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Original Article (Pages: 5677-5685)

Comparison of Health-Related Quality of Life in Mothers of Children with Spina Bifida and Cerebral Palsy

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Abstract

Background

Spina bifida (SB) is the most common abnormalities in neural tube defects in Iran. The aim of this study was to assess health-related quality of life in mothers of children with spina bifida and to compare their quality of life with mothers of children with cerebral palsy (CP).

Materials and Methods

Two-hundred and three mothers were recruited using the convenience sampling strategy in a cross-sectional study. Quality of life (QOL) in mothers was assessed using a validated Persian version of 36-item Short Form Health Survey questionnaire according to the different levels of Hoffer criteria and types of Spina Bifida of their children. Also, the quality of life of mothers in this study was compared with data on Iranian healthy women and Iranian mothers of children with cerebral palsy.

Results

This study showed that the Sf-36 scores were significantly different between mothers having Spina Bifida children of different levels of Hoffer criteria and Spina Bifida types in terms of mean of physical component summary and mental component summary scores of SF-36 ($P<0.001$). In mothers of children with Spina Bifida, the mean SF-36 scores were 27.70 $\pm$ 35.25 that reduced scores than those in the general population (66.5$\pm$ 39.1). There was no difference between QOL of mothers of children with SB and children with CP ($P>0.05$).

Conclusion

This study indicated that mothers of children with Spina Bifida suffer from poor quality of life similar to mothers of children with cerebral palsy, and should create supportive strategies for the physical and psychological aspects of their quality of life.

Key Words: Disabled children, Health status, Mothers, Spinal dysraphism.

*Please cite this article as: Dalvand H, Dehghan L, Hosseini SA, Feizi A, Kalantri M. Comparison of Health-Related Quality of Life in Mothers of Children with Spina Bifida and Cerebral Palsy. Int J Pediatr 2017; 5(9):5677-85. DOI: **10.22038/ijp.2017.23670.2000**

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Received date: Jun.13, 2017; Accepted date: Jul.12, 2017

1- INTRODUCTION

Spina bifida (SB) is a malformations of the vertebrae that accompanied by malformation of spinal cord, the meninges and the lower parts of the brain (1) which causes lifelong disability from mild to severe. The squeal of SB includes decreased mobility, bladder and bowel incontinence, and neurosensory disabilities (2). Practically all children with SB, similar to other children with other types of disabilities, grow up with their families. Due to burdens caused by physical disabilities of children with SB, mothers play a vital role in caring for these children and confront various responsibilities to perform their activity of daily living, therefore they likely experience depression and distress more than parents of normally developing children (3-5) or even children with other types of disabilities. Providing adequate care for a child with long-term functional limitations change the quality of life (QOL) of mothers over time and need to receive attention and supportive care if necessary (6). The result of a systematic review suggested that caregivers of SB undergo the multitude of issues, including physical and psychosocial problems (7).

World-wide incidence of SB ranges from 0.3 to 4.5 per 1,000 live births (2, 8). In Iran, there is information on incidence of neural tube defects ranges from 2.97 to 6.2 per 1,000 live births (9, 10) that most common abnormalities is SB, which is higher than other countries. Furthermore, according to Razavi Afzal et al. (2013) in Iranian culture, mothers of children with disability are the person primarily responsible for child caring (11) and this is likely to be harmful to both the physical and mental health of them. Compared to the amount of the studies which have been done on the different aspects of SB and parental impacts in might have in the developed countries, there is an obvious shortage of the studies in the Middle Eastern and less developed counties. It would appear that there are no studies that have addressed QOL of mothers of children with SB in Iran. Thus, in the present study using a validated Persian version of 36-item Short Form Health Survey (SF-36) questionnaire, we determined the extent of impairment of QOL in a sample of Iranian mothers of children with SB and compared specific aspects of alterations in QOL in mothers of children with SB with QOL of general sample of Iranian women (12) and mother of children with cerebral palsy (CP) (13); also examined the extent to which QOL is explained by various clinical indices, namely levels of Hoffer criteria and SB type of their children.

