

RESEARCH PAPER

## Investigation of quality of life in mothers of children with cerebral palsy in Iran: association with socio-economic status, marital satisfaction and fatigue

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**Purpose:** This study aimed to compare the quality of life (QOL) of Mothers of Children with Cerebral Palsy (MCCPs) with mothers of Typically Developing (TD) children as a Control Group (CG). The association of the mediating variables including socio-economic status (SES), marital satisfaction and fatigue with maternal QOL was also evaluated. **Method:** The MCCPs group consisted of 120 mothers (mean age:  $30.3 \pm 5.5$  years) of children with CP. The CG included 100 mothers (mean age:  $29.9 \pm 4.5$  years) of TD children. Demographic characteristics of the participants were recorded and the data was collected by World Health Organization Quality of Life-BREF (WHOQOL-BREF), SES Questionnaire, Index of Marital Satisfaction (IMS) and Fatigue Severity Scale–Persian (FSS-P). Data analysis was done by SPSS version 16.0. **Results:** The QOL and SES were lower, while FSS-P and IMS were higher in MCCPs group than CG ( $p < 0.001$ ). The SES, IMS and FSS-P associated with all domains of QOL in MCCPs group, while they did just with some domains of QOL in CG ( $p < 0.05$ ). **Conclusions:** The lower QOL in MCCPs group is supposed to be mediated by the SES, marital satisfaction and fatigue so, maternal empowerment in terms of these mediators and family-centered approach are recommended.

**Keywords:** cerebral palsy, fatigue, Iran, marital satisfaction, mothers, quality of life, socio-economic status

### Introduction

The birth of a child with developmental disability is a family stressor and mothers often feel guilty and sense of responsibility more than the other family members; hence, they involve in compensation strategies to overcome their

### Implications for Rehabilitation

- The mothers of children with CP compared to mothers of typically developing children face particular challenges relating to rearing the child with disability.
- These tedious and chronic challenges influence on QOL, socio-economic status, marital satisfaction and perceived fatigue in mothers of children with CP.
- The QOL of mothers of children with CP seems to be exacerbated by factors such as lower SES, marital dissatisfaction and higher perceived fatigue.

children's disability [1]. Cerebral palsy (CP), a developmental disorder, might require extensive care-giving even into adulthood. Impaired motor function, the hallmark of CP, might be accompanied by sensory and intellectual impairments and limitations in self-feeding, bathing, toileting, dressing and mobility that these limitations may exacerbate the QOL of the child and his or her parents [2,3].

Although care-giving a child is an innate role of parents, providing the care for a child with long-term functional limitations is completely different and impacts all aspects of parent's health such as physical or psychological health [4]. Caring for a child with CP can negatively impact on parents, in terms of demands on physical health, disrupted sleep, difficulty in maintaining social relationships, pressure on marital relationships, difficulty in taking family holidays, limited freedom, limited time, a child's long-term dependence, difficulty in maintaining maternal employment, financial burden, difficulty in accessing funding and insufficient support from services [5]. A Canadian population-based study demonstrated that caregivers of children with CP

reported more emotional, cognitive and physical problems than the general population [6]. In the study of Ones and his colleagues [7], mothers of children with CP (MCCPs) had depressive symptoms and lower quality of life (QOL).

The QOL Impairment in families of children with severe disabilities is likely to be moderated by a complex mixture of variables such as socio-economic status (SES), social support, parents and child characteristics and coping strategies [5]. A study of Norwegian parents of children with CP found that parental QOL was most related to marital satisfaction, and secondarily related to the amount of care the child required [8]. Another study relating to marital satisfaction, expressed that greater father participation in child care was associated with greater marital satisfaction [9]. Furthermore, parents of children with developmental disabilities experience impaired physical functioning, tiredness or exhaustion [10,11]. It seems that the perceived fatigue could associate with maternal QOL. There are some literature about fatigue and marital satisfaction in mothers of children with developmental disabilities [12–16] but to our knowledge, the literatures about parents of children with CP are lacking in this regards.

