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Research article

A comparative study on the quality of life and resilience of mothers with disabled and neurotypically developing children in Iran

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ABSTRACT

Background: Mothers who take care of their disabled children usually suffer from several problems, such as physical, psychological, and social problems. The disability of children can also directly impress the quality of their mothers' lives. This study is going to check out how the disability of children affects the quality of life of the mothers.

Objective: This study was conducted to compare the quality of life and resilience of mothers with disabled and typically developed children in Fasa, Iran.

Methods: The subjects of this cross-sectional study were 240 mothers (120 mothers having disabled children and 120 mothers with typically developed children) referring to Fasa State Health Centers and Fasa State Welfare Office. They were randomly selected and included in the study. All samples were collected by the convenience sampling method. The data were collected by using the World Health Organization Quality-of-Life Scale (WHOQOL-BREF) and the Connor-Davidson Resilience Scale (CD-RISC). The collected data were then analyzed by the SPSS (v.22) software. The results of the descriptive statistics, Chi-square, independent t-test, and Pearson correlation coefficient were at a significant value of P < 0.05.

Results: The mean score of quality of life of mothers with disabled children on physical, psychological, social, and environmental domains was lower than that of mothers with neurotypically and statistically significant (p < 0.05); however, the mean scores on the resilience of mothers in both groups were not significantly different (p = 0.43).

The results of the linear regression analysis showed that, having a disabled child (P < 0.001, t = 10.141), level of education (P < 0.001, t = 2.031), and resilience (P < 0.001, t = 8.205) affect the quality of life. The lower the education level is, the lower the quality of life. And higher resilience increases the quality of life.

Conclusion: The quality of life of mothers with disabled children was lower compared to mothers with typically developed children, but there was no difference between mothers' resiliency in these two groups. These results suggest the necessity to provide supportive and therapeutic programs for improving the quality of life of mothers with disabled children.

1. Introduction

Disability is a global and prevalent phenomenon [1] that prevents a person from playing a role considered to be natural according to his/her

age, sex, social, and cultural status [2]. According to the International Classification of Functioning, Disability, and Health (ICF) of the World Health Organization (WHO), disability can be understood as chronic suffering from the symptoms of illness, or limitations of executing

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capacities, or inability to participate in selected areas of life. Operationally, disability can be defined as capacity limitations, which hinder the ability to execute needed activities and participation in a given environment" [3]. According to the United Nations (UN) and the WHO, by 2010 about 10 percent of the world's population had some kind of disability, which would increase to 15 percent, or more than one billion people [4]. In Iran, according to the latest statistics, of the total population of the country, about one million and 18 thousand people have a disability. According to these statistics, 200,726 people in the population between the ages of 0 and 19 have at least one disability [5]. The 'normal child' is deemed to be well-adjusted and attained the socially desired status of normalcy [6], and the neurotypical child is, in short, not having developmental or other disorders at birth to adulthood [7].

"Children with disabilities" can be defined as having impairments, activity limitations and participation restrictions, or disadvantages, as classified under the International Classification of Functioning, Disability and Health (ICF) (WHO, 2007) [8]. The disability of one of the children affects the entire family system and its various functions, and therefore, it could do serious harm to the integrity and structure of the family leading to some changes in roles, performance, and adaptability [9]. The results of a large number of studies are indicative of the fact that families of children with disabilities are under more stress than other families due to the parents' time, energy, financial condition and emotions, and possible inadequacy about their ability to meet their children's needs [9, 10, 11], and the lower physical and mental health [12]. These disorders affect their quality of life [13]. Having a disabled child encounters the mothers to have problems in familial and social life. The psychological and physical loads lead to those mothers experiencing personal difficulties and imbalances and having depression and anxiety [10]. As a result of increasing parents' anxiety-depression levels, the quality of life may decrease [14]. Parents with a disabled child might need to spend most of their time taking care of their disabled child, especially if the child has severe disabilities, and the parents are then unable to engage in other activities, curtailing their social life, which negatively affects their quality of life [15]. In view of the WHO, the quality of life is a multidimensional concept that is the result of everyone's perception of life, values, goals, standards, and individual interests [16], which are under the influence of many important physical, psychological factors as well as individual beliefs and social relationships [17]. Having poor quality of life affects family relationships, coping mechanisms and leads to ineffective adaptations in individuals and, consequently, increases their tension [18, 19].

