

QUALITY OF LIFE IN MOTHERS OF CHILDREN WITH CEREBRAL PALSY

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SUMMARY – The aim of the study was to investigate whether there is difference in the quality of life between mothers of children with cerebral palsy and mothers of healthy children, as well as whether the quality of life in mothers of children with cerebral palsy depends on their level of education, child's mobility and child's functional status. A total of 141 mothers participated in the research. Mothers were divided into two groups, 71 mothers of children with cerebral palsy and 70 mothers of healthy children from the Tuzla Canton (Bosnia and Herzegovina). A multidimensional questionnaire PedsQL™ 2.0 Family Impact Mode was used for assessment of the impact of pediatric chronic health condition on the mothers' functioning. The level of functional disability of the child was measured by the Gross Motor Function Classification System (GMFCS levels I-V) scale. Mothers of children with cerebral palsy had poorer quality of life than mothers of healthy children in all investigated domains. In relation to mobility of the child, the quality of life was worse in mothers whose children did not move in the area of social functioning in comparison to mothers whose children had the ability to move independently. A statistically significant negative correlation existed between functional status of a child measured with GMFCS and social functioning of mothers, mothers' daily activities, parental functioning, family functioning, and overall quality of life of mothers.

Key words: Quality of life; Cerebral palsy; Mothers

Introduction

The quality of life is defined as the individual's perception of their own position in specific cultural, social and environmental context, as well as in relation to personal goals, expectations, standards and interests. It is a very broad term influenced by physical health and emotional status, as well as the level of individual's autonomy, their independence, social circumstances, personal beliefs and relations with the environment¹. The quality of life connected with health is a subjective health condition or experience of health and refers to the impact of disease, damage, disorder, or in short of the health condition on the quality of life in order to be differentiated from other aspects of the quality of

life. It has a significant clinical interest in the case of family members involved in the treatment, especially in cases when patients are children² because difficulties in the child's development require increased intensity of care, which may become a burden for parents and influence their physical and mental health³⁻⁸.

Cerebral palsy refers to a group of permanent disorders in the development of movement and posture, causing activity limitations, which are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. Motor disorders in cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, epilepsy or secondary musculoskeletal problems⁹. A child with cerebral palsy requires constant care, frequent medical examinations, continuous physical and educational-rehabilitation therapy and it affects the family dynamics¹⁰, especially mothers¹¹, because they are the carriers of care, do most of the work

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related to the child, and spend most of the time with the child.

In this research, we were interested in the quality of life in mothers of children with cerebral palsy, the way they perceived the impact of their child's disease on their own life, and how much the presence of illness affected the functioning of the family according to their own report.

The general aim of the research was to examine whether there is difference in the quality of life between mothers of children with cerebral palsy and mothers of healthy children. The specific aims of the research were to find out:

- whether there is difference in the quality of life between mothers of children with cerebral palsy and mothers of healthy children in relation to their level of education,
- relationship between mobility of the child with cerebral palsy and the quality of life in mothers of children with cerebral palsy, and
- whether there is correlation between the quality of life in mothers of children with cerebral palsy and functional condition of the child.

Subjects and Methods

Participants

The study included 71 mothers of children with cerebral palsy who live in the Tuzla Canton (Bosnia and Herzegovina) and bring the child for examination or outpatient treatment to the Clinical Department of Physical Medicine and Rehabilitation, Tuzla University Clinical Center or to the *Koraci nade* (Steps of Hope) Center for Children with Multiple Disabilities in Tuzla. Control group consisted of 70 mothers of healthy children. Control group subjects were selected randomly and satisfied the following criteria: they have healthy children of the same age and gender as mothers from the experimental group and live in the Tuzla Canton.

All the participants filled in the questionnaire before (at home) or during the scheduled meeting. The research was conducted from the late 2012 till mid-2015. The criteria for participation in the research were as follows: mothers of children aged 5–18 and diagnosed with spastic form of cerebral palsy; children had not been diagnosed with some additional chronic dis-

ease; mothers had not been diagnosed with some chronic or mental disease before the birth of the child; and living in the Tuzla Canton.

