

A Comparative Analysis on Quality of Life in Mothers of Autistic, Blind, and Normal-Functioning Children

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Abstract

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Background: Quality of life largely depends on one's perception about different aspects life. The present investigation aimed at comparing the quality of life of mothers with autistic, blind, or normal-functioning children. **Materials and Methods:** This cross-sectional comparative study was done in a population of 146 mothers of children who aged 6-15 years old, in Shiraz, within the period 2013-2014. Ninety six mothers had children who were either blind or autistic, while 50 had children with no disabilities. Participants were enrolled through multi-stage cluster sampling method. The Quality of Life (QoL) questionnaire-100 was employed to collect data and one-way ANOVA was used to analyze results. **Results:** Findings demonstrated a significant difference in QoL of mothers with autistic, blind, and normal-functioning children. Mothers with normal-functioning children had higher levels of QoL than those with blind kids. In addition, the QoL of mothers with autistic children was lower than the other two groups. **Conclusion:** Considering the importance of quality of life in mothers' life and subsequent family functioning, relevant programs need to be pursued to improve conflict resolution in distressed groups.

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Introduction

Family has always been considered as one of the key platforms to play a significant role in children's physical and psychological well-being. In fact, families are responsible for educating children, developing a healthy style of communication among family members, and helping children to experience independency(1). One of the threats for family members' mental health is the existence of physical or mental health conflicts, which indeed lead to significant levels of mental pressures on all family members. Despite people's various reactions upon confronting physical and mental disabilities, parents' behavior when facing such situations is

usually undesirable. However, depending on parents' character traits and other contributing factors, their reactions become different in terms of type and intensity(2).

Once parents find out about their children disability, all their hopes vanish and they start to face new difficulties. Coping with such a new challenging situation is especially crucial for mothers who are usually the first one to start interacting with the child. There are numerous families who suffer from difficulties of having a disabled child. On top of all challenges, families

need to accept the fact that this is going to be an everlasting health issue for their child (3).

Quality of life (QoL) is an expression about well-being, emotional, social and physical promotion, and the ability to perform daily activities. It is also related to illnesses and threatening conditions for well-being whereby a disabled child could place significant physical and emotional distress on families. Problems that women face in their lives not only affect their physical health, but especially influence family, society and even next generation's mental health. Hence, the study of QoL and women's health has long been at the center of researcher's attention. The present research was conducted to compare the QoL of mothers with autistic, blind, and normal-functioning children in order to find out the potential impact of children's disability on the QoL of their mothers. A psychologically healthy person is perhaps the one whose behaviors are balanced in the face of social issues. Accordingly, an individual's behavior is regarded as one single system through which reciprocal links between QoL and personal/social challenges are defined.

Through a systematic approach, a mutual relationship is also recognizable between biological, psychological and social factors. Family could also be regarded as a system in which a disabled child may cause parents to experience different levels of anxiety and psychological pressure. Different levels of distress are potentially due to new responsibilities that arise and ultimately cause difficulties in the family (4,5).

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), autism is regarded as one of the pervasive developmental disorders (ASD) characterized by three features including stable impairment in social interaction, qualitative impairment in communication, and restricted repetitive stereotyped patterns of behaviors. The onset of these features must be prior to age 3 years (6,7).

Based on the available evidence, almost 80% of children with ASD have limited disabilities to live independently because of their cognitive and adaptive limitations. Therefore, it is upon parents to devote time in helping children with their personal needs. Results from a longitudinal study on parents of children with developmental disabilities suggested that more than 50% of these parents take care of their disabled children in their 50's or even their older ages. The constant stress imposed on parents with autistic children could change their perception about parenting and consequently

decrease parents' level of optimism about future of their children and their own life (8-10).

Autism is characterized by abnormal development in social interaction and communication. Moreover, significant limitations in activities and interests, are among crucial yet less appreciated childhood psychological disorders. It is likely that various biological factors along with different social and psychological variables contribute to a wide spectrum of unusual behaviors in autistic children (11,12).

Vision impairment is a general term to describe inability to see, categorized from moderate disturbances (such as hyperopia or myopia) to severe and irreversible conditions, including blindness or severe sight weakness. Considering the fact that almost a third of the whole machinery of the sensory connection system is made of visual-related pathways, people could be described as visual beings. Hence, vision impairment causes people to experience disability ever more than loss of other sensory modalities (13-15).

Studies show that parents of blind or autistic children comparing to those whose children function normally not only experience more levels of anxiety and feelings of shame, but also have lower scores in psychological and general well-being performance parameters (9,10,12,13).

A study to compare the QoL of parents who had children with special needs and those with normal-functioning revealed a significant difference between social and environmental interactions sub-scale of quality of life questionnaire, while no significant difference was reported in the psychological and physical well-being sub-scales. In addition, results demonstrated a positive relationship between levels of children disability and parents' QoL. Those who had children with multiple disabilities acquired lower scores in the sections related to psychological and physical well-being (16).

In another comparative research on the QoL of parents of children with intellectual disability and those with normal-functioning children findings showed that parents of mentally-retarded children notably had lower levels of QoL (17).