2- MATERIALS AND METHODS

2-1. Study design and Participants

In a cross-sectional study, 203 mothers of children with SB that captured our study's inclusion criteria were recruited consecutively among those who referred to different clinics affiliated to University of Social Welfare Rehabilitation Sciences (USWR) in Tehran, Iran, in 2014 to 2015, during 11 months. Sample size in our study was determined considering type one error rate =0.05, standard deviation for quality of life variable =5 and possible sampling error rate=0.7; resulted 196 participants, finally 203 people were recruited. We included a sample of mothers of children who had the following inclusion criteria: caring for a child aged less than 18 years with SB without any mental and emotional disability or physical disease such as rheumatoid arthritis and lupus. Caring for more than one child with disability was exclusion criteria the study. The Ethical Committee of USWR approved the study protocol (ID code: 90/801/T/1/21481) and all participants were informed about study objectives and their written and signed informed consents were obtained.

2-2. Study instrument and variables assessment

Data were collected using validated Persian version of the SF-36. The SF- 36 is a generic instrument that has commonly been used in psychometric measurements. The SF-36 has 8 scales: physical function, role physical, bodily pain, general health, vitality, social function, role-function emotional, and mental health. It can also be summarized into 2 component scales; the Physical Component summary score (PCS), and the Mental Component summary score (MCS). Scores on each scale range from zero to 100, with zero representing the worst Health Related QOL and 100 representing the best possible score (14).

This instrument already validated and translated into Persian and the reliability of the Persian version of SF-36 was confirmed with Cronbach's alpha of 0.72 to 0.94 and convergent validity with correlation coefficient (r) of more than 0.40 (12). The QOL of recruited mothers was assessed with SF-36 by a qualified independent assessor who was not directly involved in the study.

Functional mobility of SB was classified according to the Hoffer criteria (15) as shown in **Table.1**. Children who walked outdoor (n=15), were defined as community walker. Children who walked indoor but could use a wheelchair for long distances outdoors (n=100) were defined as Household walker. Children with some walking function indoors or standing ability (n=52) were defined as Exercise walker (15).

Similarly, the other objective assessment was used to assign various types of SB according to severity of defects (Spina bifida occulta and Spina bifida cystic). The three types of Spina bifida cystic are meningocele, meningomyelocele, and myeloschisis (1). However, due to not getting myeloschisis, this division was excluded from the study. The assessment protocols were performed for each participant. The distribution of SB subtypes was specified by a pediatric neurologist, and an occupational therapist categorized all subjects according to Hoffer criteria in the rehabilitation clinics affiliated to USWR.

Table-1: Scoring of ambulation based on Hoffer criteria (15)

Score	Level	Definition
1	Community walker	Ambulating outdoors with or without braces, but using wheelchair for longer distances
2	Household walker	Using braces or crutches for indoors and using wheelchair outdoors
3	Exercise walker	Walking only in therapeutic situations
4	Non-walker	Wheelchair-dependent

2-3. Comparison groups

The data on the QOL of mothers in this study was compared with data on Iranian women (n = 2166) in a large population-based study (12), and with QOL of Iranian mothers of children with CP (n =424), in a cross sectional study during 2012 in Tehran (13). CP is a chronic developmental disability with serious impairments in motor control some of them as well have cognitive, intellectual delays, seizures or secondary musculoskeletal problems (16).

2-4. Statistical analysis

Obtained quantitative data were expressed as mean ± standard deviation (SD) while

qualitative variables as number (percentage). Normality of study's variables was evaluated using Kolmogrove-Smirnove (K-S) statistical test and for multivariate homogeneity of variance Box' M test was used. One sample multivariate Hotteling T^2 was used for comparing the mean scores QOL of participants with the counterpart values of the Iranian general population and the mothers of children with CP. Multivariate analysis of variance (MANOVA) was used for comparing the physical and mental scores of QOL in terms of Hoffer's ambulation levels and type of SB. All statistical analyses were done using SPSS version 16.0 statistical software (SPSS Inc, Chicago, IL).

