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ORIGINAL PAPER

The quality of life of patients with cerebral palsy versus the general population

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ABSTRACT

Introduction: Cerebral palsy (CP) is the most common cause of motor disability among children. This disease, as a compound syndrome, affects the biological, psychological, and social functioning of a patient and has different degrees. Feedback from studies on the quality of life (QoL) of children with CP make it possible to improve the relationship between a child suffering from CP and the surrounding external environment. Obtained information about the patient's frame of mind and the limitations caused by CP allow us to perceive the problems that children suffer and take actions aimed at solving them. Improving the QoL of children with CP becomes one of the main goals of therapeutic interaction – in parallel with the alleviation of disease symptoms.

Aim of the study: To assess the QoL of patients with CP as compared to the general population.

Material and methods: The study was conducted among 128 patients with CP. The reference group consisted of 130 healthy subjects. The study was of prospective nature, conducted using a diagnostic survey based on the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core.

Results: Healthy children are characterised by better overall QoL. They also achieved significantly higher scores in individual subscales (physical, emotional, social, school, and psycho-social functioning) excluding emotional functioning.

Conclusions: There is a need to implement comprehensive therapy for children with CP that enables self-care, or assistance in everyday self-care and school activities. It also seems important to adapt the home and school environment in accordance with the needs of patients suffering from CP.

KEY WORDS:

children, quality of life, cerebral palsy.

INTRODUCTION

Cerebral palsy (CP) is the most common cause of motor disability among children [1–3]. Motor and postural disorders as well as sensory, cognitive, perceptual, and communication disorders limit the activity of patients and may lead to a decrease in the quality of their lives [4–9]. The interest in the subject of quality of life (QoL) in patients with chronic diseases, including children, has been increasing in recent years. The QoL is a broad concept that covers various aspects of human activity. Assessment of the QoL is a very complex issue which is difficult to

ADDRESS FOR CORRESPONDENCE:

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interpret; however, it is a valuable source of information about a patient, and at the same time can be one of the main indicators of the effectiveness of modern therapy. Information obtained about the patient's physical and mental state and the limitations caused by CP allow us to perceive problems experienced by children and to take actions aimed at solving them. The QoL improvement in children with CP is becoming one of the main goals of therapeutic interventions, in parallel with the relief of disease symptoms. The aim of the paper is to present the QoL of patients with CP as compared to the general population.

MATERIAL AND METHODS

The study was carried out among 128 patients (61 boys and 67 girls) of the Josef Brudziński Provincial Children's Hospital in Bydgoszcz, who were 2 to 18 years old. The study was of prospective nature and was carried out using the diagnostic survey method. The questionnaires used in the study were not filled out by patients with CP themselves, but by their parents. The self-assessment of patients was abandoned due to mental disability and communication difficulties with the majority of them.

A total of 130 children (64 girls and 66 boys) who did not suffer from chronic diseases, aged 2 to 18, were qualified to the control group. The study on healthy children was carried out among pupils of the primary school, middle school, and kindergarten in Bydgoszcz and Więcbork.

Due to the fact that the questionnaires in the study group were filled by parents of patients with CP, the same procedure was also used for the control group due to the need to create a homogeneous group in relation to the group of respondents.

The QoL of children with CP and healthy children was assessed using the standardised research tool Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core developed by James W. Varni. Permission to use the questionnaire was obtained from the Mapi Trust Institute in Lyon.

The graphical interpretation of the data is shown in the form of categorised box plots. The material has been statistically analysed using the Mann-Whitney *U* test.

The work is part of research already published in the *Polish Journal of Paediatrics* [10].

The study has been carried out on the basis of the consent (no. KB/469/2014) of the Bioethics Committee of Nicholas Copernicus University in Torun at the Ludwik Rydygier *Collegium Medicum* in Bydgoszcz.

RESULTS

A total of 258 respondents participated in the survey based on the PedsQL 4.0. Generic Core questionnaire. Healthy children were characterised by a higher QoL as regards physical and social functioning and functioning in a nursery/kindergarten/school in comparison to the study group. In turn, children with CP had a higher QoL in terms of emotional functioning than their healthy peers. These results are statistically significant ($p < 0.05$). The distribution of results obtained in individual scales is presented in Figure 1.

