

Quality of life of parents of children with cerebral palsy

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ABSTRACT

Purpose: The aim of the study was to assess the quality of life of parents of children with cerebral palsy.

Materials and methods: The study included 40 parents of children with cerebral palsy treated at the Department of Pediatric Rehabilitation of the Medical University of Białystok. The WHOQOL-BREF questionnaire was used as a research tool; it enables obtaining a quality of life profile in four domains: physical health, psychological, social relationships and environment. The severity of a child's movement disorders was assessed using the Gross Motor Function Classification System (GMFCS).

Results: In the studied group of parents of children with cerebral palsy, more than half described their

quality of life as good and was pleased with their health. The largest differences occurred in parents of children with cerebral palsy in the environment domain, $p=0.0068$, and the psychological domain, $p=0.010$. Quality of life in all four domains was assessed as lower in parents of children with cerebral palsy compared with parents of healthy children. Only in the evaluation of health care facilities parents of children with cerebral palsy assessed them better than parents of healthy children.

Conclusion: Parents of children with cerebral palsy describe their quality of life as good and are satisfied with their health.

Keywords: quality of life, parents, cerebral palsy

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INTRODUCTION

Receiving information about an impairment in a child's development seriously affects the functioning of the entire family. The family members face numerous challenges, and difficulties abound while everyone tries to adapt to the new situation. A cerebral palsy diagnosis brings with it feelings of anxiety and a sense of unpredictability for the parents. Often, parents feel alone in the fight against the disease; they lack the support of the system. To ensure proper care for their loved one, one parent usually resigns from work [1]. Cerebral palsy is a group of symptoms associated with etiologically varied central nervous system damage. It is a heterogeneous group of movement and posture disorders caused by non-progressive damage to the immature brain [2]. It may be accompanied by other disorders such as epilepsy, deficits in speech, hearing, vision, and intellectual disability [3]. The more complex the form of cerebral palsy, the less favorable the prognosis for the child's psychomotor development and a potentially greater risk of disturbances in the quality of communication and interaction with the parents [4,5]. The situation of parents of children with cerebral palsy is considered so stressful that it can be compared with the situation of parents of children with cancer [6]. The difficult and constant struggle to improve the child's health and development is accompanied by doubt, guilt and shame, which contributes to the deterioration of the quality of life of parents [7]. Experiencing severe anxiety (e.g. before making a crucial decision) oftentimes leads to feelings of helplessness and lack of control, and this in turn may contribute to feelings of parental incompetence [8,9]. Fatigue and frequent loneliness lower resistance to stress and disturb the normal regulation of emotions [9]. Brehaut et al. [11] found that over the years parents of children with cerebral palsy, compared with parents of healthy children, more frequently complain of experiencing severe and chronic stress, emotional and cognitive problems, as well as report numerous somatic complaints. According to the definition of the World Health Organization (WHO) [12], quality of life means 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 aims, expectations, standards and interests, conditioned by the environment. Within the scope of quality of life, the WHO includes: physical health, mental state, degree of independence, social relationships, environment, religion, beliefs, convictions and views. An assessment of the level of the quality of life is a comparison of the individual's expectations and the actual state. This is done according to subjective

criteria, as each person sets their own values. The basis of assessment of quality of life is to examine the state of the patient in the areas of physical, mental and social well-being as well as satisfaction with life in various domains [13]. Quality of life as a polysemantic and multidimensional concept is very important for each individual. In day-to-day living, it can be expressed in different contexts. Namely, it is associated with a sense of happiness, life satisfaction, fulfillment of desires and needs, including the need of security. Nowadays, good quality of life is defined as personal happiness, also in the sexual sphere, professional success, good financial status, a sense of stability in life, and an optimistic approach to life and the ability to solve life's problems [14].

The aim of this study was to analyze the quality of life of parents of children with cerebral palsy in comparison with parents of healthy children.

MATERIALS AND METHODS

The study included a group of 40 parents of children with cerebral palsy aged 6-17 years treated at the Department of Pediatric Rehabilitation of the Medical University of Bialystok. In the studied group of parents, their children had the following forms of cerebral palsy: spastic tetraplegia - 18 (45%), spastic hemiplegia (hemiplegia spastica) -15 (37.5%), spastic diplegia (diplegia spastica) -7 (17.5%). Functional status was determined according to the GMFCS scale: Level I – 0 patients; Level II – 14 patients; Level III – 10 patients, Level IV – 4 patients, and Level V – 12 patients.

GMFCS (Gross Motor Function Classification System - (Expanded and Revised)

GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM

LEVEL I - Walks without limitations

LEVEL II - Walks with limitations

LEVEL III - Walks using a hand-held mobility device

LEVEL IV - Self-mobility with limitations, may use powered mobility

LEVEL V - Transported in a manual wheelchair

The Gross Motor Function Classification System (GMFCS) [15], based on observation of motor skills, enables classifying a child to one of five levels of mobility corresponding to the presented functional skills. Level I indicates the mildest damage, and level V the most severe.