One of the psychological interventions which can improve the quality of life is enhanced resilience [20]. Resilience is defined as the ability to adapt to and overcome stressful life events, such as having a child with a chronic disability and rebounding positive outcomes and personal mastery, constructing self-efficacy and hope [21]. Mothers of disabled children experience reduced resilience and their general health and quality of life are negatively affected; therefore, they perceive a heavy caregiving burden. These mothers need emotional sharing and psychological and psychosocial support to cope with their children's disability and to maintain their mental and physical health [22]. An increase in resilience reduces the level of stress and mental pressure [23], promotes mental health [24], increases indicators of wellbeing [25], and improves the quality of life [26, 27, 28]. Resilience is an individual process that increases the survival and the protective processes instigated by larger systems to provide opportunities for individuals to cope under stress [29]. Those who are more resilient can better cope with life problems, ease the burden of difficulties, and show more flexibility. Consequently, they would have a better quality of life [30].

Extensive research has been carried out on the relation between the quality of life and resilience, separately on one of the disabilities (i.e., children with cerebral palsy [31], children with intellectual disability [32, 33, 34], behavioral problems [35], but a few studies have dealt with the quality of life and resilience of mothers with disabled children). On the other hand; cultures could influence parents in the way they perceive

adverse situations and in how external factors influence resilience, which in turn, may differentially affect the quality of life of parent [36] and considering that in Iranian society, the main burden of caring for children is the responsibility of mothers and the main role of the father is to provide financial support for the family. Therefore, the present study was aimed at doing a comparative examination of the quality of life and resilience in mothers with disabled and neurotypically developing children in Fasa, so that the results, while supporting mothers with disabled children, would lead to necessary interventions for mothers. The hypothesis of the present study was that the quality of life and resilience in mothers with disabled children was different from mothers with neurotypically developing children.

Since estimating the quality of life of people is a big index for determining the quality of health service, maybe the findings of this study will set strategies for improving the quality of life and resilience of families with disabled children. Hence, these children and their families could be assisted.

2. Materials and methods

2.1. Design

The present study employed a cross-sectional and analytical approach, which was performed in Fasa in 2020.

2.2. Ethical consideration

The study was approved by the Ethics Committee of the Fasa University Medical Sciences (FUMS) under number (96072; IR.FUMS.-REC.1396.237). All participants were informed about the study and only those providing written informed consent were enrolled in the study.

2.3. Data collection

The sample size was estimated to be 108 participants through using the comparison formula for two means and the standard deviation of quality of life (5.22), confidence level (95%), power (80%), and acceptable difference (1.5) obtained from Jalili et al.'s study [30].

$$n = \frac{2\sigma^2 (Z_{1-a/2} + Z_{1-\beta})^2}{d^2} \tag{1}$$

To increase the strength of this study and to compensate for the incomplete questionnaires, the sample size was increased to 120 in each group. In this way, 120 mothers with disabled children and 120 mothers with neurotypically developing children referring to the Fasa State Welfare Office and the Fasa State Health Centers were randomly selected. The inclusion criteria were: being diagnosed with having a disability by a physician presented at the State Welfare Office or the Health Center, having literacy skills, and willingness to participate in the study through filling out the questionnaire.

After briefing the mothers about the goals of the study and obtaining informed written consent from them, demographic information of the mothers, such as age, level of education, child's gender, number of children, occupation's status, child's place of residence, and the child's demographic information including age, type of disability and severity of disability were collected through a questionnaire. The level of the severity of the disabilities was determined based on the parental reports.