In relation to the ability of independent movement of the child, we divided mothers into two groups: mothers of children who can move independently (Gross Motor Function Classification System, GMFCS I, II and III) and mothers of children who cannot move independently (GMFCS IV and V). In relation to the level of education, mothers were divided into two groups: mothers with primary school and mothers with secondary school. The number of participants with higher educational degree was so small that they were excluded from the part of research that referred to examining the influence of education on functioning of mothers and family.

Measuring instrument and procedure

Assessment of the functioning condition of children with cerebral palsy was conducted using the GMFCS scale with five degrees of disability. The first and second degrees of disability (GMFCS I and II) include children who walk independently, with minimal restrictions outside the house and at greater distance. In third degree (GMFCS III) are children who use mobility aid (crutches, walkers) with significant restrictions outside the house and at greater distances. In fourth degree (GMFCS IV) are children who use wheelchairs to move, whereas fifth degree includes immobile children (GMFCS V) whose movement is restricted even with the help of a wheelchair because of their inability to control the head and torso while sitting.

The PedsQL™ 2.0 Family Impact Mode is a multidimensional instrument designed for assessment of the impact of pediatric chronic health conditions on the functioning of parents and family. It contains eight subscales with 36 questions, as follows: physical functioning (6 questions), emotional functioning (5 questions), social functioning (4 questions), cognitive functioning (5 questions), communication (3 questions), worries (5 questions), daily activities (3 questions), and family relations (5 questions). Problems that are covered in the area of physical functioning refer to the feeling of fatigue, headache, physical weakness and presence of stomachaches. The rest of the questionnaire covers the problems of emotional functioning (anxiety, sadness, anger, frustration, and helplessness or

hopelessness); social functioning (the feeling of isolation, difficulties of receiving help from others, difficulties in finding time or energy for social activities); cognitive functioning (difficulties in the area of attention, memory and thinking); communication (the lack of understanding of situation in the family from others, difficulties of parents to talk about child's health condition with health professionals and other people); worries (worries about the effectiveness of treatment, side effects of drugs/medical therapy, concern how others will react to the child's condition, worries about the impact of child's illness on other family members, as well as worries about the child's future); daily activities (family activities take too much time and effort, difficulties in finding time to complete housework and feeling tired to finish the housework) and family relations (the lack of communication and conflicts among family members, difficulties in mutual decision-making and solving family issues, stress among family members)¹².

In every area of the questionnaire, the question of how much problems a mother has in completing certain chores has, as a result of the child's health, during the last month, is proposed and one answer is chosen. A 5-degree Likert scale was used, where 0 – never presents a problem, 1 – almost never presents a problem, 2 – sometimes presents a problem, 3 – often presents a problem, and 4 – almost always presents a problem. On data processing, responses are scored in reverse and linear transformation into 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0) is performed, so that a greater number of scores presents better functioning (less negative impact). The overall rating is calculated as arithmetic mean of the responses¹³. Parental functioning is calculated as arithmetic mean of the responses of physical, emotional, social, cognitive functioning and worry, while family functioning is calculated as arithmetic mean of responses of daily activities and family relations.

The average time necessary for completion of these questionnaires is 10 to 15 minutes. Mothers completed the questionnaires individually, at home or in the presence of the researcher. Before examination, they were given brief oral instructions on completing the questionnaire, and, in accordance with the need, they were given additional help (reading questions aloud, interpretation of questions or explanation of words that respondents did not understand).

The questionnaire showed satisfactory metric characteristics. Its content and constructive validity and easy interpretability, sensitivity and reliability (Cronbach Alpha 0.90) were confirmed. Before using the PedsQL™ 2.0 survey, a contract was signed with the MAPI Research Institute from Lyon, France, an authorized institution for issuing a license for its use.

Ethical aspect

Mothers were informed on the importance of the requested data and by completing the questionnaire and signing it they gave their consent for the research.

Statistical analysis

Descriptive methods were applied in presenting basic demographic characteristics of the sample. In order to verify the normality of data, Shapiro Wilk test was applied, accepting $p > 0.05$. Since data for the PedsQL™ 2.0 survey did not follow normal distribution, nonparametric statistical tests were used. Differences between the groups of independent continuous variables were analyzed with Man-Whitney U-test for quantitative variables (assessment for the quality of life related to health). Results of the PedsQL™ 2.0 survey were expressed as median and interquartile range (25th-75th percentile).