The research tool was the WHOQOL-BREF – World Health Organization Quality of Life BREF – Assessment Instrument: short version - contains 26 questions divided into four domains:

A. *Physical health*: general health assessment, pain and discomfort, dependence on medication and medical aids, energy and fatigue, sleep and rest,

ability to work and perform daily living activities, mobility.

B. *Mental health/Psychological*: body image, positive and negative feelings, self-esteem, personal beliefs, spirituality, religion, thinking, learning, memory and concentration.

C. *Social relationships*: personal relationships, received social support, sexual activity.

D. *Environment*: freedom, safety, environment, physical environment, transport, finances, information, accessibility of health and social care, leisure time.

Each question is assigned an appropriate number of points from 1 to 5, and the patient must choose from the following possible answers: 1 point – very dissatisfied, 2 points – dissatisfied, 3 points – neither satisfied nor dissatisfied, 4 points – satisfied, 5 points – very satisfied.

The scale includes items (questions) that are analyzed separately: Question 1: pertaining to the individual overall perception of quality of life; Question 2: pertaining to the individual overall perception of own health [16-18].

The control group comprised 40 parents of healthy children (27 mothers and 13 fathers).

Statistical analysis of the results

The t test was used for statistical analysis. A value of $p < 0.05$ was considered statistically significant. The data were analyzed with the statistical package Statistica v. 7.1 PL.

All subjects gave informed consent to complete the questionnaire. The study was approved by the Bioethics Committee, resolution no.: R-I-002/450/2010.

RESULTS

Characteristics of the group of children with cerebral palsy whose parents completed the questionnaire. The clinical data of children with cerebral palsy are presented in Table 1.

In the studied group of parents of children with cerebral palsy, more than half described their quality of life as good and 40% as "neither good nor bad". (Tab.2)

In the group of parents of healthy children, nearly ¼ described their quality of life as very good. In the analyzed group of parents of children with cerebral palsy, more than half were satisfied with their own health, 1/4 stated that they are "neither satisfied nor dissatisfied", and more than 17% were dissatisfied (Tab.3). Approximately ¾ of the parents

Table 1. Clinical data of children with cerebral palsy.

Age - 11.56 ± 1.01 years (6-17)
Females - 19
Males – 21
Apgar score 5.20 ± 2.62 (1-10)
Birth weight 2668.96 ± 712.7 (1050-4300)
Week of birth 36.28 ± 3.61 (28-41)
Preterm birth - 14
Term birth - 16
Mental development
Normal - 4
Mild mental retardation - 10
Moderate mental retardation - 12
Severe mental retardation - 14
Epilepsy - 5

2. Question 1: pertaining to the individual overall perception of quality of life;

Question 2: pertaining to the individual overall perception of own health

Table 2. Individual overall perception of quality of life.

Quality of life	Percentage of parents of children with cerebral palsy	Percentage of parents of healthy children
Very poor	0%	0%
Poor	2.5%	0%
Neither good nor bad	40%	7.5%
Good	57.5%	7.5%
Very good	0%	22.5%

Table 3. Individual overall perception of parents' own health.

Health condition	Percentage of children with cerebral palsy	Percentage of healthy children
Very dissatisfied	2.5%	0%
Dissatisfied	17.5%	2.5%
Neither satisfied nor dissatisfied	25%	12.5%
Satisfied	52.5%	75%
Very satisfied	2.5%	10%

of healthy children were satisfied with their own health, and only 2.5% were dissatisfied.

In the studied group of parents of children with cerebral palsy, the number of children in the particular levels are as follows: GMFCS I - 0,

GMFCS II - 14 persons, GMFCS III - 10 persons, GMFCS IV - 4 persons, and GMFCS V - 12 persons. (Tab.4)

The level of physical health functioning is higher in parents of healthy children compared with parents of children with cerebral palsy and is

** p=0.015. The psychological level is also higher among parents of healthy children compared with parents of children with cerebral palsy and is *** p=0.010.

Table 4. Comparison of quality of life of parents of children with cerebral palsy with parents of healthy children depending on the movement disorders of the children with cerebral palsy on the GMFCS scale.

	Parents of children with cerebral palsy n= 40	Control group n=40
Physical health domain	22 ± 1.97**	23.1 ± 2.0
Psychological domain	21.2 ± 2.8***	22.7 ± 2.4
Social relationships	11.3 ± 1.8*	12.2 ± 1.6
Environment	27.3 ± 3 ****	29.5 ± 4

GMFCS - Gross Motor Function Classification System

* p = 0.026 vs control group ** p = 0.015 vs control group, *** p = 0.010 vs control group **** p = 0.0068 vs control group.

