. This may be due to the fact that QOL evaluation is a subjective assessment of a person's feelings in relation to various aspects of life, and that each person's system of values and expectations is significantly affected by the context in which they live.

In our own study, the lowest scores were obtained in the physical dimension, and the highest in the emotional dimension, which is a similar trend in comparison with the results of other authors (Albuquerque Frota et al., 2016; Michalska et al., 2012b; Varni et al., 2006; Yang et al., 2011). However, when evaluating the QOL of children with CP using the PedsQL-CPM, the lowest scores were obtained in the dimensions of daily activities and school activities; this is analogous to the results obtained by Varni et al. (2006), Yang et al. (2011), Yun et al. (2016) and Michalska et al. (2012b). The repeatability of such a result in the many studies carried out both in Poland and abroad speaks to the need to adapt rehabilitation procedures to the requirements of everyday life, and to direct them toward the acquisition of those skills, sometimes simple and necessary, that provide independent existence. Therefore, more attention should be paid to the improvement of hand function, which is the main tool to explore the world, instead of focusing only on the issue of walking (Król, 2010). The analysis of the study by Varni et al. (2006) is interesting, as it showed that children with CP were characterised by a much higher QOL in the social dimension than our study showed (52.09 versus 38.95, respectively). This difference may result from the fact that Polish families of a child with CP feel more stigmatised and prone to give up their social lives. The effects of the condition can also make it difficult to remain in contact with friends and acquaintances.

The Penner, Xie, Binopal, Switzer, and Fehlings (2013) study confirmed that one quarter of children with CP suffer from severe pain limiting their activity. Pain is also an important factor in lowering children's QOL in the school activities dimension (Berrin et al., 2007). As with Penner et al. (2013), both Yang et al. (2011) and Yun et al. (2016) found that pain was the highest-rated area. This dissimilarity in obtained results, according to Michalska et al. (2012b), may be caused by problems in communication between child and parents or ignorance by parents about both the assessment of the intensity of pain and the

recognition of its symptoms. After pain, another highly rated dimension was fatigue (Michalska et al., 2012b; Yun et al., 2016). It is interesting to note that fatigue can increase due to either low or high amounts of rehabilitation activity. Increased fatigue is undoubtedly related to the intensification of pain in the case of medical or physiotherapy treatments. But in the study by Bednarek and Bryczek (2012), nearly half of the respondents declared that their children are not rehabilitated at home, which increases patient stress and, in turn, fatigue.

The study carried out by Bednarek and Bryczek (2012) shows that speech is the least-developed skill in the rehabilitation of children with CP. Children are often unable to express their needs clearly; therefore, traditional or alternative means of communication are important in order to enable linguistic expression, facilitate learning and increase the opportunities to participate in social life. In the speech dimension of the PedsQL-CPM measured in our study, children overall achieved a low QOL (22.56, on average), which coincides with the results of Michalska et al. (2012b). However, the speech dimension was rated diametrically higher (82.29) among children in the age group 8–12.

The analysis of sociodemographic factors did not show that a child's sex had any influence on the level of QOL, and this coincides with the results of Michalska et al. (2012b) and Maher et al. (2008). However, a child's age did significantly influence the level of QOL. Children aged 13–18 in our study had significantly higher scores in the social and emotional dimensions than did children in other age groups. This result contrasts with that of the study by Michalska et al. (2012b), which showed that as their age increases, children with CP are characterised by a lower overall QOL, with a lower QOL in the physical and emotional dimensions on a generic scale and a lower QOL in the pain and fatigue dimensions on a specific scale.

In our study, the children of parents aged 40–50 were characterised by a higher QOL in the emotional dimension ($p = 0.00$) than children of parents in other age groups. However, research by Michalska et al. (2012a) showed that the age of mothers was negatively correlated with the values of health-related QOL in the physical and fatigue dimensions, which is most probably associated with the specificity of the disease itself (disability), which progresses over time. As far as the emotional aspect is concerned, it is possible that with the passage of time parents get used to the situation, are reconciled to it, and that this affects the emotional state of their children.

Higher educational levels of parents create opportunities to achieve higher family incomes and a better socioeconomic status. Educated parents often have more knowledge about their children's disease, respond better to their needs and participate in the therapeutic process more consciously (Michalska et al., 2012a). In our study, the influence of the level of education of parents on their children's QOL was also demonstrated in that children of parents with vocational educations obtained higher results in the fatigue dimension than children of parents with secondary or higher educations. This may be due to the fact that parents without secondary and higher educations do not have sufficient funds for the rehabilitation of their children, which is often the main reason for fatigue. However, the study by Michalska et al. (2012a) indicates that children of mothers with higher educations are characterised by a higher QOL (except in the social dimension). Given the above data, it seems the relationship between education and QOL is complicated, with many factors contributing to the final result.

Being a single parent, especially of children with CP, carries with it numerous problems, if only due to the greater psychological and physical burden and lower level of support from close relatives (Okrutna, 2013). This may result in a lower QOL for both parents and their child. However, both our own study and studies by Michalska et al. (2012a) did not confirm this dependence.