Analysis of the data obtained indicates that healthy children cope better in all the fields of physical functioning, social functioning, and functioning in the nursery/kindergarten/school than children with CP. However, as regards emotional functioning, healthy children cope with the feeling of sadness and anger worse ($p < 0.05$). The results as regards the feeling fear are on the limit of significance. Detailed data are presented in Table 1.

The results of three previously analysed scales: emotional functioning, social functioning, and functioning in the nursery/kindergarten/school, make up the results of the psychosocial functioning scale (psycho-social health).

A higher score of psychosocial functioning (Fig. 2) was reported for the group of healthy children, at 80.86 points, while the average score in the group of children with CP was 64.18 points. A higher score for the overall QoL (Fig. 3) was noted in the group of healthy children, at 81.8586 points, while the average score in the group of children with CP was 52.65 points ($p = 0.000$).

DISCUSSION

The analysis of the results of the authors' own research showed a significant deficit in the QoL of children and adolescents with CP. This complies with the results obtained by other researchers. They confirm that the QoL of persons with CP is lower than that of healthy children [8, 11–17]. That QoL level can be compared to patients

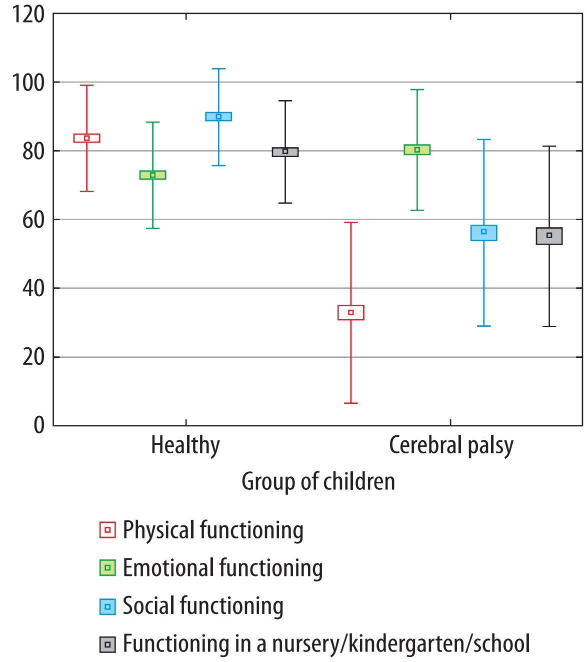


FIGURE 1. The distribution of results for the scales of functioning in the studied groups

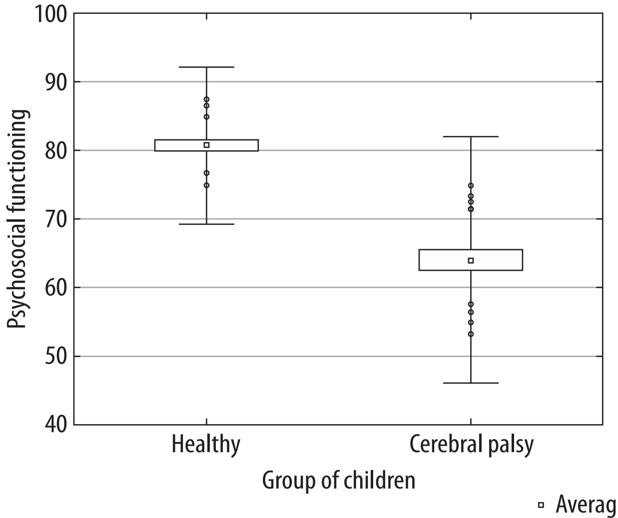
TABLE 1. Differences in Pediatric Quality of Life Inventory (PedsQL) 4.0 scale results