For parents of healthy children compared with parents of children with cerebral palsy, the level of social relationships is *p=0.026. The environment level is also higher among parents of healthy children compared with parents of children with cerebral palsy and is **** p=0.0068.

Comparing the data in Table 4, the largest differences occur in parents of children with cerebral palsy in the environment domain, p=0.0068, and the psychological domain, p=0.010.

Quality of life in all four domains (physical health, psychological, social relationships and

environment) was assessed as lower in parents of children with cerebral palsy compared with parents of healthy children.

Comparing the psychological domain of parents of children with cerebral palsy and parents of healthy children, the biggest differences were in the assessment of enjoyment of life, the meaning of life, acceptance of physical appearance and experience of negative feelings. (Tab.5) Minor differences between the two groups can be observed in the ability to concentrate and the feeling of satisfaction with self.

Table 5. Comparison of quality of life of parents of children with cerebral palsy with parents of healthy children in the psychological and environment domains.

	mean	
	Parents of children with cerebral palsy	Parents of healthy children
Psychological domain		
How much do you enjoy life?	3.5	4
To what extent do you feel your life to be meaningful?	3.9	4.5
How well are you able to concentrate?	3.8	4.1
Are you able to accept your bodily appearance?	3.8	4.3
How satisfied are you with yourself?	3.7	4
How often do you have negative feelings?	3.6	4.2
mean	3.7	4.2

Environment domain	mean	
	Parents of children with cerebral palsy	Parents of healthy children
How safe do you feel in your daily life?	3.8	4.1
How healthy is your physical environment?	3.6	3.9
Do you have enough money to meet your needs?	3	3.5
How available to you is the information that you need in your day-to-day life?	3.7	4
To what extent do you have the opportunity for leisure activities?	2.9	3.6
How satisfied are you with the conditions of your living place?	3.8	4.1
How satisfied are you with your access to health services?	3.2	2.8
How satisfied are you with your transport?	3.4	3.6
mean	3.4	3.7

The parents of healthy children chose the higher scoring answers for all the questions. In the environment domain, the biggest differences are in the *assessment of having enough money* to meet own needs. Minor differences occur in the assessment of safety in daily life, environment conducive to health, information needed in day-to-day life, opportunity for leisure activities, conditions of living, satisfaction with health care facilities, and transport.

Only in the evaluation of health care facilities parents of children with cerebral palsy assessed them better than parents of healthy children. The parents of healthy children chose the higher scoring answers for the remaining questions.

DISCUSSION

The appearance of a disabled child usually becomes a factor that disrupts the hitherto functioning of the family. Hence, the first reactions of parents after a disability diagnosis express their confusion, despair, and irrational hopes. The dominating reactions are sense of injustice, resentment against fate, blaming each other, and searching for a negation of the diagnosis or methods for quick elimination of the disease [19]. Children with disabilities require continuous visits to specialist clinics, often long hours of rehabilitation exercises, and specialist consultations [20].

In the studied group of parents of children with cerebral palsy, more than half described their quality of life as good and 40% as "neither good nor bad", while in the group of parents of healthy children nearly ¼ of parents described their quality of life as very good. More than half of parents of children with cerebral palsy were satisfied with their health, 1/4 stated that they are "neither satisfied nor dissatisfied"

and more than 17% were dissatisfied; while ¾ of parents of healthy children were satisfied with their health, and only 2.5% dissatisfied.

For the organization of family life in which there is a child with cerebral palsy, the most important are the child's functional capabilities,

which are mostly dependent upon the degree of disability. The child's independence in activities of daily living does not require of the family members an increased amount of time, effort or resources to care for him/her; nor does it require special organization of the child's environment. Limitations in the child's independence is a greater burden on the parents [19,21].

In the studied group, the most numerous group consisted of parents of children that walk with limitations, using an orthopedic device and a rehabilitation wheelchair. An analysis of the study results revealed that the quality of life of parents of children with cerebral palsy was significantly lower compared with the group of parents of healthy children. Physical health functioning, mental state, social relationships, and environment were significantly higher in the group of parents of healthy children. Comparing the data from the study, the largest differences occur in parents of children with cerebral palsy in the environment domain, $p=0.0068$, and the psychological domain, $p=0.010$. Our results are consistent with the findings of other authors [22,23].

The study by Romeo et al. [22] also showed that parents of children with cerebral palsy had lower scores in the physical health and psychological domains compared with the control group. In the domain of mental functioning, mothers of children with hemiplegia had the lowest scores; mothers had lower scores than fathers in the physical health

domain in the group of children with quadriplegia and in the psychological domain in the group of children with bilateral hemiparesis. As the authors emphasize, such studies provide useful information on the quality of life in families with various forms of cerebral palsy, which is important in planning specialist interventions.

