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THE QUALITY OF LIFE OF FAMILIES WHO HAVE CHILDREN WITH CEREBRAL PALSY

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Abstract

Objective: Quality of life is a subjective term that can be perceived in many ways. The objective side is primarily defined by an objective assessment of health and other life conditions. The subjective part includes a rational and emotional assessment of one's own life. The goal of this study was to find and compare the quality of life of children with cerebral palsy and their families to healthy children and their families.

Methods: We used the PedsQL™ questionnaire, specifically the PedsQL™ 2.0 Family impact module, to measure the quality of life of families. We also used the PedsQL™ 4.0 generic module.

Results: The research included 30 families. Children from 15 families had cerebral palsy. 120 questionnaires were filled in. Every family filled in 4 questionnaires (2× the Family impact module and 2× the generic module). The results showed that these two groups perceive their quality of life very differently (the children and their families). The quality of life by PedsQL™ 4.0 in children with CP was much lower than the quality of life of the children in the control group of intact population (by the children's and their parents' assessment). The quality of life of families with children with CP by PedsQL™ 2.0 was also much lower than that of healthy families. The time period of studying both groups was the same. It is necessary to publish the results and make them available to social services.

Keywords: *Cerebral palsy; Children; Family; PedsQL™; Quality of life*

ORIGINAL ARTICLE

INTRODUCTION

The term "quality of life" is very subjective. In the course of social development, it has been perceived from many points of view, which affects the effort to create a complex definition (Hnilicová and Bencko, 2005). The variety of fields is a large obstacle in creating a unanimous definition (Mareš, 2006). The perception of the term "quality of life" is that it affects the economical, sociological, psychological and ecological aspects (Payne et al., 2005). This study perceives the quality of life from a medical point of view. It is associated especially with health. The WHO defines health as *"a state of complete physical, mental and social well-being"*, which shows that it clearly reflects the subjective perception of one's health and personal situation (WHO, ©2020). The quality of life is mainly defined by individual perceptions (apart from objective points of view) and assessments (Payne et al., 2005). According to the authors, the subjective side is created by the rational and emotional assessment of one's own life, i.e. the level of satisfaction with it. Due to considerably subjective views, it is not possible to precisely establish and define the quality of

life, which explains why experts disagree regarding the definition of this term (Hnilicová, 2005). Reflecting on the quality of life is very important for an individual's total condition because society can see clinical results of therapies as well as their influence on practical and personal life, social contacts or independence (Hnilicová and Bencko, 2005).

The most used tool for measuring the quality of life is the HRQol (Health Related Quality of Life) questionnaire, which is focused on health, or its similar forms, such as the PedsQL™ (Pediatric Quality of Life) and its modules that are adjusted to paediatric patients (Gurková, 2011).

Cerebral palsy can be defined as a combined disorder of the central nervous system. It is permanent, does not worsen over time, and a targeted rehabilitation can help this condition to improve (Seidl, 2015). One of the components in question is cerebral paresis, which is defined by central movement disorder. The other component is associated with a series of different manifestations, such as mental disorders or sight and hearing disorders etc. Incident causes are various and may affect the embryo or a child in the prenatal, perinatal and postnatal period (Pfeiffer, 2007). One of the characteristics of cerebral paresis is abnormal muscle tension that limits or disables movement, which is related to coordination and balance disorders (Bednařík et al., 2010). Regarding cerebral paresis, these authors mention various forms, such as spastic, dyskinetic and ataxic, or combined forms. The symptoms that accompany or manifest CP include: mental retardation, epilepsy, sensory disorders, behavioural, emotional or learning disorders (Pfeiffer, 2007). Cerebral palsy is dealt with by PedsQL™ module 3.0 Cerebral Palsy, which assesses 22 components in 5 domains in toddlers, and 35 components in 7 domains in children and adolescents (Varni, 2017).

The goal of this study was to find out and compare the levels of the quality of life of children with cerebral palsy and healthy children.

MATERIALS AND METHODS

We used the PedsQL™ 4.0 questionnaire (Varni, ©1998–2020) to assess 3 scales: physical health score, psychosocial health and total score. In the second PedsQL™ 2.0 Family Impact Module (FIM), parents assessed family situations, family functioning score and the total score on the scale of "health-related quality of life" (Health-Related Quality of Life, HRQL) in the last week and month.