Spearman (r) correlation of ranks was used for testing the association between the domains of PedsQL™ 2.0 instruments and GMFCS. A strong correlation was defined at $r > 0.5$, moderate at $r \geq 0.3$, and mild, i.e. weak at $r < 0.3$.

The value of $p < 0.05$ was considered statistically significant. Data were analyzed using the Statistical Package for Social Sciences, Windows version 19.0.0.1 (SPSS Inc., Chicago, IL, USA).

Results

The median age of mothers of children with cerebral palsy was 36 years. Control group consisted of 70 mothers of healthy children, median age 36.5 years. Considering the level of education and marital status of mothers, there was no statistically significant difference between the groups, while a statistically significant difference was found in relation to employment (Table 1). Three mothers of children with cerebral palsy and eight mothers of healthy children had col-

Table 1. Demographic data of study subjects

Characteristic of mothers	Subjects		p
	Mothers of children with cerebral palsy	Mothers of healthy children	
	71	70	
Level of education:			
primary	31.00 (43.67%)	14 (20.00%)	0.006*
secondary	37.00 (52.10%)	48 (68.57%)	
college/university	3.00 (4.20%)	8 (11.43%)	
Employment:			
employed	10 (14.08%)	20 (28.57%)	0.003*
unemployed	61 (85.92%)	50 (71.43%)	
Marital status:			
married	68 (95.77%)	67 (95.72%)	
single	3 (4.22%)	3 (4.28%)	
Median age (yrs)	36.00 (34.00-42.00)	36.50 (33.00-41.25)	0.437**

* χ^2 ; **Mann-Whitney U-test

Table 2. Quality of life in mothers of children with cerebral palsy versus mothers of healthy children

PedsQL™ Family Impact Mode 2.0	No. question	Mothers of children with CP (n=71) Median (IQR)	Mothers of healthy children (n=70) Median (IQR)	Mann-Whitney U	
				z	p
Physical functioning	6	58.00 (38.00-75.00)	85.41(75.00-100.00)	-6.059	<0.0001
Emotional functioning	5	60.00 (50.00-75.00)	90.00 (73.75-100.00)	-6.501	<0.0001
Social functioning	4	69.00 (50.00-88.00)	100.00 (81.25-100.00)	-5.548	<0.0001
Cognitive functioning	5	80.00 (60.00-100.00)	100.00 (85.00-100.00)	-4.164	<0.0001
Communication	3	67.00 (42.00-83.00)	100.00 (83.33-100.00)	-7.243	<0.0001
Worries	5	50.00 (30.00-65.00)	85.00 (60.00-100.00)	-6.567	<0.0001
Daily activities	3	42.00 (17.00-67.00)	83.33 (56.24-100.00)	-6.382	<0.0001
Family relations	5	100.00 (89.00-100.00)	100.00 (90.00-100.00)	-1.422	0.155
Parental functioning	28	63.50 (48.83-74.83)	100.00 (90.00-100.00)	-9.028	<0.0001
Family functioning	8	66.50 (51.00-79.00)	90.00 (75.00-100.00)	-5.797	<0.0001
Overall rating	36	65.36 (50.06-77.92)	88.89 (79.86-97.22)	-7.340	<0.0001

CP = cerebral palsy; IQR = interquartile range

lege/university degree. Due to the insufficient number of subjects in this group, data on college/university degree of education were not processed.

The majority of respondents in both groups were unemployed. The proportion of employed mothers was greater in control group than in the group of mothers of children with cerebral palsy (28.57% *vs.* 14.08%). In

the experimental group, 46% were mothers of daughters and 54% were mothers of sons, while in control group there were 67% of mothers of daughters and 33% of mothers of sons.