In a research to study the QoL of parents whose children were suffering from high-functioning autism. Eighty nine of those parents were selected along with 46 parents whose children had normal functioning. Results revealed that the former group of parents had higher stress levels. In addition, they

had lower levels of happiness, self-esteem and QoL(18).

Another investigation was designed to study the effect of the training and support program on self-efficiency and psychological well-being of parents of children with disabilities. Findings revealed that such programs were essential for parents in terms of their psychological well-being (19,20).

Further investigations to study the features of well-being related to QoL of parents whose children were normal-functioning, afflicted with asperger syndrome or high-functioning autism. Results confirmed lower levels of emotional well-being in latter groups (18,21).

In a former research, Joyce et al studied the impact of respite care on parents' perceptions of quality of life. Findings showed that parents of children who were not receiving respite care, experienced more levels of anxiety and psychological pressures as compared to parents whose children were provided with respite care (22).

In addition, the study of Mugno et al showed that mothers of children with ASD compared to three different groups of mothers including those whose children were only suffering from intellectual disability, those who had children with cerebral palsy, and mothers of normal-functioning children, had higher levels of anxiety and experienced lower QoL(23).

Taken the existing evidence into account, we hypothesized a difference between QoL of mothers with blind, or autistic children as compared to the QoL of mothers of normal-functioning children.

Materials and Methods

The current cross-sectional comparative study was designed to compare the QoL between mothers of normal-functioning children and those whose children were autistic or blind. Normal-functioning child, in this study, refers to subjects who did not suffer from any specific physical or psychological disorders including intellectual disability, learning disorders and visual or hearing compromise. The study population comprised mothers of autistic, blind and normal-functioning students between ages 6-14 years who were studying in Shiraz in 2013-14.

The sample consisted of 146 individuals including 96 and 50 mothers of autistic or blind, and normal-functioning students, respectively. Convenience sampling method was used to choose mothers of blind and autistic students, though mothers of normal functioning children were enrolled through multi-stage cluster sampling method. The World Health Organization Quality of Life (WHO-QoL) questionnaire, which comprises 100 questions, was employed for data collection. In order to select participants, a center of education for blind individuals, five educational institutions for autistic children, a primary and a secondary school were selected. Institutions for autistic children were in the areas divided by the Education Center for Exceptional Children in Shiraz and the schools were located in the areas divided by the Education Center for Normal Students in Shiraz. Selected mothers were then asked to fill out the questionnaire.

The WHO-QoL-100 questionnaire which has been developed by WHO (1995), is a 100 question-tool to assess six different dimensions including physical, psychological, independency, social interactions, environmental and spiritual. The Cronbach's alpha showed that the reliability of this questionnaire among an English population was between 0.87 – 0.95. Furthermore, a satisfactory validity has been reported for this questionnaire after use in different countries, various age groups, and people with/without health-related issues(24).

The WHO QoL questionnaire-100 was reviewed by Karimloo et al in Iran. Using Cronbach's alpha, they found that the internal reliability of translated version of this questionnaire was between 0.5–0.83 in different dimensions. This version of questionnaire which was translated to Farsi involves Likert 5-degree scale ranging from 1-5 score, indicating never, a little, moderate, many, and plenty, respectively (25).

In this study, to assess the reliability of WHO QoL questionnaire and of its subscales, Cronbach's alpha was used. In addition, the validity of this scale was determined through calculating the correlation coefficient between the sub-scales and global score.

Table1. Demographic particulars of all enrolled subjects

Variable	Category	Frequency	Percentage
Mother's age	21-30	25	17.1
	31-40	79	54.1
	41-50	37	25.4
	51-60	5	3.4
Number of children	1-3	128	87.7
	4-6	18	12.3
Mother's educational level	Primary	18	12.4
	Secondary	35	24
	High School Diploma	56	38.4
	Post High School High School Diploma	12	8.2
	Bachelor of Science	22	2.1
	Master of Science	3	
Child's Gender	Male	93	63.7
	Female	53	36.3

Table2. One-way ANOVA used to test the study hypothesis. The significance cut-off level was considered 0.05.

	Source of Changes	Sum of Squares	Degrees of Freedom	Mean of Squares	F Ratio	Significance Level
General Quality	Between Group	510.689	2	255.344	10.500	0.001
	Within Group	3477.647	143	24.319		
	Total	3988.336	145			
Physical Dimension	Between Group	801.340	2	400.670	4.557	0.012
	Within Group	12573.674	143	87.928		
	Total	13375.014	145			
Psychological Dimension	Between Group	2054.802	2	1027.401	6.964	0.002
	Within Group	22711.808	143	158.824		
	Total	24766.610	145			
Independency	Between Group	2090.611	2	1045.306	7.933	0.001
	Within Group	18842.546	143	131.766		
	Total	20933.158	145			
Social Interactions	Between Group	779.363	2	389.681	5.625	0.004
	Within Group	9907.076	143	69.280		
	Total	10686.483	145			
Environmental Dimension	Between Group	4250.583	2	2125.291	5.712	0.004
	Within Group	53203.637	143	372.053		
	Total	57454.219	145			
Spiritual Dimension	Between Group	69.427	2	34.714	3.106	0.048
	Within Group	1598.326	143	11.177		
	Total	1667.753	145			

