

A Study on Health-Related Quality of Life, Depression, and Associated Factors Among Parents of Children with Autism in Kermanshah, Iran

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Abstract

Background: The focus of recent research has significantly shifted from explaining the causes and symptoms of autism to investigating issues related to the parents of autistic children.

Objectives: This study aimed to investigate health-related quality of life (HRQOL), depression, and associated factors among parents of autistic children in Kermanshah, Iran.

Methods: In this cross sectional study performed in 2015, a total of 97 male and female parents of autistic children completed 3 questionnaires: background/demographic checklist, 36-item short-form health survey (SF-36), and Beck's depression inventory. Data were analyzed using SPSS version 18.

Results: Analysis of the general physical health domain of HRQOL demonstrated no significant difference between men and women ($P > 0.05$). On the other hand, in all subdomains of mental health, women's scores were higher in comparison with men, and there was a significant difference in the mental health domain. Also, analysis of depression level revealed that 25.8% of the subjects had severe depression.

Conclusions: Given the low level of QOL and depressive symptoms in more than two-thirds of parents of autistic children, psychological empowerment of this group is recommended.

Keywords: Autism Spectrum Disorder, Depression, Parents, Quality of Life

1. Background

Early diagnosis of autism spectrum disorder, classified as a developmental disorder of the nervous system with increasing global prevalence, has become a challenging issue (1). Learning and mental growth disabilities occur shortly after birth among over half of autistic children, while the rest may seem healthy. These children gradually lose their speaking and social communication abilities between 18 months and 3 years (2).

The focus of recent research has significantly shifted from explaining the causes and symptoms of autism disorder to investigating issues related to the parents of autistic children (3). Accordingly, it stands to reason that the relationship between children's disorder and family functioning is reciprocal. Therefore, instead of focusing only on children with special needs, their families should be taken into consideration, as well (4).

According to 2 conventions of the United Nations, it is essential to assess the quality of life (QOL) of parents of

autistic children, considering the children's need for assistance (5). Previous research has shown that parents of children with disabilities are decidedly vulnerable to stress. In fact, 70% of mothers and 40% of fathers of these children experience stress (6).

In addition, parents of autistic children are on average exposed to a higher risk of depression and other mental health problems, compared to the parents of children with disabilities, such as intellectual developmental disabilities (IDDs) and Down's syndrome (7). Therefore, their activities become limited, and their performance noticeably decreases in terms of sexual intercourse and physical health (6). Moreover, various studies have reported higher levels of depression and psychological stress among parents of autistic children (8).

QOL has become a very important phenomenon in recent years (9). Basic information on the QOL of people with different lifestyles can be used in various interventions in the field of public health. In recent years, special

attention has been paid to QOL as a pivotal issue in public health due to people's exposure to complex situations, such as raising disabled children (10). Although there has been a great emphasis on the necessity of QOL assessment in shaping, guiding, providing, and evaluating healthcare services, there is less information available regarding the effects of raising autistic children on parents in comparison with the existing information on the impact of having children with other chronic diseases (3).

In general, having children with developmental disorders can be challenging for families. Also, family functioning is negatively influenced by the presence of an autistic child in the family. Therefore, it is necessary to target the parents' QOL, as well as family functioning, with an inclusive perspective beyond children. Nevertheless, the quality and quantity of these effects on each parent (father or mother) are not clear.

There is scarcity of information on health-related QOL (HRQOL) and psychological components in parents of autistic children residing in Kermanshah, Iran. Most previous studies in Iran have explored QOL in mothers of autistic children, while ignoring the fathers (11, 12). Therefore, in the present study, we examined a hypothesis, suggesting a significant difference in HRQOL of mothers and fathers of autistic children.

2. Objectives

The present study aimed to investigate HRQOL, depression, and associated factors among parents of autistic children in Kermanshah, Iran.

3. Materials and Methods

3.1. Study Design and Participants

The present cross sectional study was conducted in Kermanshah, one of the western provinces of Iran, during April-August, 2015. The target population consisted of the parents of autistic children residing in Kermanshah. A total of 130 autistic children with clinical records in medical centers of Kermanshah were identified. All eligible individuals were invited to participate in the study, although only 109 cases accepted our invitation. After distributing the questionnaires, only 97 people met the inclusion criteria and were recruited for the final analysis (response rate, 75%).