To sum up, there are lots of literatures about MCCPs in terms of depression, stress and QOL, but most of them are related to developed countries. Iranian parents may experience a different parental stress, social support, life style and SES, as it is uniquely different culture, so the present study assumed necessary. Since, the lower QOL in mothers of children with disabilities has been verified in lots of literatures, we decided to find out the influencing factors relating to maternal QOL. In this study, we considered the mother's related factors and the child's related factors such as severity of the problem, type of CP and child's behavioral problems have been considered in another study by authors. The aim of our study was (i) to determine the QOL, SES, IMS and FSS-P in MCCPs compared to CG and (ii) to examine the association between the SES, IMS and FSS-P with four domains of QOL in two groups.

## Methods

### Participants

The goal population was all mothers of children with CP aged 2–14 years in city of Tehran. The MCCPs group consisted of 120 mothers (mean age:  $30.3 \pm 5.5$  years) of children with CP (mean age:  $5.3 \pm 3.1$  years). The participating children of the MCCPs group were recruited through convenience sampling from regular and special schools, diagnostic clinics, rehabilitation centers and announcements in Tehran. At entry into the study, the MCCPs group met four criteria: (i) Their children had received a diagnosis of CP; (ii) The age of their children, ranged from 2 to 14 years; (iii) Give written consent to participate; and (iv) Reside in Tehran. Exclusion criteria were: (i) Unwilling to continue the study; (ii) Any acute changes in health condition or experience of traumatic events, for example dying a close relative, in last two weeks ending to study; and (iii) Questionnaires missing more than 20% of data, missing Q1 or Q2 items or missing more than two items from the domains of World Health Organization

Quality Of Life-BREF (WHOQOL-BREF) (more than 1 for social relationships domain).

The CG included 100 mothers (mean age:  $29.9 \pm 4.5$  years) of TD children (mean age:  $5.2 \pm 2.9$  years). The TD children were recruited from nursery and elementary schools. The inclusion criteria for the CG consisted of: (i) Their children should had the same age to those in MCCPs group; (ii) Their children had no mental, developmental, or physical disabilities according to school medical records and were not receiving ongoing prescription medication; (iii) Resided in the same local communities as MCCPs group; and (iv) Give written consent to participate. The exclusion criteria were the same as the MCCPs group.

### Procedure

This cross sectional study conducted at Vali-Asr Rehabilitation Institute in Tehran, from August 2009 to January 2010. At the first step of project, the children of potential participants were evaluated. The participating children with CP were evaluated by pediatric neurologist to verify their diagnosis. The type of CP was assigned as four forms including: (i) spastic Diplegia, (ii) Spastic Quadriplegia, (iii) Spastic Hemiplegia and (iv) Dyskinetic. The severity of motor disability was classified into five categories based on the Gross Motor Function Classification System (GMFCS) [17]. A cover page, gave information about the study, brief instructions and an example of how to respond to the questions. Then, demographic information including age, educational level, marital status, child's age and gender were recorded. All participants completed the WHOQOL-BREF and FSS-P questionnaires and the married ones filled out the IMS. At the final step, the SES questionnaire was completed by a social worker through face-to-face interview with every participant.

### Instruments

The maternal QOL was assessed by WHOQOL-BREF. It is a 26-item instrument, consisting of four domains: physical health (7 items), psychological health (6 items), social relationships (3 items) and environmental health (8 items); and two overall QOL (Q1) and general health (Q2) items. The physical health domain includes items on mobility, daily activities, functional capacity, pain and sleep. The psychological domain measures self-image, negative thoughts, positive attitudes, self esteem, mentality, learning ability, memory, concentration, religion and the mental status. The social relationships domain contains questions on personal relationships, social support and sex life. The environmental health domain covers issues related to financial resources, safety, social services, living physical environment, opportunities to acquire new skills, knowledge, recreation, general environment (noise, air pollution, etc.) and transportation. The scores are transformed to reflect 4–20 for each domain, so that higher scores corresponding to a better QOL [18]. There is no overall score for the WHOQOL-BREF. The questionnaire had been translated to Farsi language, and its psychometric properties had been tested [19]. In test-retest analysis, the IntraClass Correlation Coefficient (ICCs) for the four domains, were within the range of acceptable values (physical health = 0.77; psychological health = 0.77; social relationships = 0.75; and environmental health = 0.84).