The median age of children with cerebral palsy and of healthy children was 9 and 8 years, respectively. In the group of children with cerebral palsy, 9 (12.68%)

Table 3. Quality of life in mothers of children with cerebral palsy versus mothers of healthy children according to the level of education

PedsQL™ Family Impact Mode 2.0	Subjects	Years of education		Mann Whitney U	
		Primary education Mothers of children with CP (n=31) Mothers of healthy children (n=14) Median (IQR)	Secondary education Mothers of children with CP (n=37) Mothers of healthy children (n=48) Median (IQR)	z	p
Physical functioning	Mothers of children with CP	54.00 (38.00-71.00)	58.00 (35.50-87.50)	-0.432	0.666
	Mothers of healthy children	85.41(73.95-100.00)	83.33 (75.00-98.95)	-0.376	0.707
Emotional functioning	Mothers of children with CP	55.00 (45.00-70.00)	61.00 (50.00-75.00)	-1.039	0.299
	Mothers of healthy children	100.00 (70.00-100.00)	90.00 (71.25-100.00)	-1.064	0.287
Social functioning	Mothers of children with CP	69.00 (50.00-81.00)	69.00 (44.00-94.00)	-0.558	0.577
	Mothers of healthy children	100.00 (85.93-100.00)	100.00 (81.25-100.00)	-0.310	0.757
Cognitive functioning	Mothers of children with CP	75.00 (50.00-100.00)	80.00 (65.00-97.50)	-0.597	0.551
	Mothers of healthy children	100.00 (81.25-100.00)	100.00 (85.00-100.00)	-0.229	0.819
Communication	Mothers of children with CP	67.00 (42.00-83.00)	65.00 (42.00-87.50)	-0.366	0.715
	Mothers of healthy children	95.83 (83.33-100.00)	100.00 (91.67-100.00)	-1.371	0.170
Worries	Mothers of children with CP	60.00 (35.00-75.00)	49.00 (30.00-60.00)	-1.534	0.125
	Mothers of healthy children	85.00 (58.75-100.00)	85.00 (60.00-100.00)	-0.292	0.770
Daily activities	Mothers of children with CP	33.00 (17.00-58.00)	42.00 (12.50-63.00)	-0.600	0.548
	Mothers of healthy children	100.00 (95.83-100.00)	75.00 (80.00-100.00)	-2.873	0.004
Family relations	Mothers of children with CP	100.00 (95.00-100.00)	90.00 (70.00-100.00)	-2.729	0.006
	Mothers of healthy children	100.00 (100.00-100.00)	100.00 (90.00-100.00)	-1.907	0.057
Parental functioning	Mothers of children with CP	64.00 (46.83-73.50)	63.00 (44.83-79.67)	-0.234	0.815
	Mothers of healthy children	88.92 (78.63-99.37)	91.11 (85.90-96.67)	-0.228	0.820
Family functioning	Mothers of children with CP	66.50 (56.00-79.00)	60.00 (46.50-76.50)	-0.795	0.427
	Mothers of healthy children	100.00 (97.29-100.00)	91.25 (78.12-100.00)	-3.064	0.002
Overall rating	Mothers of children with CP	64.00 (50.06-75.06)	65.36 (49.65-79.28)	-0.129	0.897
	Mothers of healthy children	90.97 (81.07-99.48)	87.50 (77.77-95.65)	-0.902	0.367

CP=cerebral palsy; IQR = interquartile range

children had been diagnosed with spastic hemiplegia, 38 (53.52%) with spastic diplegia, and 24 (33.80%) with spastic quadriplegia. According to the degree of functional disability as assessed with GMFCS, 28 (39.44%) children with cerebral palsy had a certain form of independent movement, while 43 (60.56%) children had no possibility of independent movement.

In all the areas tested except for family relations ($p=0.155$), mothers of children with cerebral palsy had poorer quality of life in comparison to mothers of healthy children. Mothers of children with cerebral palsy rated the quality of life in the area of communi-

cation, worries, emotional functioning and daily activities as poorest (Table 2).

The quality of life related to health of mothers of children with cerebral palsy, according to their own report, was statistically significantly lower in the area of family relations in mothers with secondary education ($p=0.006$) than in mothers with primary education. Mothers of healthy children with secondary education, according to their own report, had a statistically significantly lower quality of life in the area of family functioning ($p=0.002$) than mothers with primary education who had healthy children (Table 3).