3.2. Inclusion Criteria

The inclusion criteria were as follows: 1) active clinical records in Kermanshah-based screening centers; 2) availability; 3) parents' satisfaction; 4) lack of severe mental dis-

orders; and 5) diagnosis of autism confirmed by neuropsychologists using the autism spectrum screening questionnaire (ASSQ). Informed consents were obtained from all the participants. Twelve parents, who did not meet the mentioned criteria, were excluded from the study (3 due to mental disorders and 9 for other reasons).

3.3. Questionnaires

To collect the required data, 3 questionnaires were used:

Background/demographic questionnaire: This tool consisted of questions on age, gender, age of marriage, education, number of household members, employment status, income, financial assistance from supporting organizations, chronic diseases, place of residence, and feeling of happiness. The variable of happiness was measured by 1 question on a 4-point scale ("ultra-happy", "very happy", "a little happy", and "not happy at all").

Short form-36 health survey (SF-36): This questionnaire measures HRQOL in 2 general domains (physical and mental health) and 8 subdomains (4 subdomains for each index). The physical health domain consists of physical functioning (10 questions), physical limitations (4 questions), bodily pain (2 questions), and general health (5 questions). The mental health domain comprises of vitality (4 questions), social functioning (2 questions), emotional limitations (3 questions), and mental health (5 questions). The validity and reliability of the questionnaire have been examined in an Iranian study, conducted by Montazeri et al. (2005). The results demonstrated that the Persian version of the questionnaire has adequate reliability and validity (13).

Beck's depression inventory: This tool consists of 21 questions and aims to assess the feedback and symptoms of depressed patients, essentially based on observations, attitudes, and common symptoms among psychiatrically depressed patients. This scale determines varying degrees of depression (from mild to very severe), and the scores range from a minimum of 0 to a maximum of 63 (14). Having reviewed previous studies applying this tool, Beck et al. in a retest found that the validity coefficient of the scale varied from 0.48 to 0.86, considering the time intervals between the studies and target populations. Overall, many Iranian studies have focused on the psychometric analysis of this tool. The study conducted by Kaviani et al. (2000), indicating a reliability coefficient of 0.91, is a good example in this area (15).

3.4. Statistical Analysis

For data analysis, descriptive and analytical statistics were calculated using SPSS version 18. The applied mea-

asures included calculation of mean and standard deviation, MANCOVA test (for indicating significant differences in QOL based on sex), Spearman's correlation test (for indicating the correlation between severity of autism in children and parents' QOL), and multiple regression analysis (for indicating the effect of each context variable on QOL and depression).

3.5. Ethical Considerations

Informed consents were obtained from the parents of all children, and they were informed about the purpose of the study. The patients' information remained confidential and anonymous in this study.

4. Results

A total of 97 subjects were recruited in the present study. Overall, 78.4% of the participants were women ($n = 76$), while the rest were men. The average age of marriage in women was nearly 5 years less than that of men. Also, around 28.9% of the respondents had academic education. Based on the findings, 81.6% of women were unemployed, while 85.4% of all respondents did not receive any support from relevant organizations. Furthermore, 10% of the respondents resided in rural areas (Table 1).

The results regarding HRQOL in the parents of autistic children demonstrated that the scores of physical functioning and physical limitations (in the general physical health domain) were better in men in comparison with women, although the difference was not statistically significant ($P > 0.05$). However, in all subdomains of mental health, women's scores were higher in comparison with men, and there was a significant difference in the mental health domain ($P < 0.020$) (Table 2).

Moreover, the results showed that depression scores were higher among men than women. The percentage of men and women suffering from severe depression was 27.6% and 19%, respectively (Table 3).

According to the autism spectrum screening questionnaire (ASSQ), 28.1%, 47.9%, and 24% of the children had mild, moderate, and severe disorders, respectively. The Spearman's correlation test showed no significant correlation between the severity of autism in children (mild, moderate, and severe) and the physical health domain of HRQOL in parents ($r, -0.050; P = 0.628$). However, an inverse significant correlation was found between the severity of autism in children and the mental health domain of HRQOL in parents ($r, -0.238; P = 0.019$). Therefore, increasing severity of autism in children was associated with reduced mental health domain of HRQOL in parents.