The Pediatric Quality of Life questionnaire deals with the assessment of the quality of life of children and it is intended for children and their parents. It is used for the assessment of the life of healthy children and adolescents, as well as children with acute or chronic health disorders (Varni, ©1998–2020).

The questionnaire combines general scaling methods with specified modules for specific health problem areas (Varni, ©1998–2020). As stated by Varni (©1998–2020), the main advantages of this questionnaire are that it is practical and short, flexible and adaptable. These factors increase its reliability and validity. The author also points out that the questionnaire is specified by age (groups between 2 and 18 years), it can comprise many domains (physical, psychological and social changes) and it can react in time to the changes in clinical conditions. The questionnaire deals with the basic domains of health, psyche and school – specifically, they are 4 multidimensional scales and 3 total scores regarding physical, emotional, social and school domains and total scores regarding physical and psychosocial health and the total score of all.

Specific modules for specific illnesses include modules for bronchial asthma, diabetes mellitus, rheumatic, oncological or cardiovascular diseases, epilepsy, cerebral palsy and others (Varni, 2017).

The research included 30 families – children from 15 families had cerebral palsy, and 15 families had healthy children who served as a control group. The average age of the disabled children was 9.93. The average age of the healthy children was 10.8 (Table 1). The assessment of the PedsQL™ questionnaire was carried out according to its authors' instructions. The PedsQL 2.0 (monthly and weekly versions) and PedsQL 4.0 (for parents) were given to the parents at a personal meeting and they filled them in in the presence of a data collector. The PedsQL 4.0 (for children and adolescents) questionnaires were filled in in the presence of a data collector. The PedsQL 2.0 (monthly and weekly versions) and PedsQL 4.0 (for parents) were given to the

parents at a personal meeting and they filled them in in the presence of an interviewer. The PedsQL 4.0 questionnaires (for children and adolescents) were filled in in the presence of an interviewer (who was more of a consultant).

The achieved average scores were processed using non-parametric methods – box charts and Mann–Whitney tests (for independent selections) and Wilcoxon test (paired comparison). The selected level of significance (α) in all tests is 0.05. We kept to the ethical code of research.

RESULTS

The differences in the achieved score between the two groups of respondents (DMO and healthy) were assessed in two subscales, as well as the total score in every questionnaire. We carried out 12 tests (Table 1). We proved highly significant differences between the quality of life in the two groups of respondents.

Table 1 – The assessment results of the achieved scores of the monitored subgroups with CP and healthy respondents using the PedsQL™ 4.0 and the Mann–Whitney test

Questionnaire	Respondents	Scale	Achieved level of significance
PedsQL™ 4.0	Children	Physical health score	<0.001
		Psychosocial health score	<0.001
		Total score	<0.001
	Parents	Physical health score	<0.001
		Psychosocial health score	<0.001
		Total score	<0.001
PedsQL™ 2.0 FIM – last month	Parents	HRQL	<0.001
		Family score	0.005
		Total score	<0.001
PedsQL™ 2.0 FIM – last week	Parents	HRQL	<0.001
		Family score	0.005
		Total score	<0.001

Chart 1 shows the score values. The CP group always achieved a lower score, i.e. a worse quality of life. Regarding the physical health of children with CP and their parents, the median score was only 11 points. Whereas healthy respondents achieved the highest score of 100 points (more than half of the respondents). The median score regarding psychosocial health was 29 (27 points in children with CP and their parents; 97 points in healthy children and their parents). The median total score of the quality of life using the PedsQL™ 4.0 in children with CP achieved almost a quarter of the maximum value (25 points) in comparison to the control group (97 points).

The assessment of the PedsQL™ 2.0 FIM confirmed significant differences between the CP parent group and healthy children parent group. Families with CP achieved median scores between 42 and 49 points in individual scales, and healthy families achieved double that score, i.e. between 94 and 99 points (Chart 2).

The Wilcoxon paired test was used to compare the children's scores to their parents' scores on the PedsQL™ 4.0 scales. We also compared the last month and week assessments using the PedsQL™ 2.0 FIM. We did not find significant differences in any of the cases (Table 2 and Charts 1 and 2). The children and their parents showed similar assessments. The last month and week assessments of family situations were not different.