3- RESULTS

The sample of this study consisted of 203 mothers of children with SB with mean age 35.33 (SD = 6.57). Demographic data of participated mothers of children with SB and their children are shown in **Table.2**. As it is illustrated, the majorities of such participants were householder (94.1%), and had one child (61.1%). More prevalent SB type were meningocele (72.4%) and level 2 and 3 of Hoffer criteria consisted of majority of participants i.e. 49.3% and 25.6%, respectively.

3-1. Comparison with an Iranian normal women population

The results of multivariate one-sample Hotelling T^2 was used for comparing the mean scores of different subscales of SF-36 in current sample with counterpart values of Iran's women population. The total mothers of children with SB sample were characterized by significantly reduced scores in all aspects of QOL compared with a healthy reference group ($P<0.01$) (**Table. 3**). Mothers of children with SB reached a minimum mean SF-36 score in physical role functioning of only 27.70 compared with 66.5 in the normal woman population from the total score of (**Table.3**).

3-2. Comparison with mothers of children with CP

No significant differences were seen between QOL mothers of children with SB and mothers of children with CP (**Table.2**). Furthermore, mothers of children with CP had little more scores in 8 scales (physical function, role physical, bodily pain, general health, vitality, social function, role-function emotional and mental health) than the mothers of children with SB (**Table.3**).

3-3. Relation between different level of Hoffer criteria and type of SB and QOL

Descriptive findings from different domains of SF-36 are given in **Table.3**. As can be seen from **Table.4**, based on MANOVA's results, the mean scores of PCS and MCS scores of QOL ($P<0.001$) were significantly different between mothers having children with different levels of Hoffer criteria. Tukey's test was used as post hoc pairwise comparisons statistical test; its results showed that the observed overall differences were related to community walker level from other levels of Hoffer criteria. This finding indicates that mothers having children with lower level of problem were at higher levels of QOL. No statistically significant differences were found in the mean PCS and MCS scores of QOL among mothers having children in different age groups (**Table.4**). Comparing the QOL of mothers having children with different types of SB showed that the differences were statistically significant in terms of PCS and MCS scores of QOL ($P<0.001$). Post hoc statistical test showed that the observed differences were related to mothers having children suffering from occulta from those who have children with meningocele and meningomyelocele.

Table-2: Demographics and clinical characteristics of the study participants (n=203)

Demographic characteristics of mothers of children		Number (%) or mean ± SD
Age, years (mean ± SD)		35.33 ± 6.57
Education	Illiterate	3 (1.5%)
	High school	62 (30.5%)
	Diploma and associate degree	107 (52.7%)
	Bachelor's degree or higher	31(15.3%)
Job	Householder	191 (94.1%)
	Part time	-------
	Full time	12 (5.9%)
How many children does she have?	1	124 (61.1%)
	2	49 (24.1%)
	3	30 (14.8%)
Demographic and clinical characteristics of children		Number (%)
Gender	Girls	81 (39.9%)
	Boys	122 (60.1%)
Age, years (mean ± SD)		7.37 ± 3.41
Type of SB	Occulta	17 (8.4%)
	Meningocele	147 (72.4%)
	Meningomyelocele	39 (19/2)
Hoffer criteria	1	15 (7.4%)
	2	100 (49.3%)
	3	52 (25.6%)
	4	36 (17.7%)

SB: Spina bifida; SD: Standard deviation.

