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FAMILY SOCIOECONOMIC STATUS AND HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: ASSESSING DIFFERENCES BETWEEN CLINICAL AND HEALTHY SAMPLES

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Objective – The objective of this study was to assess the health-related quality of life (HRQoL) in children with cerebral palsy (CP) in relation to socioeconomc status (SES) of family. **Methods** – The cross-sectional study included 75 children with CP between ages 5 and 18 years and their parents. The control group was formed by random selection by matching each patient with one or two healthy control participants. To evaluate the generic HRQoL in children with CP we used the PedsQL™ 4.0 Generic Core Scales which include both a parent proxy-report and a child self-report with age-appropriate versions. SES was determined using a classification system based on the parents' job and educational level. **Results** – Lower-SES children with CP showed significant lower medians of total scores, physical health, psychosocial health, and social functioning HRQoL than lower SES control participants and, middle SES children with CP showed significant lower medians of total scores, physical health, psychosocial health, than middle SES control participants. Parental reports revealed significantly poorer HRQoL in lower SES children with CP in total scores, physical health, psychosocial health, social functioning, and school functioning than lower SES control participants. Also, the parental proxy reports for middle SES children with CP were significantly lower in total scores, physical health, psychosocial health, and social functioning than middle SES control participants. **Conclusions** – This study showed that low and middle SES children with CP have lower HRQoL than low and middle SES healthy children. Our results call for the creation of social-economic and psychological programs which might have beneficial effects for children and adolescents with CP and their families.

Key words: HRQoL ▪ Cerebral palsy ▪ Socioeconomic status ▪ Children ▪ PedsQL.

Introduction

The quality of life is defined by WHO as "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 goals, expectations, standards and concerns" (1). Today it is widely accepted that the functional effect of a medical condition and/or its consequent therapy upon a patient is health-related quality of life (HRQoL) (2). HRQoL is a multidimensional construct covering physical, emotional, mental, social and behavioural components of well-being

and functioning as perceived by patients and/or other individuals (3).

Cerebral palsy (CP) is a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems (4).

In families who have children with CP the "constant attendance" of the disease is present, through strict consistent long-term care of family and many other factors, such as services, support and physical aspects of the environment, which all can lead to deterioration of the patient's quality of life.

In addition, problems of a socio-economic nature (lack of financial resources in the family, unemployment and poor parental education, inadequate care and lack of understanding from the wider community) may also contribute to the deterioration of the patient's quality of life. This is especially expressed in low- and middle-income countries, where social and health security systems are not well-developed.

Several previous studies have reported HRQoL in children and adolescents with CP (5, 6, 7, 8) but little is known about specific factors (9) such as socioeconomic status (SES) of the family, with their HRQoL outcomes. Within the group of papers available for review, Groce et al. (10) identify a small but growing evidence base that indicates that there are substantial links between disability, poverty and health; however emerging research indicates that these links are more complex and nuanced than is currently assumed.

Bosnia and Herzegovina (BH) is undergoing a political and economic crisis. The social status of the population is extremely difficult as the result of a high unemployment rate (11), which increases the percentage of families that are classified as poor. This situation disrupts the SES of the family, particularly in the case of families who have members suffering from chronic diseases. An interesting feature of this study is that participants ended up clustered in two (middle and lower) SES levels, because only one children with CP came from the upper social classes of families.

A better understanding of the direct effect of SES on HRQoL in children with CP can help various professionals and institutions to improve the quality of care for this population and in that way improve their HRQoL outcomes. We hypothesized that children with CP, when compared with healthy children in relation to SES, would have worse findings of HRQoL.

The objective of this study was to assess the health-related quality of life (HRQoL) in children with cerebral palsy (CP) in relation to SES of family.

Methods

Participants

The cross-sectional study included 75 consecutive children (37/75, 49.3% males and 38/75, 50.7% females) with CP, between the ages of 5 and 18 years ($\bar{x}$±SD=9.4±3.6) who came for check-ups or outpatient physical therapy at the Department of Physical Medicine and Rehabilitation in Tuzla, and children who are receiving treatment or receive home visits through the "Steps of Hope" Centre for Children with Disabilities in Tuzla. The children's characteristics in terms of type of CP, severity of motor impairment, and associated impairments are presented in Table 1.

The severity of motor impairment was assessed by using the gross motor function classification system (12).

