

Research Article

Quality of Life in Mothers of Children with Cerebral Palsy

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Objective. To investigate health-related quality of life (HRQoL) in mothers of children with cerebral palsy (CP) and to determine factors into HRQoL. *Materials and Method.* Participants comprised 137 mothers of children with spastic-type CP, and controls comprised 140 mothers with healthy children. Functional levels of children with CP were evaluated using Gross Motor Function Classification System (GMFCFS). HRQoL of mothers with CP children and control groups was assessed with 36-Item Short-Form Health Survey (SF-36) and depression levels with Beck Depression Inventory (BDI). *Results.* Social function, mental health, role limitation emotional, and vitality as subscale of mental component of SF-36 were found to be lower in CP children's mothers than controls. BDI scores were higher in CP children's mothers than controls. Among mothers with CP children, a negative correlation was detected between BDI scores and all subscale scores of SF-36 and age rate of mothers and physical function, bodily pain, and physical component scale scores, among subscales of SF-36. *Conclusion.* Our study indicates that HRQoL is impaired in CP children's mothers, and depression is a significant symptom affecting HRQoL of mothers with CP children. Therefore, to increase HRQoL, mothers of children with CP should be motivated to join social activities related to their interests, and mothers with depressive symptoms should be psychologically supported.

1. Introduction

Quality of life (QoL) has been described as an individual's perception of own his/her status in life as to cultural features and value system. Health-related quality of life (HRQoL), however, is a subcomponent of QoL including physical, social, and emotional status of wellbeing. HRQoL is the happiness and satisfaction of individuals in different parts of life influencing or influenced by individuals' health [1–3]. QoL is one of the signs of health. Similar to traditional mortality and morbidity rates, QoL is also among considerable factors essential to be taken into account while individuals' health status is determined [4]. Seen in brains of those from fetal to early childhood periods with symptoms such as ataxia, spasticity, walking with one foot or leg dragging or on toes, crouched or scissored gait, and muscle tone, cerebral palsy (CP) is a neurologic nonprogressive disorder permanently affecting body movement and muscle coordination and leading to limitations in activities [5]. Functional deficits developing due to physical, cognitive, emotional, and social disorders prevent children with CP from performing their roles in society [6, 7]. Families of children with CP fail to be into

the children and themselves because of children's continuous requirements for special care, frequent medical checkups, and continuous physiotherapy treatment modalities and to take over their roles in society. Therefore, HRQoL of family members undertaking medical care of children with CP is influenced negatively [4, 8, 9]. In our study, it was aimed to determine HRQoL of mothers of children with CP and to investigate factors affecting HRQoL.

2. Material and Method

The study was performed in the Physical Medicine and Rehabilitation Department of Konya Training and Research Hospital in Konya, Turkey, between September 2011 and January 2013, and 137 mothers with CP children and 140 with healthy children were included into the study. An approval was obtained from the local ethical board of Meram Medical School of Selcuk University. Those accepting to participate were informed, and written consents were obtained. Demographic, medical, and developmental histories of children with CP were taken from families, and age, gender, clinical type, and body involvement of children were

defined. Subjects were categorized under Swedish classification. Mothers with CP children are put into classifications as spastic (diplegic, quadriplegic, and hemiparetic), ataxic, dyskinetic (including athetosis and dystonia), and mixed type according to this classification [10]. Only spastic-type children were enrolled into our study. Functional level of children with CP was assessed using Gross Motor Function Classification System (GMFCS). Sociodemographic data of mothers in both groups were determined. HRQoL of mothers was assessed with 36-Item Short-Form Health Survey (SF-36) and depression level with Beck Depression Inventory (BDI).