Table-3: Mean of SF-36 scores the mothers of children with SB, mothers of children of CP and a general Iranian population (higher scores indicate a better condition)

Short Form-36 Subscales	SB group	General population *	CP group**	P-value***
Physical Functioning	51.62±25.18	82.9 ± 22.1	55.35±24.76	.082
Physical Role	27.70±35.25	66.5 ± 39.1	29.59±34.96	.528
Bodily Pain	45.56±21.68	76.4 ± 26.2	47.40±22.34	.331
General Health	42.20±21.09	65.0 ± 20.8	43.58±21.95	.457
Vitality	40.44±1.90	62.9 ± 17.8	42.09±19.88	.323
Social Functioning	46.92±23.36	74.2 + 25.1	48.61±23.55	.399
Role Emotion	27.75±35.89	61.4± 42.4	29.24±36.78	.632
Mental Health	47.96±19.96	65.0 ± 18.6	49±20	.543
PCS	41.78±2.01	----	39.21±8.40	.083
MCS	40.76±1.89	----	41.23±9.97	.740

*Derived from a study by Montazeri et al. (2005); ** Derived from a study by Dehghan et al. (2014); *** P-value are related to comparing mean score QOL of mothers of children with SB with QOL mothers of children with CP. PCS: Physical component summary; MCS: Mental component summary.

Table-4: Result of MANOVA for comparing the mean scores of QOL of mothers of children with SB according to Hoffer criteria, age, type of SB

Short Form-36 scales			Mean ±SD	F*	P-value
PCS	Hoffer,s levels	1	72.61±1.25	15.421	<0.001**
		2	39.74±1.93		
		3	39.75±2.04		
		4	37.52±1.32		
MCS		1	63.76±2.04	9.052	<0.001**
		2	38.49±1.92		
		3	40.16±1.68		
		4	38.36±1.37		
PCS	Age	0-2	47.64±2.29	1.372	.245
		2-4	51.23±2.23		
		4-6	40.79±2.16		
		6-12	40.55±1.89		
		12-18	40.10±1.98		
MCS		0-2	32.27±2.31	.515	.725
		2-4	42.98±2.31		
		4-6	39.42±1.75		
		6-12	41.56±1.93		
		12-18	40.43±1.57		
PCS	Type of SB	Occulta	69.32±1.50	22.490	<0.001**
		Meningocele	40.49±1.96		
		Meningomyelocele	34.64±1.34		
MCS		Occulta	60.76±2.16	11.448	<0.001**
		Meningocele	39.04±1.87		
		Meningomyelocele	38.53±1.26		

*F values resulted from multivariate analysis of variance (MANOVA) test. **P <0.01; PCS: Physical component summary; MCS: Mental component summary.

4- DISCUSSION

The QOL of family caregivers of children with SB is an important topic, due to high incidence of SB in Iran. In our study, there was not any different between QOL of mothers of SB children with QOL of mothers of CP children, but there was significantly different in all aspects of QOL mothers of children with SB, compared with a healthy reference group. It means that a lifelong disability of child can affect negatively QOL of mothers and they, regardless of type of child's disability, appear to face a similar problem. These results are comparable with findings of other studies (17, 18). Civilibal et al. (2014) showed that mothers of children with SB had a lower quality of life in all the analyzed domains compared with mothers of healthy children. In our study, mothers of children with SB in the community walker level of the Hoffer criteria reported significant difference PCS and MCS scores SF-36 than other levels of Hoffer criteria. It means that QOL of mothers reduce along with increasing level of their children's disability. Another interesting finding of our study is that significant differences in PCS and MCS scores of SF-36 were found in QOL of their mothers between three types of SB. This significant difference was for type of occulta than types of meningocele and meningomyelocele. In occulta, the outer part of some of the vertebrae is not completely closed and the spinal cord does not protrude, but in meningocele and meningomyelocele, the unused portion of the spinal column allows the spinal cord to protrude through an opening and these