Table 1 Characteristics of children with CP (n=75) cerebral palsy and the control groups

Characteristics	n (%)
CP type	
Spastic hemiplegia	7 (9.3)
Spastic diplegia	39 (52.0)
Spastic quadriplegia	29 (38.7)
Gross motor function	
Levels I: walks, climbs stairs	9 (12.0)
Levels II: walks inside	4 (5.3)
Levels III: walks with limitation	15 (20.0)
Levels IV: moving limited	13 (17.3)
Levels V: moving severely limited	34 (45.3)
Vision impairment	36 (48.0)
Hearing impairment	2 (3.0)
Epilepsy	21 (28.0)
Feeding	
Feeds by mouth without problems	60 (80.0)
Feeds by mouth but with difficulty	15 (20.0)
Communication ability	
Normal communication	37 (49.3)
Problem but communicates with speech	26 (34.7)
Uses alternative formal methods to communicate	1 (1.3)
No communication	11 (14.7)
Child's pain/discomfort (parent's view)	
None	51 (68.0)
Moderate	23 (30.7)
Severe	1 (1.3)

Eleven children who did not have the capacity for self-report were excluded from participation. The other 64 children with CP and mothers of all the patients completed all the questionnaires separately in the waiting room area, before their scheduled appointment. For all children aged 5 to 7 years who did not have the capacity for self-administration but did have the capacity for self-report, the PedsQL™ was administered by interview.

The control group was formed by matching each patient with one or two healthy children from primary and high schools in the places of residence of the participants. They had to meet the following criteria: they did not suffer from any other chronic disease and they were the same age, sex and place of residence as the participants. A total of 76 healthy children (37/76, 48.7% males and 39/76, 51.3% females) aged 5 to 18 years ($\bar{x}$±SD=9.9±3.4) were enrolled in the control group.

Measures and procedures

The demographic questionnaire for evaluation of the characteristics of children with CP and the control groups completed by parents, includes data about the date of birth, age and gender of the participants, and information required to calculate the Hollingshead SES index (13).

To evaluate the HRQoL we used the PedsQL™ 4.0 Generic Core Scales (GCS) (14) which are brief and very easy to use, resulting in minimal missing data, and include both a parent proxy-report and a child self-report with age-appropriate versions. User agreement was signed with the MAPI Research Institute, Lyon, France, prior to using the PedsQL™ questionnaires.

The 23-item PedsQL™ 4.0 GCS encompasses: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items) scales. The PedsQL™ scales are composed of parallel child self-report and parent proxy-report formats. The child self-report and parent proxy reports cover ages 5 to 7, 8 to 12, and 13 to 18 years (15). To create a psychosocial health summary score, the mean is computed as the sum of the items divided by the number of items in the Emotional, Social, and School Functioning Scales. The total scale score is calculated as the average of the individual item responses.

The PedsQL™ was self-administered for parents and for children and adolescents aged 5 to 18 years and administered by an inter-

viewer for children aged 5 to 7 years. The average time required to complete the PedsQL™ GCS was 20 to 30 minutes. Data about the family SES of participants were unknown to the interviewer.

Scale internal consistency reliability for the PedsQL™ GCS was determined by calculating Cronbach's coefficient alpha. The value of Cronbach's alpha for the PedsQL™ 4.0 GCS in the study ranged from 0.73 to 0.84, which is in the acceptable range for group comparisons.

A 5-point Likert scale was used for the child self-report questionnaire for ages 8 to 18 years and the parent proxy-report (0, never a problem; 1, almost never a problem; 2, sometimes a problem; 3, often a problem; 4, almost always a problem). For additional ease of use for the young child self-report (ages 5-7 years), the Likert scale was reworded and simplified to a 3-point scale (0, not a problem; 2, sometimes a problem; 4, a big problem). The items were reverse-scored and linearly transformed to a scale from 0 to 100 points, so that higher scores indicate better HRQoL (15).

To categorize the families' SES, the parents' education level and current employment were recorded and analysed using the Hollingshed two-factor index of social position (ISP) (14). The higher score values obtained by this index correspond to a lower SES class, and vice versa. Based on the value range of the social index, participants were categorized into three social classes (lower, middle, upper) (16). Only one children with CP in the sample came from a family in the upper social class, so we categorized our children with CP into lower (58/75; (77.3%) and middle (17/75; (22.7%) social classes.