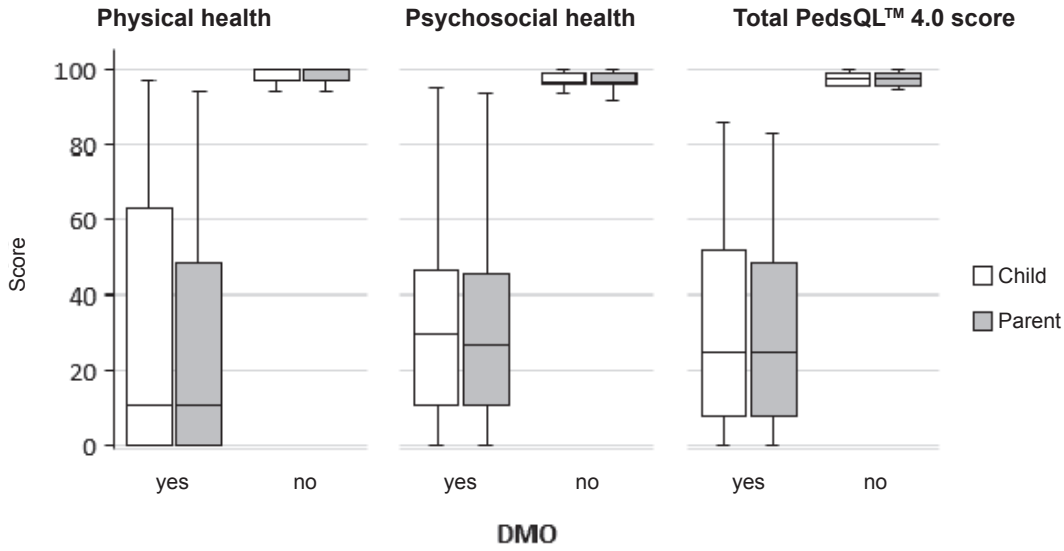

Chart 1 – Box chart of the achieved PedsQL™ 4.0 score

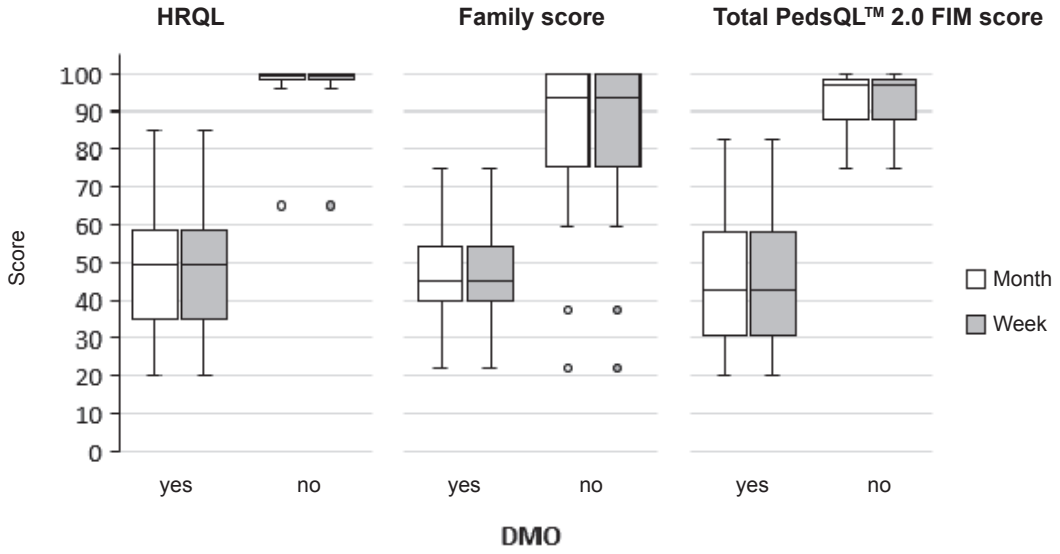

Chart 2 – Box chart of the achieved PedsQL™ 2.0 FIM score

DISCUSSION

We used the PedsQL™ questionnaires to study the quality of life of families with children suffering from cerebral palsy. We specifically used 4.0 Generic Core Scales and Family Impact Module 2.0. Our previous experience showed that these questionnaires were suitable for such research (Baloun and Velemínský 2019a, b; Baloun et al., 2019). We compared the quality of life of children with CP and their families to healthy families to find out how different the views of the quality of life between these two groups were. Varni et al. (2006a, b) also dealt with the comparison of the quality of life of children with CP to the healthy population – to verify the validity and reliability of the PedsQL™ 4.0 Generic Core Scales module