Inclusion criteria of mothers were composed of having a child with CP, living with the child, not having chronic disorder, not having a rheumatologic, orthopedic, and neurologic problem that will markedly affect HRQoL, not being pregnant, having no history of psychological disorders, not using antidepressant and anxiolytic drugs, and not have another patient or disabled individual along with the CP child. On the other hand, inclusion criteria of controls consisted of having a healthy child and living together, not living with another patient or disabled individual, lacking a history of psychological disorders, not using of antidepressant and anxiolytic drugs, without chronic disorders, not using assisted device, not having pregnant and not having a rheumatologic, orthopedic and neurologic problem that will markedly affect HRQoL.

Assessing the last 4-week period, SF-36 is a valid and frequently used scale to evaluate HRQoL, specific for no groups of age, disorder, and treatment, includes general health concepts, and composed of 36 questions with 8 subscales as physical function, role limitation physical, role limitation emotional, bodily pain, social function, mental health, vitality, and general health. Scores of items are encoded for each subscale and formed as a scale ranging from 0 (poorest health status) to 100 (best health status). SF-36 has two summary measures as physical component scale (PCS) and mental component scale (MCS). PCS is comprised of subscales of physical function, role physical, bodily pain, and general health, and MCS is comprised of subscales of vitality, social function, role emotional, and mental health [11, 12]. BDI consists of 21 self-evaluating items, scored between 0–3 and including depressive symptoms. A BDI score of 17 and over is evaluated in favour of depression [13]. Likewise, the score of 17 and over was assessed in favour of depression in our study. As the total score increases, depression becomes severe [13]. GMFCS used to define functional levels in individuals with CP is a classification system scored between level 1 and 5. While performing comfortably indoor and outdoor activities with no requirements for assisted devices in level 1, a patient is completely dependent as to mobility in level 5. Differentiation between levels is determined according to the functional restrictions and use of assisted devices [14, 15].

3. Statistical Analyses

For statistical analyses, SPSS 20 package software was used. Descriptive statistical findings were given as mean \pm SD. In comparison of parameters, Student's *t*- and chi-square tests

were used. Educational status, level of income, and type of family were assessed using crosstabs. Whether a difference was present between groups as to such frequencies was detected via chi-square or Fisher's exact tests. Analyses were performed with Spearman's rho correlation test. Statistically significance rate and confidence interval were accepted as $P < 0.05$ and 95%, respectively. As correlation coefficients, the correlations between 0 and 0,25 were assessed as "none", between 0,25 and 0,50 as "weak-moderate," between 0,50 and 0,75 as "severe," and between 0,75 and 1,00 as "much severe."

4. Results

Mean age rate of children with CP was 9.27 ± 5.34 , and 54.8% ($n = 74$) were girls and 46.0% ($n = 63$) were boys. Of CP children, 40.2% ($n = 55$) were determined to be diplegic, 39.4% ($n = 54$) to be quadriplegic, and 20.4% ($n = 28$) to be hemiplegic. GMFCS levels were as follows: 16.1% ($n = 22$), level 1; 17.5% ($n = 24$), level 2; 17.5% ($n = 24$), level 3; 19.0% ($n = 26$), level 4; and 29.9% ($n = 41$), level 5. All mothers in both groups were housewives, and sociodemographic and clinical features of all mothers were presented in Table 1. No statistically significant difference was found between participants in the two groups as to educational level, type of family, number of living children, and level of income ($P > 0.05$) (Table 1). On the evaluation of those with BDI ≥ 17 in favour of depression, the rates of depression were determined as 48.9% in mothers with CP children and 13.6% in controls ($P < 0.001$). In mothers with CP children, scores of social function, mental health, role limitation emotional, vitality, and mental component among subscales of SF-36 were statistically and significantly lower, compared to controls (Table 2). BDI scores, however, were statistically and significantly higher in mothers with CP children than controls ($P < 0.001$). When those with BDI ≥ 17 were evaluated in favour of depression in mothers with CP children, all subscale scores of SF-36, mental component scale, and physical component scale scores were found to be lower in depressive mothers with CP children than those without (Table 3). In mothers with CP children, a negative correlation was detected between BDI scores and SF-36 subscales such as physical function ($r = -0.464$), bodily pain ($r = -0.307$), role limitation physical ($r = -0.441$), health perception ($r = -0.295$), social function ($r = -0.433$), mental health ($r = -0.489$), role limitation emotional ($r = -0.525$), vitality ($r = -0.393$), mental component scale ($r = -0.538$), and physical component scale scores ($r = -0.501$). Additionally, no correlation was found between all subscales of SF-36, mental and physical component scale scores, GMFCS, and body involvement of CP in mothers with CP children ($P > 0.05$). A negative correlation was observed between the age level of mothers with CP children, and SF-36 subscales like physical function ($r = -0.255$), bodily pain ($r = -0.233$), and physical component scale scores ($r = -0.228$). No correlation was present between all subscale scores of SF-36 and GMFCS, body involvement of CP, educational status, level of income, and number of living children ($P > 0.05$).