Variable	Sum of ranks		*U*	*Z*	*p*-value	*Z* correct.	*p*-value	*n* import.	
	Healthy	CP						Healthy	CP
Physical functioning									
Hard to walk more than one block	24149.0	9262.0	1006.0	12.204	0.000	13.197	0.000	130	128
Hard to run	24054.5	9356.5	1100.5	12.046	0.000	12.722	0.000	130	128
Hard to do sport or exercise	23772.0	9639.0	1383.0	11.575	0.000	12.083	0.000	130	128
Hard to lift something heavy	23699.5	9711.5	1455.5	11.454	0.000	11.870	0.000	130	128
Hard to take bath or shower	23487.0	9924.0	1668.0	11.099	0.000	11.716	0.000	130	128
Hard to do house chores	22074.0	11337.0	3081.0	8.741	0.000	8.962	0.000	130	128
Hurt or ache	20482.0	12929.0	4673.0	6.085	0.000	6.346	0.000	130	128
Low energy	19962.5	13448.5	5192.5	5.218	0.000	5.467	0.000	130	128
Emotional functioning									
Feel afraid or scared	15762.0	17391.0	7247.0	–1.691	0.091	–1.799	0.072	130	128
Feel sad or blue	14617.5	18535.5	6102.5	–3.612	0.000	–3.820	0.000	130	128
Feel angry	13694.0	19459.0	5179.0	–5.162	0.000	–5.443	0.000	130	128
Trouble sleeping	16768.0	16385.0	8253.0	–0.003	0.998	–0.003	0.998	130	128
Worry about what will happen	16412.0	16741.0	7897.0	–0.600	0.548	–0.695	0.487	130	128
Social functioning									
Trouble getting along with peers	18045.5	15365.5	7109.5	2.019	0.043	2.277	0.023	130	128
Other teens do want to be friends	20957.5	12453.5	4197.5	6.878	0.000	7.408	0.000	130	128
Teased at	21193.0	12218.0	3962.0	7.271	0.000	7.844	0.000	130	128
Doing things other peers do	23329.0	10082.0	1826.0	10.835	0.000	11.454	0.000	130	128
Hard to keep up with peers	22907.0	10504.0	2248.0	10.131	0.000	10.724	0.000	130	128
Functioning in nursery/kindergarten/school									
Hard to concentrate	11774.0	6754.0	2194.0	6.268	0.000	6.416	0.000	97	95
Forget things	11815.5	6712.5	2152.5	6.376	0.000	6.518	0.000	97	95
Trouble keep up with nursery/kindergarten/school work	18606.0	7959.0	2073.0	8.964	0.000	9.255	0.000	122	108
Missed nursery/kindergarten/school – not well	15319.0	11246.0	5360.0	2.437	0.015	2.642	0.008	122	108
Missed nursery/kindergarten/school – see doctor	15109.5	11455.5	5569.5	2.021	0.043	2.173	0.030	122	108

treated for neoplastic and rheumatic diseases [8, 18] and patients with meningomyelocele [19].

The results obtained in the authors' own research using the PedsQL 4.0 Generic Core questionnaire for children and adolescents with CP are lower than the results of healthy children, excluding the emotional functioning, which was rated higher (80.12 ±17.519 vs. 72.81 ±15.713). The overall QoL was rated lower by the parents of children suffering from CP (81.85 ±11.441 vs. 52.65 ±19.264). The physical functioning was rated the lowest by the parents of children with CP, i.e. 32.79 ±26.275 in comparison to the value of 83.61 ±15.398 reported in the group of healthy children. The remaining domains of the scale were rated statistically significantly lower by the parents of children with CP.

The obtained results for the QoL of children in the studied groups may be associated with the education of mothers of children with CP who answered questions in the questionnaire. Analysis of the authors' own research results shows that the highest score as regards emotional functioning was recorded for the group of mothers with primary education, then for those with higher, vocational, and secondary education (97.50 vs. 83.11 vs. 81.40 vs. 73.06). It should be noted that mothers of children with CP with higher education constituted less than 30% of the studied group (29.7%). People with higher education usually have higher knowledge about the child's disease, they better adapt to the therapeutic regime, and consciously participate in the therapeutic process. Von Rueden *et al.*