Ethical aspects

Before the examination by the first author of this study, every parent of a child with CP was acquainted with the purpose of the review and was asked to sign a pre-filled form of consent to participate in the study. Written informed consent was obtained from participating mothers for their child to take part in the study. Also, informed consent was obtained from each child with CP. The study received approval from the Ethics Committee of the University Clinical Centre Tuzla, Bosnia and Herzegovina.

Statistical analysis

Data are presented as absolute and relative numbers, the median and interquartile range and analysed using descriptive statistics. To perform statistical analysis, the statistical package Arcus QuickStat Biomedical version (17) was used. To verify normality of the data, we applied the Shapiro-Wilk test, accepting $p>0.05$. Descriptive analyses comparing groups were performed with the Chi-square test for categorical variables (gender, age and SES of participants characteristics) and with the Mann-Whitney U test for quantitative variables (scores of HRQoL). The level of significance was defined as $p<0.05$.

Results

The demographic data of the participants are summarized in Table 1.

The median age of the children with CP at the time of study was 8.9 years (range, 5–17.3 years). Of the 75 children with cerebral palsy, 40 (53.3%) were males and 35 (46.7%) were females. Twenty-nine (29) children were 5–7 years of age, 30 were 8–12 years, and 16 patients were 13–18 years. The median SES of the 75 children with CP who took part in our research was 23 (range: 6.0-45.0) which on average indicates a low SES, in 58 of them (77.3%) it was 21.5 (range 6-27) indicating on average a lower SES, and in 17 (22.7%) it was 38 (range 28.5-45.0) indicating a medium SES on the basis of the Hollingshead indeks (13).

Table 1 Demographic data of children with cerebral palsy and the control groups

Demographic data	Participants					
	Children with cerebral palsy			Control participants		
	Total (n; %)	Male (n; %)	Female (n; %)	Total (n; %)	Male (n; %)	Female (n; %)
Age						
5-7	29 (38.7)	16 (40.0)[C]	13 (37.1)[C]	32 (42.1)	16 (43.2)	16 (41.0)
8-12	30 (40.0)[A]	17 (42.5)[D]	13 (37.1)[D]	29 (38.2)	14 (37.8)	15 (38.5)
13-18	16 (21.3)[A]	7 (17.5)[E]	9 (25.7)[E]	15 (19.7)	7 (18.9)	8 (20.5)
Total	75 (100.0)	40 (53.3)[F]	35 (46.7)[F]	76 (100.0)	37 (48.7)	39 (51.3)
Socioeconomic state of family						
Lower	58 (77.3)[B]	29 (72.5)[G]	29 (82.7)[G]	35 (46.1)	17 (48.6)	18 (51.4)
Middle	17 (22.7)[B]	11 (27.5)[H]	6 (17.1)[H]	41 (53.9)	20 (48.7)	21 (51.2)

Chi-square analysis: [A]p=0.9289; [B]p=0.0001; [C]p=0.616; [D]p=0.604; [E]p=0.723; [F]p=0.627; [G]p=1; [H]p=0.234; compared with the groups of the control participants.

The median age of healthy children at the time of study was 9.5 years (range, 5.1–16.8 years). Of the 76 healthy children 37 (48.7%) were males and 39 (51.3%) were females, and 32 children were 5–7 years of age, 29 were 8–12 years, and 15 patients were 13–18 years. The median SES of the 76 healthy children who took part in our research was 29 (range: 15.5-47.0) which on average indicates a medium SES, in 35 of them (46.1%) the median was 24.5 (range 15.5-27.0) which on average indicates a low SES, and in 41 of them (53.79) it was 39 (range 28.5-47.0) indicating a medium SES on the basis of the Hollingshead indeks (13).