Satisfaction with life is often equated with happiness, well-being or QOL. Previous studies (Basińska & Wędzińska, 2014) indicated that parents of children with CP are characterised by a low level of satisfaction with life. This does not coincide with the results of our study, where the parents of children with CP are characterised by an average level of

satisfaction with life. Only 40% of respondents defined the level of satisfaction with life as high. Interestingly, no relationship was found between marital status and the level of satisfaction with life. Perhaps this is due to the fact that the fathers in general are less involved in the direct care of their children, as they are more often away from home because of their employment, and mothers look after their child with disability all day. In the study group, a relationship was found between the age of parents and the dimensions of the SWLS. People aged 40–50 were characterised by a higher level of satisfaction with life than other age groups. It is worth noting that parents have a greater sense of satisfaction with life when their children perform better in the physical dimension and they manage in school more easily. In truth, researchers in Poland and abroad increasingly deal with the subject of families of children with CP, but there are still few reports analysing the relationship between the level of QOL and everyday satisfaction with life. This limits the possibility of conducting discussions with other authors who analyse the subject empirically.

Family functioning has a great influence on family members' health (Santos, Crespo, Canavarro, & Kazak, 2015). On the other hand, a child's illness (e.g. cancer) has a negative impact on family functioning in all dimensions (Modanloo, Rohani, Shirinabadi Farahani, Vasli, & Pourhosseingholi, 2018). Our study is the first in Poland, and one of the few in the world (Glinac, 2017; Zuurmond et al., 2015, 2018), to investigate the impact of CP on the functioning of the family as measured by the PedsQL-FIM. Data analyses showed that the parents of children with CP assess the impact of their children's disease on the functioning of the family at 46.04, which is consistent with the results of research by Zuurmond et al. (2015) conducted in Bangladesh (52.4) and Glinac (2017) in Bosnia and Herzegovina (65.36). However, in Ghana, the parents of children with CP declared that their children's disease significantly influenced family functioning (12.5). It was shown that their children's disease mainly reduced family functioning in the daily activities dimension, which is consistent with the results of studies by Zuurmond et al. (2015, 2018) and Glinac (2017).

The birth of a child with CP challenges parents to provide the best level of care and development opportunities as much as, if not more than, does a healthy child (Babaei, Hosseini, Rigi-Khas, & Khayatzaadeh-Mahani, 2014). Although parenthood is part of every parent's life, this role is particularly unique when a child is diagnosed with a disability. Stress caused by the presence of a child with CP in the family increases the need to learn to deal with the difficult situation, something that is not easy in addition to the normal challenges faced by parents. It has not been shown so far why some parents are better at this, while others are less so (Raina, 2005).

The study by Rosińczuk et al. (2013) shows that in every fifth family there are misunderstandings and strained relations between spouses. This is not consistent with the results of our own research, confirmed by Glinac (2017), which shows that family relations is one of the highest-rated dimensions. Our study shows that people with a higher education obtained statistically significant ($p = 0.032$) higher scores in the cognitive dimension than people with a secondary or vocational education, while in Bosnia and Herzegovina (Glinac, 2017), mothers with a higher education obtained a lower result in the family relations dimension.

Our study shows that families living in cities significantly ($p = 0.040$) performed better in the physical dimension than families living in villages. Most likely, this is related to the differences in access to resources which is much more difficult in rural than urban areas in Poland. For instance, children with CP require frequent medical appointments and specialist rehabilitation which means the necessity of frequent trips to remote urban centres (Wędzińska, 2013).

Study limitations

The first limitation is that QOL is being assessed only by parent's perspective. The second is the lack of assessment of the clinical status of the children, which may significantly affect the QOL score.

Practice implications

Learning about the factors that influence QOL will allow health care providers to properly plan actions aimed at minimising the negative impact of CP on children's QOL and improving the functioning of their families. Analysis of the relationship between child physical development and his quality of life may lead to better understanding of all aspects that influences the course of his development. Moreover, this study indicates areas of management that require closer attention by health care professionals both in the community care and in hospital such as physical skills rehabilitation expansion, occupational therapy development, communication skill development, social skill development, child, sibling, and parental emotional support, resource accessibility, and stressor identification.

Conclusion

The QOL of children with CP as perceived by their parents is reduced, and their disease has a significant negative correlation with family functioning. Therefore, learning about the factors that influence QOL will allow health care providers to properly plan actions aimed at minimising the negative impact of CP on children's QOL and improving the functioning of their families.

Author statement

Each author's contributions to the manuscript are listed below;

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- Data curation; Paulina Budzińska
- Formal analysis; Paulina Budzińska, Aleksandra Kołtuniuk
- Funding acquisition; Aleksandra Kołtuniuk, Anna Rozensztrauch, Joanna Rosińczuk
- Investigation; Aleksandra Kołtuniuk
- Methodology; Aleksandra Kołtuniuk, Anna Rozensztrauch
- Project administration; Aleksandra Kołtuniuk
- Resources; Aleksandra Kołtuniuk
- Software; Aleksandra Kołtuniuk, Anna Rozensztrauch, Paulina Budzińska
- Supervision; Joanna Rosińczuk
- Validation; Aleksandra Kołtuniuk, Anna Rozensztrauch
- Visualization; Aleksandra Kołtuniuk, Anna Rozensztrauch, Joanna Rosińczuk
- Roles/Writing – original draft; Aleksandra Kołtuniuk, Anna Rozensztrauch, Paulina Budzińska
- Writing – review & editing; Aleksandra Kołtuniuk, Anna Rozensztrauch, Joanna Rosińczuk

Declaration of Competing Interest

None to declare.

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