The World Health Organization Quality of Life questionnaire was used to assess the quality of life of mothers. It contained 26 questions and 4 subscales. The subscales consisted of physical health (7 items), mental health (6 questions), social relationships (5 questions), and environmental health (8 questions). A Likert scale with five categories (not at all, low, moderate, high, and very high) was used to give a score to each question item. In the end, the questionnaire was scored in 2 formats, in one the scores ranged between 0 and 20 and in another from 0 to 100 [37].

In this study, the scores were ranged from 0 to 20. In Iran, this questionnaire has satisfactory reliability and validity. The coefficient of internal consistency of the questionnaire was reported to be 0.70 in the study by Nejat et al. [38].

Connor and Davidson's questionnaire (2003) was used to measure the resilience of mothers [37]. The questionnaire consisted of 25 questions, the answer to each question was on a 5-point Likert Scale, scored between 0 and 4; 0 for 'totally wrong', 1 for 'seldom correct', 2 for 'sometimes correct', 3 for 'often correct' and 4 for 'always correct'. The range of attainable scores is 0–100. The closer the score is to 100, the more resilience it shows. It should be noted that in the Iranian study by Mohammadi et al. [39], this questionnaire was adapted, and its reliability through an internal consistency method was reported to be 0.89 and 0.87 for its validity by factor analysis.

2.4. Statistical analysis

Mean and standard deviation were reported to describe quantitative variables and frequency and frequency were reported to describe qualitative variables. An independent t-test was used to compare the scores of quality of life dimensions and resilience between mothers with disabled children and mothers with healthy children. Chi-square test was used to compare the frequency of child's gender, the number of children, level of educations, occupations status, and child's place of residence between mothers with disabled children and mothers with neurotypically developing children. Pearson correlation coefficient was also used to measure the correlation between the quality of life dimension score and resilience. All analysis was performed with the SPSS (V.22) software.

3. Results

3.1. Descriptive statistics

The mean and standard deviation of the age of the mothers participating in the group of mothers with disabled children and mothers with neurotypically developing children were 42.60 ± 5.29 and 43.25 ± 4.41 years, respectively. Other demographic characteristics of mothers in both groups are reported in Table 1. The Chi-square test showed that there was not a significant difference in the two groups in terms of demographic variables (Table 1).

The mean and standard deviation of the age of neurotypically developing children and disabled children were 8.92 \pm 3.29 and 9.15 \pm 3.19 years, respectively.

Table 2 shows the type and severity of the disability of children. The highest prevalence of disability seen in children is related to physical and mental disability (% 56.70), and the degree of disability was classified as severe (Table 2).

Based on the independent t-test, the mean score of quality of life of mothers with disabled children in the domains of physical, social, and mental environment was lower than those with neurotypically developing children (P < 0.05); however, the mean score of the resilience of mothers in both groups was not statistically significant (P = 0.43) (Table 3).

Pearson correlation coefficient was used to determine the correlation between the quality of life and resilience of mothers with disabled and neurotypically developing children. The results showed that there was a positive and direct correlation between the quality of life in such four domains: physical, psychological, social, and environmental domains and the resilience of mothers in both groups with neurotypically developing and disabled children which were statistically significant (p < 0.001). In other words, betterment in the level of resilience would lead to an increase in the dimensions of quality of life (physical, mental, social, and environmental) in both groups of neurotypically developing and disabled children (Table 4).

The results of the linear regression analysis showed that having a disabled child, education and resilience are the variables that affect the quality of life. The lower the education level is, the lower the quality of life. And higher resilience increases the quality of life (Table 5).

4. Discussion

This study has dealt with a comparison between the quality of life and resilience of mothers with disabled children and mothers with neurotypically developing children. When parents' hopes and expectations for having a healthy child are not met, the family condition might lead to frustration and disappointment. Giving birth to a child with a disability leads to feelings of guilt, fault, frustration, and exclusion. These feelings could finally appear in the form of grief or depression. Many studies have been conducted on the quality of life of mothers or fathers with disabled children by Iranian researchers, but there are a few studies about their Resilience [40, 41, 42].