Table3. Results of post-hoc Tukey's test to compare groups for given variables

Dependent Variable	Two by Two Comparison		Means Difference	Standard Error	Significance Level
General Quality	Blind	Normal	-1.78750	1.02327	0.192
		Autistic	2.73074	0.98260	0.017
	Normal	Autistic	4.51824	0.99964	0.0001
Physical Dimension	Blind	Normal	-4.90139	1.94571	0.34
		Autistic	0.31329	0.86838	0.985
	Normal	Autistic	5.21468	1.90078	0.019
Psychological Dimension	Blind	Normal	-5.07778	2.61500	0.131
		Autistic	4.11006	2.51108	0.234
	Normal	Autistic	-9.18784	2.55462	0.001
Independency	Blind	Normal	-9.23889	2.38186	0.001
		Autistic	-2.68082	2.28720	0.472
	Normal	Autistic	-6.55807	2.32686	0.15
Social Interactions	Blind	Normal	-0.57361	1.72711	0.941
		Autistic	4.50354	1.65847	0.020
	Normal	Autistic	5.07715	1.68723	0.009
Environmental Dimension	Blind	Normal	-4.14722	4.00237	0.555
		Autistic	8.67374	3.84330	0.065
	Normal	Autistic	12.82096	3.90995	0.400
Spiritual Dimension	Blind	Normal	-1.58750	0.69371	0.061
		Autistic	-0.20008	0.66614	0.952
	Normal	Autistic	1.38742	0.67769	0.105

Any significant *F* ratio suggested a notable difference between the QoL of mothers whose children were blind, autistic, or normal-functioning.

Further to the above, post-hoc Tukey's test was done to define order of the subscales presence percentage.

Results

Demographic particulars, between group and within group analyses and the post-hoc results are outlined in tables 1 through 3, respectively.

One-way analysis of variance (ANOVA) was employed to assess the main hypothesis speculating that the QoL and its subscales are different between mothers who have autistic, blind, or normal-functioning children. Results indicated

that the QoL of mothers with blind children and of those who had normal-functioning kids in all the subscales, apart from dependency was not significantly different. In addition, mothers whose children were autistic compared to those with normal-functioning children had lower QoL in all the subscales, except for environmental and spiritual dimensions. Findings also demonstrated that mothers whose children were blind compared to autistic children mothers had higher QoL in general quality and social interaction subscales.

Discussion

This research was conducted to examine the impact of children's disabilities on the QoL of their mothers. Mothers with autistic, blind, and normal-functioning children were enrolled in this investigation.

Pregnancy and child birth are joyful events, while they may have their own difficulties and pressures. The hope for having a healthy and normal-functioning child make the physical and mental pressures of pregnancy period easier to be tolerated and also help parents to build their own confidences. However, when parents' hopes and expectations for having a healthy child are not met, the condition might lead to frustration and disappointment.

Giving birth to a child with disability, leads to feelings of guilt, fault, frustration, and exclusion. These feelings could finally appear in the form of grief or depression. When a mother faces with the fact that she lacks a normal-functioning child (especially in the cases of autism), she comes to realize the importance of her being mentally stable and strong and therefore her natural functioning is reinforced. This is due to the high and continuous levels of attention which should be given to autistic children and their special developmental needs which all comes from these children stereotyped behaviors, language problems, and lack of caring skills. However, this is not the same for all the mothers, considering the fact that in some cases, having children with disabilities lead to psychological disorders in mothers. Depression is found to be the most common consequence in parents of children with mental retardation (26-30).

According to the present investigation, mothers with autistic children had lower QoL in all subscales, except for spiritual and environmental dimensions as compared to mothers of normal-functioning children. In addition, mothers of blind children comparing to those of autistic and of normal functioning ones, in general quality and social interactions subscales, had higher QoL, whereas in independency subscale, they scored lower QOL. The results were in agreement with findings from earlier reports (13,18,19)

The higher QoL for mothers of blind children in general quality and social interaction subscale could be explained based on their children behaviors. In fact, blind kids, as compared to autistics, have more individual and social activities, and in some cases they have similar interest to what normal-functioning children do, such as learning music, painting, learning second language, etc. As

such, mothers of blind children have to accompany their kids, to be involved in their social activities, and therefore have more individual interactions, hence experience more level of social support. However, given such a constant accompaniment, mothers with blind children, as compared to mothers of the other two groups, experience lower levels of individual independency, their capacity to do various activities decrease and therefore their daily activities are more focused on the accompaniment of their blind children.

Results of the present study are based on the investigations on a sample selected from only one city, which makes it difficult to make generalization. In fact, it is plausible to arrive at varied results when considering multiple population strata. Some recommendations to extend this line of research are considering the severity of disabilities, including more variables in the studies (such as marriage satisfaction, educational level, social status, and socioeconomic status). It is also helpful to do face to face interview along with using questionnaires. In addition, results would be more accurate and informative when both mothers and fathers are involved in the study.

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