children suffer the severe complications (1). Therefore, these children are more independent to their mothers in many occupations compared to type of occulta. Overall, functional limitations in terms of levels of Hoffer criteria and type of SB can impair QOL of mothers of children with SB. Our finding is in agreement with several other study findings (19-22). QOL of the mothers of children with chronic condition were directly related to the child's condition, such as physical care and the child's psychological (20). Child-related factors such as poor walking ability and dependency on others to perform activities of daily living (ADLs) have been reported that affect negatively parental mental health (19). Grosse et al. (2009) reported that the intensive long-term care can negatively impact caregiver health and well-being and were also found for the caregiver's reports of lower Quality of well-being score, often feeling unhappy and depressed, fair or poor health, lack of leisure days, and not hosting friends (22).

Therefore, a holistic approach (level of ambulation and type of SB) is essential to monitor QOL of mothers of children with SB. The QOL of mothers of children with SB is complex and mediated through global perceived social support and supportive family relationships (23). However, Iranian mothers of children with disability such as SB have restricted access to supportive services, especially any functional social network and have difficulty accessing the social insurance that may allow them to stay healthy and improve your health (24). The national health plan should consider providing supportive systems for this population. Shifting from disability-focused services to more family centered services seems to be an important issue which needs to be considered by Iranian policy makers in the field of support and services for the children with developmental disabilities. To start such a change, the support and services provision should consider the children with special needs as a part of the family and consider their needs in the family context. Parental impacts should be considered, trusted and respected by professionals and; their different needs should be addressed (25). SB and other related conditions might have different types of impacts on various aspects of the family as a whole. This is in accord with latest ideas about disability. According to the International Classification of Functioning (ICF), Disability and Health, known more commonly as ICF (26) the notions of ‘health’ and ‘disability’ are put in a new light. The social aspects of disability are considered in the ICF’s definition of disability and it does not consider disability as a solely 'medical' or 'biological' dysfunction. One on the advantages of this study was to looking at the SB from mothers’ QOL perspective.

4-1. Limitations of the study

This study also had some limitations. One of the limitations was that the data only reflected the perspective of a group of selected mothers. Iran is a multicultural society and although there were parents with different ethnic backgrounds in this study, it was not representative of all Iranian ethnic groups and further studies in other areas of Iran with different parental groups may report some different findings. The other limitation was excluding fathers due to lack of the cases in the clinical settings. Therefore, influence of SB on fathers was not considered. Findings of the available literature on parental reaction on the child’s disabilities revealed different reaction (27). Research on the impact of taking care of a child with disabilities on fathers has been infrequent (28) and this is also true for the fathers of children with SB. Although the word "parents" is in the title of most of the available studies, the research often was undertaken exclusively with mothers, but recognizing fathers and their needs has received more attention in

the recent studies (29). This is recommended for further research studies on impacts of SB on family as a whole.

5- CONCLUSION

The study findings provided information on Iranian mothers of children with SB that there were significantly lower scores in all aspects of QOL than the healthy reference group. Furthermore, this study showed that there was no difference between QOL of mothers of children with SB and children with CP. It is evident that caring of children with SB is very difficult and has effects on QOL of their mothers, like mothers of children with CP. These need to be further investigated through more comparative studies in order to establish the similarities and differences in the way families are affected by caring for a child with SB in different societies. This information could provide valuable bases for policymakers and practitioners to offer more sufficient services and support within their countries. Therefore, policy makers, who play a crucial role in the health system, need to focus on the QOL of these people. It is our hope that the results of this survey will be added to the existing literature addressing QOL in mothers of children with SB in Iran, and perhaps more importantly, be used to provide better service to improve their QOL.

6- CONFLICT OF INTEREST

The authors had not any financial or personal relationships with other people or organizations during the study. So there was no conflict of interests in this article.

7- ACKNOWLEDGMENTS

We gratefully acknowledge all mothers of children with SB who agreed to participate in this study. Also, our thanks go to the University of Social Welfare and Rehabilitation Sciences, Tehran, for its official support.

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