The socio-economic status was investigated by Iranian constructed of SES questionnaire. The questionnaire revealed well internal consistency reliability (Cronbach's  $\alpha = 0.89$ ) [20]. It consisted of four domains including educational level, occupational status, income and housing situation. The highest completed education of mothers was considered as educational level. The occupational status and income level of both parents were calculated. The type, size of housing and the total number of rooms, were also used as housing situation. After adding up the scores of each domain, each participant was categorized into five SES categories including low, low-middle, middle, middle-high and high. The questionnaire was filled out by social worker in rehabilitation clinic, through face-to-face interview with every participant.

The marital satisfaction was evaluated by IMS questionnaire that was designated by Walter W. Hudson, 1993. We used its Persian version, which translated and validated for Iranian population. It received well reliability (Cronbach's  $\alpha = 0.97$ ) and diagnostic validity (0.68) [21]. It consists of 25 items presented on 7-grade scale. The final score of IMS is obtained, through summing up item points. The range of possible total score is from 0 (maximal satisfaction) to 100 points (minimal satisfaction). The higher the score, the more dissatisfaction with the relationship is indicated. Clinically significant marital dysfunctions are diagnosed at 30 points and more (cut-off point) [14].

The amount of perceived fatigue was evaluated by FSS-P questionnaire. It consists of 9 questions that require the subject to assign a number from 1 (completely disagree) to 7 (completely agree), to rate his or her own level of fatigue so that, a higher score implies greater fatigue. It has been translated to Farsi language and validated for Iranian population. The internal consistency reliability (Cronbach's  $\alpha$ ) for the FSS-P total score was 0.96. Test-retest reliability (ICC) was 0.93 for the FSS-P total score. The score equal or more than 5 was considered as high fatigue cut-off point [22].

### Data analysis

All statistical analyses were computed by using the Statistical Package for Social Sciences (SPSS Version: 16.0, SPSS Inc, USA). Descriptive information was presented in tables and diagram.  $\chi^2$  test was used to reveal significant differences between two groups in terms of SES, mother's educational level, marital status, marital dissatisfaction and high fatigue. Independent sample T test was run to identify any significant differences between MCCPs group and CG in terms of the IMS, the FSS-P and maternal QOL. Multivariate analysis was performed using the linear regression analysis (enter model) to identify the relationships between domains of QOL and SES, IMS and FSS-P; where QOL domain scores were considered as dependent and SES, IMS and FSS-P as independent variables. Significance level  $p < 0.05$  was considered as statistically significant.

### Ethics

The study was approved by ethical committee of Vali-Asr Rehabilitation Institute, Tehran. All included participants filled out the written consent form to participate in the study.

## Results

Among the 181 potential participants of MCCPs group, 40 mothers did not meet the inclusion criteria, constituting a drop-out rate of 22.1%. Of the 141 included participants, 21 mothers excluded according to exclusion criteria as following: not responded the questionnaires ( $n = 21$ ), missed data ( $n = 6$ ) and experienced an acute problems or traumatic events during last two weeks ending to study ( $n = 4$ ). The distribution of children with different CP subtypes were: (i) spastic Diplegia (46.7%), (ii) Spastic Quadriplegia (24.2%), (iii) Spastic Hemiplegia (17.5%) and (iv) Dyskinetic (11.7%). The five categories of GMFCS were: I (15%), II (7.5%), III (35%), IV (15%) and V (27.5%). Of the 130 potential participants in CG, 18 participants did not include according to inclusion criteria, constituting a drop-out rate of 13.8%. Of the 112 included participants, 12 mothers excluded as following: not completed the questionnaires ( $n = 5$ ), missed data ( $n = 4$ ) and reported acute problems or traumatic events ( $n = 3$ ).