Table 4. Quality of life in mothers of children with cerebral palsy according to movement of the child

PedsQL™ Family Impact Mode 2.0	No. question	Moveable (n=28) Median (IQR)	Immovable (n=43) Median (IQR)	Mann-Whitney U	
				z	p
Physical functioning	6	58.00 (34.25-89.75)	54.00 (42.00-75.00)	-0.702	0.483
Emotional functioning	5	67.50 (50.00-75.00)	55.00 (40.00-70.00)	-1.388	0.165
Social functioning	4	75.00 (51.50-100.00)	69.00 (38.00-81.00)	-2.074	0.038
Cognitive functioning	5	85.00 (61.25-100.00)	75.00 (60.00-95.00)	-1.226	0.220
Communication	3	67.00 (44.00-98.00)	67.00 (42.00-83.00)	-0.432	0.666
Worries	5	57.50 (18.75-75.00)	49.00 (35.00-60.00)	-0.904	0.366
Daily activities	3	50.00 (25.00-79.00)	42.00 (8.00-58.00)	-1.685	0.092
Family relations	5	100.00 (90.00-100.00)	95.00 (85.00-100.00)	-0.980	0.327
Parental functioning	28	69.42 (48.87-80.08)	63.00 (46.83-73.00)	-1.418	0.156
Family functioning	8	71.00 (57.75-89.50)	66.00 (50.00-76.50)	-1.890	0.059
Overall rating	36	72.87 (53.66-83.13)	64.00 (48.72-75.06)	-1.630	0.103

IQR = interquartile range

The quality of life in relation to the health of mothers of children with cerebral palsy whose children did not move, according to their own judgment, was statistically significantly ($p=0.038$) poorer in the area of social functioning than in the group of mothers whose children could move independently. In relation to mobility of the child, the quality of life of mothers, according to their own judgment, was not statistically significant in respect of the domains examined (Table 4).

There was a statistically significant negative correlation between functional status of the child measured with GMFCS and social functioning of mothers ($r=-0.286$; $p<0.05$), daily activities ($r=-0.314$; $p<0.01$), parental functioning ($r=-0.255$; $p<0.05$), family functioning ($r=-0.327$; $p<0.01$) and overall quality of life of mothers ($r=-0.270$; $p<0.01$).

Discussion

Results of this research indicated that, according to their own report, the quality of life in mothers of children with cerebral palsy was statistically significantly poorer than in mothers of healthy children. The mothers assessed that they had the most evident difficulties in communication, worries, emotional functioning and daily activities. Previous studies showed that mothers of children with cerebral palsy¹⁴⁻¹⁷, as well as parents of chronically ill children^{18,19}, had a lower quality of life in comparison to parents of healthy children. Mothers of children with difficulties had significantly more negative emotional conditions and more symptoms of de-

pression¹⁴ because they had lack of positive feelings such as joy, pleasure, loveliness, pride and fulfillment of hope²⁰. It was found that over years, parents of children with cerebral palsy, in comparison to parents of healthy children, more often complained of experiencing severe and chronic stress, emotional and cognitive problems, as well as numerous somatic difficulties²¹⁻²⁵. Mothers of children with cerebral palsy are exposed to psychological pressure, are under the impact of stress and depression, are worried for their child's future, most of their time spend on the child's nutrition, health, treatment, rehabilitation, are subjected to financial burdens (transport, child care, therapy, providing adaptive equipment and modifications in the house)²⁶, which causes decline in the quality of life of mothers (both physically and psychologically), whereas mothers of healthy children have more free time, are more involved in social activities, entertainment and work²⁷. A significant factor that causes stress in parents is the lack of access to the existing possibilities of treatment and rehabilitation of children due to economic barriers. This leads to the feeling of incompletely executed parental obligations, guilt because of disability, fatigue, lack of rest, which often leads to conflict and crisis in the family²⁸. Chronic illness of a child, in terms of quality of life, affects family and parents more than the child²⁹, because restrictions in the child's independence cause greater burden on the parents³⁰. Contrary to the results of our study, in the study by Okurowska *et al.* half of the parents of children with cerebral palsy described their quality of life and health as good³¹.