The reports of children with CP with lower SES families showed statistically significant lower median total scores, physical

Table 2 Comparison of generic health-related quality of life assessed by PedsQL™ 4.0 Generic Core Scales child self-report between children with cerebral palsy and the control groups in relation to socioeconomic state

Scale PedsQL™ 4.0 Generic Core	Generic Health-Related Quality of life				
	No. of items	Children with CP (n=64)		Control (n = 76)	
		Socioeconomic state of family		Socioeconomic state of family	
		Lower (n = 47)	Middle (n = 17)	Lower (n = 35)	Middle (n = 41)
		Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
Child self-report					
Total score	23	68.7 (43.7-80.0)[A]	60.0 (37.5-80.0)[E]	87.5 (80.0-95.0)	90.0 (80.0-100.0)
Physical health	8	37.5 (25.0-51.6)[B]	31.2 (25.0-56.2)[F]	87.5 (78.1-93.7)	87.5 (81.2-98.4)
Psychosocial health	15	70.0 (60.0-80.0)[C]	70.0 (51.2-85.0)[G]	90.0 (80.0-100.0)	90.0 (80.0-100.0)
Emotional functioning	5	70.0 (53.7-80.0)	75.0 (55.0-82.5)	85.0 (65.0-90.0)	90.0 (77.5-100.0)
Social functioning	5	72.5 (70.0-80.0)[D]	65.0 (45.0-90.0)	95.0 (90.0-100.0)	90.0 (80.0-100.0)
School functioning*	5	70.0 (57.5-80.0)	67.5 (53.7-82.5)	85.0 (75.0-95.0)	90.0 (80.0-97.5)

CP=cerebral palsy; IQR=Interquartile range; *Children with CP: Lower socioeconomic state; (n=26); Middle socioeconomic state; (n=7). Mann-Whitney U test: There were no significant differences in scores between lower and middle SES of children with cerebral palsy across all domains. [A, B, C, D] p<0.0001 compared with the lower group of control; [E, F, G]p<0.0001 compared with the middle group of control.

Table 3 Comparison of generic health-related quality of life assessed by PedsQL™ 4.0 Generic Core Scales parent proxy-report between children with cerebral palsy and the control groups in relation to socioeconomic state

Scale PedsQL™ 4.0 Generic Core	No. of items	Generic Health-Related Quality of life			
		Children with CP (n=75)		Control (n=76)	
		Socioeconomic state of family		Socioeconomic state of family	
		Lower (n = 58)	Middle (n=17)	Lower (n=35)	Middle (n=41)
		Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
Parent proxy-report					
Total score	23	55.0 (30.0-70.0)[A]	55.0 (40.0-81.2)[G]	90.0 (80.0-100.0)	90.0 (75.0-100.0)
Physical health	8	25.0 (18.7-35.9)[B]	25.0 (21.8-67.2)[H]	90.6 (84.4-100.0)	87.5 (79.7-100.0)
Psychosocial health	15	60.0 (50.0-72.5)[C]	60.0 (50.0-85.0)[I]	90.0 (75.0-100.0)	90.0 (75.0-100.0)
Emotional functioning	5	60.0 (50.0-70.0)[D]	55.0 (45.0-85.0)[J]	85.0 (75.0-90.0)	80.0 (67.5-97.5)
Social functioning	5	60.0 (50.0-75.0)[E]	70.0 (47.5-90.0)	100.0 (85.0-100.0)	95.0 (80.0-100.0)
School functioning*	5	60.0 (45.0-75.0)[F]	62.5 (48.7-71.2)	90.0 (70.0-100.0)	85.0 (72.5-100.0)

CP=cerebral palsy; IQR=Interquartile range; *Children with CP: Lower socioeconomic state; (n=26); Middle socioeconomic state; (n=7). Mann-Whitney U test: There were no significant differences in scores between lower and middle SES of children with cerebral palsy across all domains. [A, B, C, D, E, F]p<0.0001 compared with the lower group of control; [G, H, I, J]p<0.0001 compared with the middle group of control.

health, psychosocial health, and social functioning HRQoL summary scores than in the healthy children control group with lower SES families. Also, the reports of children with CP with middle SES families showed statistically significant lower median total scores, physical health, psychosocial health, functioning HRQoL summary scores than in the healthy children control group with middle SES families.

Parental reports revealed statistically significantly poorer HRQoL in children from lower SES families in the total scale score and in terms of physical and psychosocial health, emotional, social and school functioning as compared with the control group with middle SES families.

Discussion

The results of this study show that children with CP from lower SES families had a poorer HRQoL by their own assessment in terms of total scores, and in the area of problems with their physical health, psycho-social health, and social functioning in comparison with the healthy children from identical SES families, and that children with CP from middle SES families had poorer HRQoL in terms of total scores, and in the area of problems with their physical and psycho-social health compared to healthy controls from middle SES families. Also, according to the reports by parents, children with CP in the lower SES group also had lower HRQoL scores in terms of the total score, and in the areas of physical and psycho-social health, emotional functioning, social functioning and school functioning domains, compared with the control group, and for the middle SES group they had lower HRQoL in terms of the total score, and in the domains of physical and psychosocial health and emotional functioning, compared with the appropriate control group of SES. This finding is consistent with our hypothesis.