The parents' income status, educational level, and employment status were considered as socioeconomic variables, and the relationship between these variables and QOL was measured. The results indicated no significant relationship between the parents' educational level and their general physical and mental health. Similarly, there was no significant relationship between the income level and QOL domains ($P > 0.05$).

The results of multiple linear regression analysis (backward method) showed that after entering the variables (gender, education, employment status, organizational support, chronic disease, income status, and place of residence), only 2 variables of organizational support ($\beta, 0.235; P = 0.018$) and chronic disease ($\beta, -0.262; P = 0.009$) remained in the model. The adjusted coefficient was 0.104, indicating that these variables could determine 10% of changes in the physical health domain of parents' QOL.

The multivariate linear regression analysis of the mental health domain of HRQOL in parents showed that only the variable of organizational support ($\beta, 0.305; P = 0.003$) remained in the model; the adjusted coefficient was 0.083. Moreover, the results showed that the variables of organizational support ($\beta, -0.304; P = 0.002$) and chronic disease ($\beta, 0.292; P = 0.003$) could affect depression; the adjusted coefficient for depression was 0.159.

5. Discussion

The present study aimed to investigate HRQOL and depression among parents of autistic children residing in Kermanshah, Iran. HRQOL is increasingly recognized as an important aspect of health (16) and is a key variable in the assessment of parents' adaptation to their children's disabilities. The results of regression analysis showed that the variable of chronic disease affected the physical health domain of HRQOL and depression. This finding is similar to some previous studies performed in Iran (17, 18). Also, the variable of organizational support was influential in both physical and mental health domains of HRQOL and depression. In fact, support (eg, social, emotional, and organizational support) seems to be associated with continuous distress in life, which has a major relationship with health consequences and reduced risk of physical and mental health problems (19).

Comparison of physical health subdomains of HRQOL among women suggested that the scores of physical functioning, physical limitations, and bodily pain were higher than those reported in a study by Gorji et al. in 2014 (11). Similarly, in the present study, score of the physical health domain of HRQOL was higher than that reported in the mothers of children with IDD, as introduced in a study by

Table 1. Demographic Variables in the Participants^a

Variables	Male	Female	Total
Parents' age	39.38 ± 7.17	36.05 ± 6.90	36.77 ± 7.06
Age at marriage	27.67 ± 5.81	22.57 ± 5.65	23.91 ± 6.17
Number of family members	3.85 ± 1.04	4.08 ± 1.14	4.03 ± 1.11
Family income	902.631 ± 543771	1.265.135 ± 772.821	1.142.000 ± 719.509
Educational level			
Illiterate	1 (4.8)	3 (3.9)	4 (4.1)
Diploma and under diploma	11 (52.4)	54 (71.1)	65 (67)
University degree	9 (42.9)	19 (25.0)	28 (28.9)
Parents' employment status			
Employed	15 (71.4)	13 (17.1)	28 (29.2)
Unemployed	6 (28.6)	62 (81.6)	68 (70.8)
Supportive organization			
Yes	3 (14.3)	11 (14.5)	14 (14.6)
No	18 (85.7)	64 (84.2)	82 (85.4)
Chronic disease			
Yes	2 (9.5)	5 (6.6)	7 (7.2)
No	19 (90.5)	71 (93.4)	90 (92.8)
Place of residence			
Urban	17 (81.0)	70 (92.1)	87 (89.7)
Rural	4 (19.0)	6 (7.9)	10 (10.3)

^aValues are expressed as mean ± SD or number (%).

Taghizadeh and Asadi in Babol, Mazandaran Province, Iran (20).

In the present study, the mean score of the physical domain of HRQOL was 59.65 in women, which seems inadequate compared to a study conducted by Dardras and Ahmad in 2014 on women with autistic children (average score, 64.91) (3). Given the higher average age of women in the present study, this significant difference might be due to both maternal age and use of different measurement tools in these studies.