The results of this study showed that mothers with disabled children had lower quality of life in the physical, social, mental, and environmental domains than mothers with neurotypically developing children.

About the physical domain, the mothers of disabled children, sometimes have to spend lots of time to take care, feed, provide hygiene care,

Variables	Group	Mothers with neurotypically developing children (in percentage)	Mothers with disabled children (in percentage)	p-value
Child's gender	Girl	52 (43.34)	48 (40)	0.63
	Воу	48 (40)	54 (45)	
	Boy & girl	20 (16.66)	18 (15)	
Number of children	1-2 Children	23 (19.16)	21 (21.67)	0.48
	3-4 Children	49 (39.17)	47 (37.50)	
	+5 Children	50 (41.67)	49 (40.83)	
Level of education	Illiterate	47 (39.17)	53 (44.17)	0.12
	Below diploma	45 (37.50)	53 (44.17)	
	Diploma	15 (12.5)	7 (5.83)	
	Above diploma	13 (10.83)	7 (5.83)	
Occupation's status	Housewife	98 (81.67)	100 (83.34)	0.57
	Working	22 (18.33)	20 (16.66)	
Child's place of residence	In family	89 (74.16)	92 (76.66)	0.54
	In maintenance centers	31 (25.84)	28 (23.34)	
* Chi-square Test				

Table 1. Comparison of the percentage of frequency of mothers with neurotypically developing children and disabled children in terms of demographic information.

Table 2.	The	percentage	of fr	requency	of	disabled	children	in	terms	of	the	type
and sever	rity.											

Variable		Number	Percentage
Type of disability	Visual	8	5.80
	Auditory	5	2.50
	Kinetic	4	1.70
	Intellectual and physical	69	56.70
	Intellectual and neural	27	21.70
	Audiovisual	5	3.30
	Cerebral paralysis	2	0.80
Severity of disability	Mild	29	23.30
	Moderate	39	32.50
	Severe	53	44.20

provide therapeutic exercises, cope with the behavioral problems of children, and take children to different medical centers. Some parents suffered from low back pain and wrist pain as a result of assisting their children in daily chores, such as transferring, toileting, and bathing. Because of the severe disabilities of their children, parents may become physically exhausted in the provision of intensive care and attention to their children. Some parents may develop chronic pain due to repetitive strain. The mothers of disabled children are at the center of all problems and difficulties, therefore they receive the highest negative impact, and therefore, their physical domain of quality of life will be lowered. All of these can harm the well-being resulting in a stress-induced dysregulation of the immune system [43]. The finding was consistent with previous research results [30, 44, 45, 46, 47].

Also, the results of this study explored that mothers with disabled children had lower quality of life, in the social domain than mothers with neurotypically developing children. The parents of disabled children face more problems in their social interactions, activities, and family functioning. They avoid doing activities that require them to have social contact. Some parents abandon their jobs to help the professionals and other family members with taking care of the disabled children [48]. Jalili et al., quoting from Reina Vitaliano, stated that "having a child with cerebral palsy causes physical and psychological stress on the family and especially the mothers. Moreover, those parents experience problems such as: worthlessness, isolation, fear of the future, social rupture, fatigue, social and economic problems" [30]. The finding was consistent with previous studies but was different from the results of the study of Leung & Tsang and Atkin as their results showed that some parents actively participate in parental self-help support groups. These parents tend to be educated with higher intellectual functions, stable family backgrounds, strong financial status, outgoing, confident, efficient, and motivated. Parents' attitudes rather than their children's level of disabilities seem to be the main determinant for active social participation [15, 49].

Moreover, the results indicated that mothers with disabled children had lower quality of life in the mental domain than mothers with neurotypically developing children. Some research showed that children's disabilities lead to psychological disorders in mothers. Depression is

Table 3. Comparison between the mean score of quality of life in different domains and the resilience of mothers with neurotypically developing children and disabled children.