Demographic characteristics of participants are illustrated in Table I.  $\chi^2$  test showed significant differences between two groups in terms of Marital dissatisfaction and High fatigue ( $p < 0.001$ ), but no significant differences in terms of child's gender, mother's educational level and marital status ( $p > 0.05$ ). The SES categories between two groups are shown in Figure 1.  $\chi^2$  test revealed significant difference between two groups ( $p < 0.05$ ) so that the MCCPs group had lower SES categories than CG.

The average amount of marital satisfaction and fatigue among participants are shown in Table II. Independent sample T test showed lower marital satisfaction as well as higher level of fatigue in MCCPs group than CG ( $p < 0.001$ ). Comparison of QOL between MCCPs and CG by Independent sample T test, revealed a significant difference between them in terms of all domains of QOL, Overall perception of quality of life (Q1) and Overall perception of Health (Q2) ( $p < 0.001$ ) (Table II).

The association of the SES, IMS and FSS-P with four domains of QOL by linear regression is shown in Table IV. According to results, the SES associated with all domains of

Table I. Demographic characteristic and the significant differences between participants in two groups.

Variable	MCCPs	CG	p value
	n = 120 (%)	n = 100 (%)	
Child's gender (boy/girl)	60/60	51/49	NS
Marital dissatisfaction <sup>a</sup>	36 (35.3)	15 (16.1)	<0.001
High fatigue <sup>b</sup>	27 (22.5)	6 (6.0)	<0.001
Marital status			
Married	102 (85.0)	87 (87.0)	NS
Divorced	16 (13.3)	11 (11.0)	
Widow	2 (1.7)	2 (2.0)	
Educational level			
Primary	31 (25.8)	26 (26.0)	NS
Secondary	66 (55.0)	39 (39.0)	
University	23 (19.2)	35 (35.0)	

CG, control group (mothers of typically developing children); MCCPs, mothers of children with cerebral palsy, NS, not significant.

<sup>a</sup>IMS score  $\geq 30$ .

<sup>b</sup>FSS-P score more than 5.



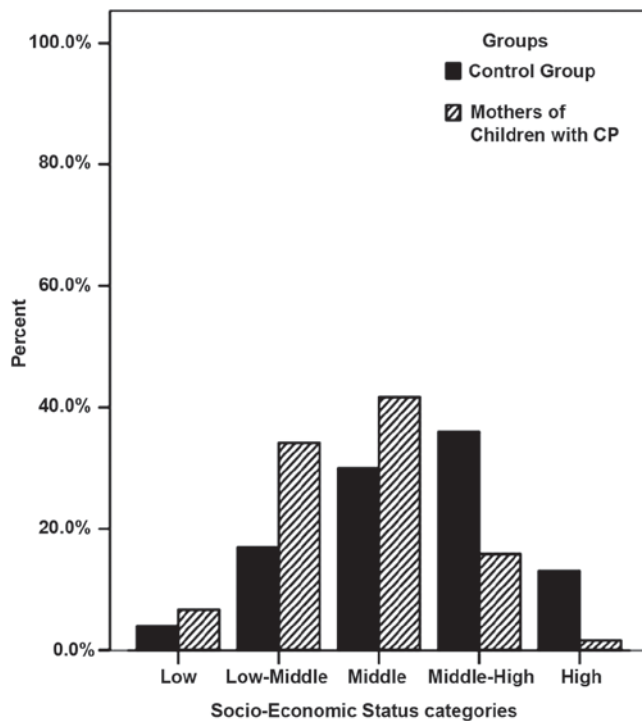


Figure 1. Distribution of participants among different Socio-Economic status categories in two groups.