Table 2 – The results of paired comparisons of the assessments of children and their parents on the PedsQL™ 4.0 scales, and monthly and weekly assessments of family situations using the PedsQL™ 2.0 FIM (Wilcoxon test)

Group	Questionnaire – comparison	Scale	Achieved level of significance
CP	PedsQL™ 4.0 – children vs. parents	Physical health score	0.374
		Psychosocial health score	0.626
		Total score	0.626
	PedsQL™ 2.0 FIM – month vs. week	HRQL	1.000
		Family score	1.000
		Total score	1.000
Healthy	PedsQL™ 4.0 – children vs. parents	Physical health score	1.000
		Psychosocial health score	1.000
		Total score	1.000
	PedsQL™ 2.0 FIM – month vs. week	HRQL	1.000
		Family score	1.000
		Total score	1.000

and 3.0 Cerebral Palsy (which were adjusted to CP). Yang et al. (2011) confirmed the reliability of these modules.

The assessment of the PedsQL™ followed the authors' instructions. The respondents' average score was processed using non-parametric methods: box charts and tests. We proved significant differences in all comparisons between the groups – children with CP and healthy children. The results showed that the groups (children and families) perceived their quality of life very differently. The PedsQL™ 4.0 questionnaires were filled in by the children, and their parents filled in the version for parents. Regarding physical and psychosocial health, the total PedsQL™ 4.0 score was lower in children with CP and their parents than the healthy control group. The perception of the quality of life can be affected by other CP-caused disabilities that worsen an individual's health condition (Seidl, 2008). As stated by Hnilicová and Bencko (2005), an individual's health condition has an impact on other life areas, i.e. subjective perception and assessment of the quality of life.

Similar results were seen in the assessment of the PedsQL™ 2.0 family module. Families with children with CP had a significantly lower score than families with healthy children in the monthly and weekly assessments. The research of Mann et al. (2019) was similar but it dealt with a different type of illness. When the assessments of the quality of life in the PedsQL™ 4.0 and the monthly and weekly assessments in PedsQL™ 2.0 were compared, none of the groups showed statistically significant differences. This proves that children's and their parents' perceptions of the quality of life in individual groups are not different even from the point of view of the time period.

Using different methods and questionnaires to monitor and study the quality of life is a very useful method that can help to identify the danger of a bad quality of life in connection to CP or ADHD – and this has been shown by Varni and Burwinkle (2006). The PedsQL™ questionnaires are associated with other crucial constructs in paediatric care, as stated by Varni (2017), which can be improved using feedback. The fact that children with CP and their families perceive their quality of life as worse than healthy families needs to be published so that it can be remedied by e.g. the improvement of social health determinants – as stated by Frier et al. (2018). The decline in these areas affects the perception of the quality of life of people with disabilities and their families.

The limitations of this article include the similar responses of parents in the PedsQL™ 2.0. The parents filled in two questionnaires – weekly and monthly. The parents stated that

their condition did not change and responded in the same way in both versions of the questionnaire. Another limitation could be that healthy children (and their parents) stated that they did not have any problems, i.e. the parents and children respond in the same way. Another limitation could also be the low number of respondents.

CONCLUSIONS

The goal of this article was to compare the quality of life of families and children with CP to healthy families. We used the assessment of the PedsQL™ 4.0 Generic Core Scales and PedsQL™ 2.0 Family Module Impact tests in the same number of respondents in each group – 15 families with children with CP, and 15 families with healthy children. Each family filled in 4 questionnaires. We assessed 120 questionnaires in total. The results showed that the quality of life (according to the PedsQL™ 4.0) in children with CP was significantly lower than in children from the control group, which was proven by the assessments of their children and their parents. We also discovered that the quality of life of families with children with CP (according to the PedsQL™ 2.0) was also significantly lower than the quality of life of families with healthy children (in the same time period).

It is necessary to publish this fact and make the results available to the public and social workers. The purpose should be taking steps toward the improvement of the perception of the quality of life – and it would contribute to co-ordinated rehabilitation.

Conflict of interests

The authors have no conflict of interests to declare.

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