Variable	Mothers with neurotypically developing children (No.120)		Mothers with disabled children (No.120)		Test statistics (t)	Degree of freedom	p-value
	mean	SD	mean	SD			
Physical function	19.13	3.766	16.01	5.131	12.24	238	$p \leq 0.001$
Mental function	18.52	2.678	15.97	3.03	6.89	238	$p \leq 0.001$
Social function	15.93	2.578	11.22	2.77	13.60	238	$p \leq 0.001$
Environmental function	15.54	2.737	11.75	3.981	8.59	238	$p \leq 0.001$
Resilience	68.01	13.06	69.63	18.77	-0.77	238	0.43

Table 4. Coefficient correlation between quality of life and resilience in mothers with neurotypically developing children and disabled children.

Group	Domains of life quality	Resilience		
		Coefficient Correlation	p-value	
Mothers with neurotypically developing children	Physical functioning	0.77	$p \leq 0.001$	
	Mental functioning	0.72	$p \leq 0.001$	
	Social functioning	0.68	$p \leq 0.001$	
	Environmental functioning	0.54	$p \leq 0.001$	
Mothers with disabled children	Physical functioning	0.68	$p \leq 0.001$	
	Mental functioning	0.68	$p \leq 0.001$	
	Social functioning	0.53	$p \leq 0.001$	
	Environmental functioning	0.64	$p \leq 0.001$	

Table 5. The relationship between the study variables and quality of life.

Model	Unstandardized coefficients		Standardized coefficients	t	P- Value
	В	Std. error	Beta		
(Constant)	20.478	4.940		4.145	.000
Age	1.487	1.192	.103	1.248	.215
Level of education	2.509	1.235	.164	2.031	.045
Child's gender	.280	1.215	.016	.231	.818
Resilience	.410	.050	.609	8.205	.000
Group	17.692	1.745	.588	10.141	.000

found to be the most common consequence in parents of children with mental retardation [42].

About the environmental domain, the results indicated that mothers with disabled children had lower quality of life. The finding was consistent with previous research results [30, 40, 44, 45, 46, 47].

Pierre's research (2014) found that chronic stress affects the health of parents with a physically and mentally handicapped child. It also overshadows their ability to meet the needs of their children. However, there is a subgroup of parents with disabled children who confront meaningful life stresses. The way they adapt to stress, positive thinking, and social support are reported to be among the factors for the resilience of these groups of parents [33].

The results of this study on resilience showed that there was no difference between the resilience of mothers with disabled children and mothers with typically developed children. But the study of Keniş-Coşkun showed that stressful life events, such as having a child with a disability, result in a lower level of resilience [21]. Mothers of disabled children experience reduced resilience and their general health and quality of life are negatively affected; therefore, they perceive a heavy caregiving burden [22]. It seems that the reason for the lack of difference between the resilience of mothers with disabled children and typically developed ones in Fasa lies in the similarity of individual characteristics, the cultural ground dominating this city including people's patience and tolerance, especially the lady fellow-citizens in dealing with the problems, adaptation processes.

The results of the present study explored that having a child with a disability within a family affects the quality of life of their mothers. This finding is in line with the results of the studies performed by Rassouli et al. [50], showing that mothers' interaction with children having behavioral problems and special needs affects the quality of their lives and reduces their performance. Previous studies have also shown that caring for a disabled child affects the quality of life of mothers [51, 52, 53, 54]. These findings were revealed to be in agreement with those of the present study. According to Hsiao [55], parents of children with disabilities often experience higher levels of stress than parents of children without disabilities, regardless of the category of disability. As a result of increasing parents' anxiety-depression levels, the quality of life may decrease [14]. Parents with a disabled child might need to spend most of their time taking care of their disabled child especially if the child has severe disabilities, and the parents are then unable to engage in other activities, curtailing their social life and negatively affecting their quality of life [15].