QOL in MCCPs group and it had the most association with environmental domain ( $p < 0.001$ ), whereas it just associated with environmental domain of QOL in CG ( $p < 0.05$ ). Despite negative association of IMS with all domains of QOL in MCCPs group ( $p < 0.001$ ), it just related to psychological and social domains of QOL in CG. The negative association means increasing the IMS score result to decreased QOL. FSS-P associated reversely with all domains of QOL (especially the physical and psychological domains) in MCCPs group, while it just related to physical and psychological domains of QOL in CG. The reverse association means increasing the FSS-P score result to lower QOL.

## Discussion

Results of this study showed lower QOL in MCCPs group than CG. This result supported our hypothesis and it was consistent with the previous studies [5,23–30]. MCCPs have too much problems in carrying their children, because there is not proper transportation system, suitable wheelchair and special assistive technologies in Iran. The health-care demands of the disabled child such as frequent visits to physiotherapy or occupational therapy, arrangement for the purchase of aids or appliances, take a toll on the routine activities and leave little time for family leisure. Most of them (especially the people from lower SES categories) also do not have enough money to purchase proper equipment, and to pay for rehabilitation services. Furthermore, child behavioral problems are the most important predictor of caregiver psychological well-being [31]. Children's temperament has been related to feelings of depression in the caregivers and to decreased QOL in mothers of children with disabilities [32]. The severity of a child's

disability has been linked to family functioning including marital quality, parenting stress and social support [4,33]. In addition to above mentioned reasons, the lower level of SES, higher amount of marital dissatisfaction and higher level of perceived fatigue in MCCPs, as it showed in our study, could deteriorate the maternal QOL. Finally, there are some more possible factors that might affect the QOL of Iranian parents such as: (i) Lack of reimbursement of rehabilitation costs by insurance companies; (ii) No existence of any governmental or non-governmental agencies to deliver respite care to parents for decreasing caregiver burden; and (iii) No specific and comprehensive attention, by professionals and health policy makers, paid toward the family as a whole.

Another result of our study was significant attribution of MCCPs to lower SES categories. This finding is concordant to some studies that report a socio-economic gradient for CP [34–37]. The SES had also significant relationship with all domain of QOL especially the environmental domain, which supported our hypothesis. Raina et al. [4] reported that contextual factors such as SES, has been associated with psychological or physical wellbeing of parents and higher SES has been related to fewer psychological life stressors; better emotional well-being in caregivers; fewer child behavior problems; fewer care-giving demands; and improved psychological and physical health. However, Blacher et al. [38] reported that, SES may not serve as a buffer against depression in the presence of specific stressors such as intellectual disabilities. The accessibility to free transportation services in western families may further decrease the impact of SES on parental QOL. Most parents also receive a monthly financial grant to compensate for expenses, which may decrease extreme stress and financial burden in families from the lowest SES groups. Since the SES had most relationship with environmental domain of QOL and none of these services exists in Iran, the QOL of parents from lower SES groups might be more affected. It is suggested to governmental and non-governmental agencies to concentrate on empowerment of these susceptible groups, in terms of social and financial support.

The results also showed the association of marital satisfaction with maternal QOL (especially the social domain). The amount of marital dissatisfaction among MCCPs group was significantly higher than CG. Laskar et al. [39] revealed that conflicts among the family members arising from the burden of rearing a disabled child and often these conflicts lead to marital problems. Marital dissatisfaction may stem from the tension of having an abnormal child or sexual dissatisfaction. The mothers of children with disabilities spend too much time for child care and eventually less time for intimacy, companionship and privacy in the marriage [40]. Father's support, in terms of verbal expression, has been shown to serve as a predictor of the course of care and perceived availability of support for the mothers [41]. Hostility of husband has been showed significantly higher in families with disabled children [42]. When marital dissatisfaction occurs, the potential emotionally as well as physically supports won't be delivered by fathers. For some mothers, their spousal relationship may be their primary support mechanism; so many mothers find themselves isolated from other social supports [43]. So, as

Table II. Comparison of Fatigue Severity Scale–Persian and Index of Marital Satisfaction scores between participants in two groups using Independent sample T test.