TABLE 1: Sociodemographic data of CP children's mothers and controls.

	CP children's mothers (<i>n</i> = 137)	Controls (<i>n</i> = 140)	χ^2	<i>P</i>
Age (year)	35.96 ± 9.02	37.22 ± 8.91		0.254
BMI (kg/m ²)	27.35 ± 5.22	28.27 ± 5.01		0.135
Level of income (dollar/month)	612.97 ± 394.19	715.72 ± 771.99		0.165
Number of living children	2.75 ± 1.20	2.56 ± 1.27		0.229
BDI scores	18.29 ± 12.79	9.85 ± 7.34		<0.001
Type of family				
Core family <i>n</i> (%)	105 (76.6%)	99 (70.7%)	1.254	0.263
Combined family <i>n</i> (%)	32 (23.4%)	41 (29.3%)		
Educational status				
Illiterate	34 (24.8%)	35 (25%)		
Primary (8 years)	79 (57.7%)	73 (52.1%)	1.946	0.584
High school (11 years)	11 (8%)	18 (12.9%)		
College (12 years and over)	13 (9.5%)	14 (10%)		

BMI: body mass index. BDI: Beck Depression Inventory.

SF-36: 36-Item Short-Form Health Survey.

TABLE 2: SF-36 subscale scores in CP children's mothers and controls.

	CP children's mothers (<i>n</i> = 137)	Controls (<i>n</i> = 140)	<i>P</i>
SF-36-physical component	51.83 ± 23.10	56.52 ± 21.55	0.101
Physical function	59.10 ± 29.14	63.04 ± 25.16	0.169
Bodily pain	54.07 ± 33.32	56.85 ± 27.03	0.445
Role limitation physical	50.11 ± 39.24	53.53 ± 38.16	0.462
Health perception	44.08 ± 19.45	52.64 ± 21.92	0.001
SF-36-mental component scale	51.20 ± 24.49	65.63 ± 17.87	<0.001
Social function	52.33 ± 26.36	65.06 ± 20.30	<0.001
Mental health	53.62 ± 22.50	67.49 ± 19.90	<0.001
Role limitation emotional	45.44 ± 40.41	61.93 ± 37.36	<0.001
Vitality	53.39 ± 26.07	68.06 ± 19.96	<0.001

SF-36: 36-Item Short-Form Health Survey.

5. Discussion

In the literature, studies investigating HRQoL and related factors in mothers of children with CP report different findings. Some studies report that HRQoL of mothers with CP children is affected negatively [4, 9, 16–19]. While HRQoL of mothers is reported to be associated with depression [4, 16, 18, 19], anxiety [19], educational status [9, 19, 20], and functional levels [9], others assert that no correlation is present between HRQoL of mothers and functional levels of CP children [4]. In a study performed by Diwan et al. [16], 70% of mothers with CP children were reported to have mild-to-moderate depression, and the depression was reported to have a negative effect on HRQoL of mothers. Erdoganoglu and Gunel [9] reported that, HRQoL of mothers with CP children is affected at a higher rate, compared to fathers, and HRQoL is influenced due to motor and functional levels of CP children. In a similar study, Oneş et al. suggested that, HRQoL of mothers with CP children is affected negatively; HRQoL is negatively correlated with levels of depression and education in mothers, and no correlation is present between HRQoL and functional levels [4]. In their study, Bumin et al. [19]