The results of the present study showed that resilience is one of the variables affecting the quality of life; therefore, higher resilience increases the quality of life. The studies conducted by Mehrafraz et al. [56] and Haghranjbar et al. [57] revealed that resilience has a positive and significant relationship with the quality of life of mothers with children having behavioral problems and mental retardation. In conformity with the results of the present research, the findings of a study performed by Albalat et al. [58] showed that the main predictor regards health-related quality of life is resilience. In a study conducted by Farshad et al. [35] in mothers of children with behavioral problems, it was revealed that 66% of the variance in quality of life was explained by resiliency. Savari et al. [59] and Gheysaranpour Gheysaranpour et al. [60], by showing a positive relationship between resilience and quality of life, stated that the higher the resilience of parents is, the higher the ability to perform positively in adverse and difficult conditions and the more resistant they are to suffering, the higher the quality of their life. This finding is in line with the results of the present study. Kaveh et al. [61] reported that resilience increases their quality of life by creating coping strategies and better defense mechanisms in people.

By explaining these findings, it can be said that resilience is one of the personality traits of individuals which can play a decisive role in the occurrence of behavior, satisfaction, and quality of life. Mothers with children with disabilities are slow to progress and learn, and they give a poor and frustrating performance. In addition, their children endure hardships and fruitless efforts that these fruitless efforts may reduce their tolerance, and if resilience decreases, they may lose the ability to cope with life's problems and act fragile on any small issue. Therefore, this reduction in resilience leads to a decrease in their quality of life. But mothers who have a strong personality trait and high resilience, have a lot of tolerance and instead of accepting failure. They seek to find the right solution, although they face many difficulties along the way. But they do not give up trying to achieve the desired result and are satisfied with their success, which leads to a high quality of life in them.

The results of the present study revealed that the level of education of mothers with disabled children affects their quality of life; thus, mothers with lower levels of education have a lower quality of life. The results of this study are in line with the studies of Klassen et al. [62], Zareinejad et al. [63], and Misura et al. [54]. The results of the study of Gheysaranpour et al. [60] on parents with a child with thalassemia showed that parents with higher education had a better quality of life.

By analyzing the results of this study, we can say that the mother's education is related to the child's health in several ways; better family income, participation in decision-making, better use of existing services, and better child care [64, 65]. Also, Misura et al. [54] reported that higher education usually means better socio-economic status (SES), so the effect of educational level might be mediated through the influence of SES. Higher income means less exposure to emotional and physical stress and in turn, can lead to higher QOL.

4.1. Limitations

We are aware of the limitations of our study. The first is that as the focus of this research has been only on mothers, similar evaluations will not be appropriate for the quality of the life of fathers. It is suggested that further research be carried out on the quality of life of fathers. The second is the small sample size. More research is recommended with larger sample sizes. The third limitation was the determination of the severity of the child's disability based on the parents' report, and it is suggested that in future studies, the severity of the disability be measured based on the opinion of specialists and a formal diagnosis.

5. Conclusion

The results of this study showed that the quality of life of mothers with disabled children was lower compared to mothers with neurotypically developing children. Having a disabled child, level of education and resilience are the variables that affect the quality of life. These results suggest the necessity to provide supportive and therapeutic programs for improving the quality of life of mothers with disabled children. Service providers, policymakers, rehabilitation and welfare centers, or other potential groups can be benefitted from the results of the present study. Based on the outcomes of the present study, all these respective bodies are suggested to design educational programs and training courses encouraging the improvement of resilience to improve the quality of life. Such measures can boost the quality of life in mothers with disabled children, especially in those who have a low quality of life.

Declarations

Author contribution statement

Zhila Fereidouni: Conceived and designed the experiments; Wrote the paper.

Zahra Khiyali: Conceived and designed the experiments; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Amir Hossein Kamyab: Performed the experiments; Analyzed and interpreted the data.

Razie Toghroli: Performed the experiments.

Arash Ziapour: Analyzed and interpreted the data; Wrote the paper. Nafiul Mehedi: Analyzed and interpreted the data; Wrote the paper.

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Azizollah Dehghan: Contributed reagents, materials, analysis tools or data.

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Data availability statement

Data included in article/supplementary material/referenced in article.

Declaration of interests statement

The authors declare no conflict of interest.

Additional information

No additional information is available for this paper.

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