Variable	MCCPs (mean ± SD) (n = 120)	CG (mean ± SD) (n = 100)	Mean difference	95% CI of difference	T statistic	p value
FSS-P <sup>a</sup>	4.20 ± 1.01	3.20 ± 1.22	-1.00	(-1.29, -0.69)	-6.584	<0.001
IMS <sup>b</sup>	25.73 ± 21.55	11.56 ± 10.66	-14.17	(-19.05, -9.30)	-5.735	<0.001

CG, control group (mothers of typically developing children); MCCPs, mothers of children with cerebral palsy.

<sup>a</sup>Fatigue Severity Scale–Persian (higher score = higher perceived fatigue).<sup>b</sup>Index of Marital Satisfaction (higher score = lower marital satisfaction).

Table III. Comparison of quality of life between MCCPs and CG using Independent sample T Test (n = 220).

	MCCPs (mean ± SD) (n = 120)	CG (mean ± SD) (n = 100)	T statistic	p value
WHOQOL-BREF				
Q1	3.05 ± 0.74	3.46 ± 0.73	4.008	<0.001
Q2	2.95 ± 0.83	3.53 ± 0.78	5.292	<0.001
Physical	12.15 ± 2.56	14.17 ± 2.36	6.052	<0.001
Psychological	11.93 ± 2.34	14.10 ± 2.13	7.199	<0.001
Social	12.71 ± 3.62	14.69 ± 2.61	4.564	<0.001
Environmental	11.36 ± 2.89	13.55 ± 2.20	5.846	<0.001

CG, control group (mothers of typically developing children); MCCPs, mothers of children with cerebral palsy; Q1, overall perception of quality of life; Q2, overall perception of health.

Table IV. The association of maternal QOL with Socio-Economic Status, Index of Marital Satisfaction and Fatigue Severity Scale–Persian in two groups by linear regression (n = 220).

Variables	QOL domains	MCCPs		CG	
		β coefficient	p value	β coefficient	p value
Socio-Economic Status	Physical	0.166	0.023	0.063	0.440
	Psychological	0.180	0.020	0.092	0.329
	Social	0.182	0.019	0.065	0.404
	Environmental	0.452	<0.001	0.236	0.017
Index of Marital Satisfaction	Physical	-0.548	<0.001	-0.159	0.062
	Psychological	-0.514	<0.001	-0.347	<0.001
	Social	-0.766	<0.001	-0.603	<0.001
	Environmental	-0.428	<0.001	-0.183	0.066
Fatigue Severity Scale–Persian	Physical	-0.695	<0.001	-0.547	<0.001
	Psychological	-0.464	<0.001	-0.436	<0.001
	Social	-0.276	0.002	-0.154	0.070
	Environmental	-0.304	0.002	-0.161	0.065

CG, control group (mothers of typically developing children); MCCPs, mothers of children with cerebral palsy.

a consequent of marital dissatisfaction, the QOL could be affected. Therefore, focusing on child as a client is not sufficient and the whole family members should be covered in a family-centered approach. Psychological consultation toward increasing marital satisfaction is also recommended.

Another result of our study revealed significant higher experience of fatigue among MCCPs group and the association of fatigue with maternal QOL. Unfortunately, there is dearth of literature about the fatigue in this group. Kaya et al. [26] showed higher significant bodily pain in MCCPs group. As we mentioned, caring a child with CP take lots of time and energy so, the mothers need a break for recovery. Lack of respite care and little spousal support as well as the endless demands of child, force them to continue in spite of the

chronic fatigue. Although, the perceived fatigue looks mostly physical, it could be psychological too. Thus, this prolong fatigue may deteriorate their QOL, especially the physical and psychological domains.

This study had several limitations including: (i) the sample size could have been more if there was a comprehensive registry center for caregiver's data collection, and (ii) The QOL of mothers was only measured by the WHOQOL-BREF questionnaire, and no physical examination or review of the medical records of the mothers was performed. There are also a number of strengths for this study: (i) this study was the first one conducted about QOL of mothers of children with CP in Iran, and (ii) we investigated about the SES, marital satisfaction and fatigue in our sample that has been overlooked in many literatures.

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