emphasized that HRQoL of disabled children is associated with depression and anxiety levels, and a negative association is also present between HRQoL and mothers' educational status. Kaya et al. [17] reported that the deterioration of mental health in mothers with CP children gives rise to experiencing further low back pain by mothers, leading to more deterioration in HRQoL. In a study by Keller et al. [21], disability in children was reported to decrease social activities of mothers and to have an influence on routine deterioration.

Disability in a child, the basic component of a family, and accompanying challenges affect profoundly other members of the family and may be an intensive source of anxiety. In members of family having to take care of the disabled child all day and for ages, physical and psychosocial health is influenced in a negative way [9, 22]. As a result of cultural impacts in Turkey, mothers mostly take over the responsibility for disabled children and have to be interested in the challenges stemming from the disability alone for a long time. Therefore, we consider that physical and emotional health status of mothers is poorly affected. Present studies indicate that HRQoL of mothers of CP children is affected negatively, but the factors concerning HRQoL and related

TABLE 3: SF-36 subscale scores in those with depression (BDI ≥ 17) and without depression (BDI < 17) in CP children's mothers.

	BDI score < 17	BDI score ≥ 17	P
SF-36-physical component scale	63.01 \pm 20.68	40.15 \pm 19.53	< 0.001
Physical function	72.85 \pm 24.85	44.66 \pm 26.31	< 0.001
Bodily pain	64.29 \pm 31.50	43.40 \pm 32.0	< 0.001
Role limitation physical	64.93 \pm 36.94	34.63 \pm 35.64	< 0.001
Health perception	50.00 \pm 18.11	35.13 \pm 15.53	< 0.001
SF-36-mental component scale	63.04 \pm 21.78	37.91 \pm 20.00	< 0.001
Social function	62.97 \pm 23.02	41.22 \pm 25.14	< 0.001
Mental health	62.62 \pm 20.41	44.20 \pm 20.78	< 0.001
Role limitation emotional	64.36 \pm 37.26	25.67 \pm 33.74	< 0.001
Vitality	62.21 \pm 24.81	44.18 \pm 24.26	< 0.001

SF-36: 36-Item Short-Form Health Survey.
BDI: Beck Depression Inventory.

factors are controversial. In our study, it was determined that, as consistent with the literature, HRQoL especially mental components of mothers with CP children is definitely deteriorated, and high levels of depression affect negatively HRQoL of mothers. However, we could detect no association between HRQoL of mothers and functional level of CP children, body involvement of CP, educational status of mothers, level of income, and number of children.

We consider that comprehensive studies including numerous participants are needed to determine HRQoL of mothers with CP children and related factors. Our study includes several limitations. Firstly, our study involves no findings generalized to whole society in that it was a single-centered study. Another limitation is that only spastic-type cerebral palsied children were included into the study. In order to obtain more comprehensive results, mothers of children with ataxic, dyskinetic, and mixed involvements, as well as those with spastic-type, should also be included into studies.

In light of the literature and our findings, HRQoL of mothers with CP children is considered to be affected negatively. Therefore, in planning a rehabilitation program for CP children, HRQoL of mothers should also be evaluated in detail, as well as that of CP children, and as to problems defined, solutions should be produced. Additionally, mothers should be encouraged to take part in social activities related to their interests, and those with depressive symptoms should be supported psychologically. Therefore, it is considered that mothers, undertaking the most significant role in the rehabilitation and caring for the child, should be interested in CP children in a better way.

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