The difference in vision of HRQoL between children and parents can be explained by the fact that parents of children with disabilities continue to experience high levels of

distress (18, 19, 20) and to have impairment of quality of life (21) so that in their assessment of an existing problem they perceive it to be greater than their sick child would perceive it (22). Another potential explanation regarding the difference in vision of HRQoL between children and parents is that parents rated their child's functioning in all of the domains as significantly lower than their child self-reported, which replicates the findings from past HRQoL research (7), that children usually adapt more easily to their circumstance, and thereby report better scores.

The findings of the studies by Varni et al. (7) and Vargus-Adams (5) also found a lower HRQoL in children with CP than the healthy controls. However, these studies did not review the HRQoL in children with CP in relation to SES of their family.

In our study, poor the HRQoL of lower-SES children with CP in the domains of physical health, psycho-social health and social functioning appears to be mediated by elevated exposure to different acute and chronic stressors of children with CP and their parents.

One of the stressors in the families of our participants is the poor family budget. Namely, the gross domestic product per capita in BH in 2012 amounted to 4,392 USD according to the Agency for Statistics of BH (23). In addition, most of the parents of our participants are unemployed, so that it frequently happens that the modest financial resources that families of children with CP receive from health insurance are the only income in the family. Another possible explanation for this is that the low SES of the family can lead to poor disease control in the home setting, which adversely affects the HRQoL.

On the other hand, children with a chronic disease are often confronted with life's difficulties in the same way as adults, which also may have a negative impact on their HRQoL. Lower-SES children, just like adults, experience more negative life events (stressors) than higher-SES individuals; in addition, they perceive a greater negative impact from any given event (stress appraisal) (24). Today in BH, children with CP do not have completely free health care, as seen in developed countries so the difficulties arising from their illness for the child and parents are events that can lead them to a state of depression. Finally, it should not be forgotten that low SES by itself can lead to a poorer quality of life.

The findings of this study suggest that those who care about the treatment of children with CP should be thoroughly familiar with their healthcare, psychological and social problems. The pratical implications can be organized in two dimensions: first, sustainable SES assistance programs are needed to counteract the deleterious effects of these families' social background; and second, those initiatives could be complemented with psychosocial programs aimed at buffering the negative impact of adverse family socioeconomic circumstances on the HRQL of children with CP.

Limitations of the research and future directions

There are a number of limitations to this study. First, we did not use standardized screening instruments to determine whether a child was physically or cognitively able to complete the HRQoL survey. Second, a sample of 75 is relatively small when attempting to determine factors associated with HRQoL, and third, in this study there were no families with high SES, so that we do not know what the quality of life is like for children with CP in that sector. Also, the current study only included mothers, which could have affected the results, thereby limiting the conclusions that may be drawn regarding the fathers of children with CP, which may be very important to consider. The inclusion of fathers in

future research would result in an alternative view of the specific problems encountered by these children. In this study no dyadic parent-child approach to HRQoL assessment was included. Nevertheless, future research needs to include this assessment because it is an important insight into the development of psycho-social interventions in the context of paediatric CP (25). The instrument for assessing SES that we used was not appropriate for all ages, which may be another limitation. For future research to assess SES in children/adolescents an age-appropriate Family Affluence Scale should be used (26).

Conclusion

Despite these limitations, this study showed that the low and middle SES of families of children with CP is associated with lower generic HRQoL as compared to healthy children from low and middle SES families. The examination of this premise in children with CP is particularly important for a better understanding of other reasons, such as the interplay between poverty and disability/illness or increased/multiple disadvantaged populations. It calls for the creation of effective and sustainable social-economic and psychological programs which might have beneficial effects for children and adolescents with CP and their families in countries with low income.

Authors' contributions: Conception and design: HT, AG; Acquisition, analysis and interpretation of data: AG, HT, AD; Drafting the article HT; Revising it critically for important intellectual content: AD, AG, HT.

Conflict of interest: The authors declares that they have no conflict of interest.

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