Table 5. Correlation of five dimensions of health measured with PedsQL™ 2.0, parental functioning, family functioning, overall ratings and GMFCS

PedsQL™ Family Impact Mode 2.0	Physical functioning	Emotional functioning	Social functioning	Cognitive functioning	Communication	Worries	Daily activities	Family relations	Parental functioning	Family functioning	Overall rating
GMFCS	-0.124	-0.209	-0.286*	-0.214	-0.150	-0.185	-0.314**	-0.096	-0.255*	-0.327**	-0.270**

*significant at $p < 0.05$; **significant at $p < 0.01$; GMFCS = Gross Motor Function Classification System

According to the results of our study, mothers of children with cerebral palsy, who had secondary education, had a statistically significantly poorer quality of life only in the area of family relations ($p = 0.006$) in comparison to mothers of children with cerebral palsy who had primary education. Bumin *et al.*¹⁰ and Erdoğanoğlu and Günel³² report opposite results, indicating that the quality of life in mothers of children with cerebral palsy depends on the level of education.

According to the child's ability to move, the quality of life related to the health of mothers of children with cerebral palsy whose children did not move, according to their own judgment, was statistically significantly worse ($p = 0.038$) only in the area of social functioning, in comparison to the group of mothers whose children had the ability to move independently. Keller and Honig also indicate that disability in children reduces social activity of the mother³³.

There was a statistically significantly negative correlation between functional condition of the child measured with GMFCS and social functioning of mothers ($r = -0.286$; $p < 0.05$), daily activity ($r = -0.314$; $p < 0.01$), parental functioning ($r = -0.255$; $p < 0.05$), family functioning ($r = -0.327$; $p < 0.01$) and overall quality of life of mothers ($r = -0.270$; $p < 0.01$). Research on the impact of functional condition of the child with cerebral palsy on the quality of life of mothers failed to show uniform results. On the one hand, there are authors who emphasize connection^{32,34}, whereas on the other hand, there are those who emphasize that there is no connection¹⁷.

Conclusion

The results of our study yielded statistically significant differences between the quality of life in mothers of children with cerebral palsy in comparison

to mothers of healthy children. When planning the program of rehabilitation of children with cerebral palsy, it is also necessary to assess the quality of life of mothers who have the most significant role in the process of care and rehabilitation of the child. Proper functioning of mothers and family increases the possibility of creating conditions necessary for optimal development of the child.

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Sažetak

KVALITETA ŽIVOTA MAJKI DJECE S CEREBRALNOM PARALIZOM

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Cilj ovoga istraživanja bio je ispitati postoji li razlika u kvaliteti života između majki djece s cerebralnom paralizom i majki zdrave djece te ovisi li kvaliteta života majki djece s cerebralnom paralizom o stupnju obrazovanja majki, pokretljivosti djeteta i funkcionalnom statusu djeteta. U istraživanju je sudjelovala ukupno 141 majka. Majke su bile podijeljene u dvije skupine: 71 majka djece s cerebralnom paralizom i 70 majki zdrave djece s područja Tuzlanskog kantona (BiH). Za procjenu utjecaja pedijatrijskih kroničnih zdravstvenih stanja na funkcioniranje majki korišten je višedimenzionalni upitnik *PedsQL™ 2.0 Family Impact Mode*. Stupanj funkcionalne onesposobljenosti djeteta procijenjen je primjenom ljestvice *Gross Motor Function Classification System* (GMFCS razine I.-V.). Majke djece s cerebralnom paralizom su imale lošiju kvalitetu života u usporedbi s majkama zdrave djece u svim ispitivanim domenama. U odnosu na pokretljivost djeteta kvaliteta života bila je lošija kod majki čija se djeca ne kreću, u području društvenog funkcioniranja, u odnosu na majke čija djeca imaju sposobnost neovisnog kretanja. Statistički značajna negativna povezanost je postojala između funkcionalnog statusa djeteta mjenog GMFCS i društvenog funkcioniranja majki, dnevnih aktivnosti majki, roditeljskog funkcioniranja, obiteljskog funkcioniranja i ukupne kvalitete života majki.

Ključne riječi: *Kvaliteta života; Cerebralna paraliza; Majke*