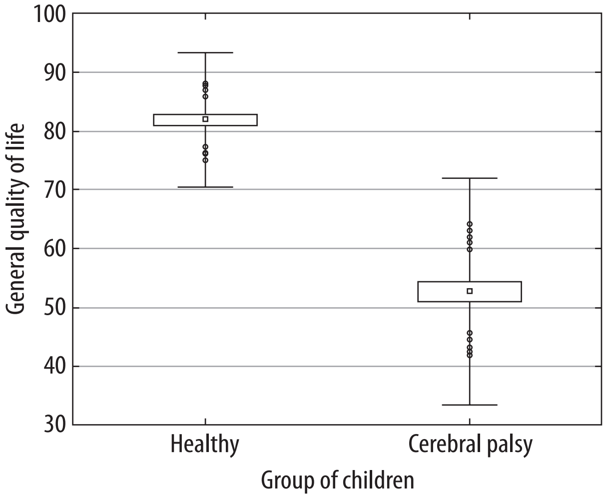


FIGURE 2. The distribution of average results of psychosocial functioning in the studied groups

FIGURE 3. The distribution of mean values of general quality of life in the studied groups

reported the relationship between low level of education and low HRQOL scores, with significant differences concerning physical and mental well-being, emotional and school functioning, as well as financial resources [20].

The review of the literature shows that it includes studies in which the authors report a similar QoL of children and adolescents suffering from CP as that of the general population. When examining the QoL using KIDSCREEN, Dickinson *et al.* found that in the case of CP, the obtained results were similar to the results in the general population; they differed only as regards physical and school functioning [21]. In turn, Majnemer *et al.* used in her study two generic scales: the Child Health Questionnaire (CHQ) and PedsQL, and found that the QoL of half of the respondents was similar to the QoL of typically developing children [22]. When preparing for the study on the QoL, and then during their implementation, one can encounter difficulties related to the selection of an appropriate assessment strategy. HRQOL can be measured in two ways: objectively, i.e. by third parties, by determining the patient's situation in life; or subjectively, by the patient herself/himself. At present, the significance of the assessment subjectivity is underlined as the patient's own characteristic of the sense of QoL [11, 23–25]. In 1993 the WHO and the International Association for Child and Adolescent Psychiatry and Allied Professions recommended self-reporting as the most appropriate way to measure the QoL in children. In some situations, however, its use may be associated with some limitations, as in the case of the young age of subjects, a serious degree of dysfunction resulting from the disease, and mental disability. In this case, the QoL can be assessed by the parents (proxy-report). Both types of assessment are considered as important, mutually complementary sources of information on the children's QoL, but they are often incompatible with each other [11, 26]. The differences between the self-report and the assessment performed by other persons are referred to using the term "cross-informant variance" [11, 18, 27]. The professional literature includes inconsistent information on the level of compliance of the QoL assessment between parents and children [11, 27].

When planning our own study on the QoL of patients with CP, it was assumed that the assessment would be performed both by the patients and their parents. Unfortunately, mental disability and communication difficulties in most subjects forced the surveyors to modify the study and limit the analysis to the assessment made only by the carers of patients with CP.

As noted by Owczarek [28], the perception of the disease by patients' surroundings can be very diverse. The family can treat the disease as a task that needs to be dealt with effectively (among others, through changes in the current way of functioning) by deepening knowledge about the disease and active cooperation with physicians. The disease can also be perceived as an embarrassing weakness that should be hidden from the external world by avoiding contact with others. The condition can also be treated as a loss, i.e. it is perceived as incurable, and the patient as someone who can no longer be helped, which manifests itself in the passivity of the people around. The situation is different when the disease is treated as an enemy, i.e. close relatives try, often in a very aggressive way, to fight the disease. Sometimes the disease becomes a strategy of action, which consists of constant demand for help from other people, e.g. from social welfare. For some families, the occurrence of a chronic disease is a kind of facilitation because it can justify their failures. The disease can also be treated as a punishment for all possible offenses of the family, in the face of which a passive attitude is taken, or as a new experience that should be familiarised with [28]. Wyrwa-Raniszewska claims that the way the disease is perceived by the closest environment affects the patient herself/himself, who notices the attitude of the close family and thus can perceive his/her condition as more or less troublesome, and himself/herself as an obstacle to the normal functioning of the family, which aggravates his/her discomfort associated with the disease experience [29].

CONCLUSIONS

The QoL of children with CP is lower than that of healthy children. The results achieved in individual domains of the applied questionnaires suggest that there is a need to implement comprehensive therapy for children with CP that enables self-care or assistance in everyday self-care and school activities. It also seems important to adapt the home and school environment in accordance with the needs of patients suffering from CP.

DISCLOSURE

The authors declare no conflict of interest.

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