A study by Garel et al. [23] revealed that the main problems reported by mothers at one year after giving birth prematurely were fatigue, depressed mood, anxiety and physical symptoms. Depressed mood was associated with social isolation, post-traumatic symptoms, withdrawal and feelings of guilt. Manuel et al. [24] assessed the significance of the severity of the disability and the child's functional status as predictors of depressive symptoms in the mother. Thirty percent of the 270 mothers participating in the study had symptoms of depression. The severity of the disability and the functional status of the child did not affect the occurrence of depression. However, social support had a very significant impact, because it moderated the relationship between the child's functional status and the occurrence of depressive symptoms in the mother.

Also, Sajedi et al. [25], in their study, undertook to determine the severity of depression in mothers of children with cerebral palsy compared with mothers of healthy children, and the dependence upon the form of the disease and the severity of the disability using the Gross Motor Function Classification System (GMFCS). There were no significant differences in occurrence of depression ($p=0.003$) in both groups, but having a child with cerebral palsy more than doubled the risk of occurrence of depression. The authors emphasize that the treatment or prevention of depression in mothers of children with cerebral palsy should be recommended to improve the rehabilitation process and to attain better functioning.

In our research, comparing the psychological domain of parents of children with cerebral palsy and parents of healthy children, the biggest differences were in the assessment of enjoyment of life, the meaning of life, acceptance of physical appearance and experience of negative feelings. Minor differences between the two groups could be observed in the ability to concentrate and the feeling of satisfaction with self. The parents of healthy children chose the more positive answers for all the questions. Similar observations were made by Ones et al. [26] who assessed the quality of life and the mental state of mothers of children with cerebral palsy, and assessed its influence in relation to the degree of disability of the child. The researchers found that the quality of life of these mothers is much lower than among mothers of healthy children, even

though the results did not differ significantly between the groups.

In the environment domain, the biggest differences occurred in the assessment of having enough money to meet own needs. Minor differences occurred in the assessment of safety in "daily life, environment conducive to health, information needed in day-to-day life, opportunity for leisure activities, conditions of living, satisfaction with health care facilities, and transport." A significant factor causing stress for parents is being aware of existing opportunities in treatment and rehabilitation, while at the same time not having access to these opportunities due to economic barriers. There is then a feeling of unfulfilled obligation, guilt because of the disability, fatigue due to the many hours of caring for the child, lack of rest, which often lead to the emergence of conflicts and crises in the family [27]. In our study, only in the evaluation of health care facilities, the parents of children with cerebral palsy chose the more positive answers.

According to Wanamaker et al. [28] the use of a positive reformulation, search for support and passive assessment had the biggest effect on the adaptation of parents. More frequent use of the first two strategies with less frequent use of passive assessment leads to better adaptation. Searching for and receiving support, for example through participation in support groups or talking with a psychologist, facilitates reformulation - in other words, perceiving the positive aspects of the situation. This enables confronting the problems and taking planned action to deal with it. Parents who use planned action to solve the problem and take advantage of social support are better able to cope with the burden than the parents who use methods involving focusing on their emotions [28]. Our observations indicate that an increasing number of people seek help from patient organizations and associations. This may cause that despite the difficulties associated with access to medical services, parents of children with cerebral palsy evaluate health care facilities more positively. Raising a child with cerebral palsy is a major challenge for the entire family. The needs of families with children with developmental disorders are specific and change as the children grow. The research by Peeters shows that parents of young children consider diagnosis and the implementation of an individual treatment program, help with childcare and financial support as their most important needs.

Parents of older children also emphasize the need for: education of the children, particular preparation of teachers, guidance on sex education, and availability of centers that can provide care in case of random events [29].

Arnaud et al. [30] stress in their report that most healthy children are less likely to need specialist health care. Although care is a normal part of being a parent of a young child, this role has a completely different meaning when the child has functional limitations and possible long-term dependence. One of the main challenges for parents is to solve chronic health problems associated with disability and to effectively meet the demands of day-to-day life. Therefore, the task of caring for a disabled child at home can be difficult for the parents. Providing such care can have adverse effects on both the physical and mental health of the parents, which we have also found in our research. It is worth noting that Sjøbu [31] emphasizes that the quality of life also depends on the parents' satisfaction with being with each other and the degree of mutual openness and well-being. Making the family aware of this fact should take place at the moment of the appearance of a child with a disability.

CONCLUSIONS

Parents of children with cerebral palsy describe their quality of life as good and are satisfied with their health. They have adapted to this situation and accepted it, because the family through some of its characteristic features, such as cohesion, flexibility in fulfilling roles, the resourcefulness of its members, their psychological resistance, is able to reduce to some extent the negative impact of the stressful situation of disability and give adequate support to the child. We must keep in mind that most of the difficulties are mainly due to financial problems rather than inadequate preparation to care for the child or lack of understanding of the disease.

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