As for the mental health component of QOL, the average score of happiness was 49.60 in the present study, which was less than the average score reported in the study by Gorji et al. in 2014 (average score, 52.25) (11). Similarly, the average score of women's social functioning in the present study was less than that found in the study by Gorji et al. in 2014 (11). Also, the general score of women's mental health in the present study (score, 50.93) was much lower than that reported in the study by Dardras and Ahmad (score, 59.68) (3).

In general, low levels of mental health among parents

of autistic children expose them to mental health challenges, given their concerns about the future, their perspectives on disabled children, and the sense of guilt developed over time. These parents are faced with additional stressors throughout the day, resulting in reduced safety and mental health level. Also, the mean scores of all QOL domains (physical and mental health domains) in mothers of autistic children were lower than those of rural women (general population) in Kermanshah, Iran (61.55 and 53.22, respectively). The results indicated that mothers of autistic children had a more undesirable status, compared to the general female population (17).

Lack of research in Iran on the status of QOL in fathers of autistic children is a major challenge. In fact, the majority of domestic studies in this area have focused on the mothers' QOL. The results of the present study regarding the mental and physical health domains of HRQOL in men (average scores, 59.88 and 47.92 for the physical and mental health domains, respectively) demonstrated that the scores of both domains were lower than those reported in the study by Dardras and Ahmad in 2014 (67.67 and 63.48, re-

Table 2. Health-Related Quality of Life (HRQOL) Scores in Male and Female Participants^a

	Male	Female	Total	P Value ^b	Observed Power
Physical health domain					
Physical functioning	75.48 ± 19.43	70.17 ± 26.10	71.32 ± 24.81	0.388	0.138
Physical limitations	63.09 ± 36.75	52.67 ± 39.01	54.92 ± 38.58	0.276	0.192
Bodily pain	53.94 ± 23.86	63.45 ± 28.32	61.39 ± 27.58	0.163	0.285
General health	47.01 ± 16.14	52.30 ± 21.87	51.15 ± 20.80	0.305	0.175
Total physical health domain	59.88 ± 14.67	59.65 ± 22.94	59.70 ± 21.35	0.965	0.050
Mental health domain					
Vitality	45.83 ± 10.88	46.90 ± 15.38	46.67 ± 14.48	0.766	0.060
Social functioning	58.33 ± 18.25	60.90 ± 26.92	60.34 ± 25.23	0.613	0.069
Emotional limitations	46.03 ± 38.69	48.71 ± 41.57	48.13 ± 40.78	0.791	0.058
Mental health	41.52 ± 8.57	47.22 ± 10.09	45.99 ± 10.02	0.020	0.648
Total mental health domain	47.92 ± 12.97	50.93 ± 18.07	50.28 ± 17.08	0.478	0.109

^aValues are expressed as mean ± SD.^bMANCOA test*.**Table 3.** Depression Severity in Male and Female Parents^a

	Male	Female	Total
Depression level			
No depression	5 (23.8)	27 (35.5)	32 (33)
Minor depression	7 (33.4)	16 (21.1)	23 (23.7)
Mild depression	5 (23.8)	12 (15.8)	17 (17.5)
Severe depression	4 (19.0)	21 (27.6)	25 (25.8)
Total	21 (100)	76 (100)	97 (100)
Total score of depression	20.43 ± 11.31	19.44 ± 12.19	19.66 ± 11.95

^aValues are expressed as mean ± SD or number (%).

spectively) (3). Since the average age of fathers was almost similar in these 2 studies, the significantly lower score of HRQOL among men in our study is debatable.

The results showed no significant difference between men and women with autistic children in terms of the domains of QOL (physical and mental health domains). This finding was consistent with the results reported by Dadras and Ahmad in 2014 and was inconsistent with the results of studies by Mugno et al. in 2007 and Yamada et al. in 2012 (3, 10, 21). Although there was no significant difference between fathers and mothers in terms of their perception of QOL, they did not necessarily have the same understanding of the concept of QOL. In fact, responses of parents of autistic children regarding QOL reflect their personal assessment of their subjective experiences. However, it should be noted that the QOL of fathers and mothers was not signifi-

cantly different, considering the common ground of being the parent of an autistic child.

There was no significant relationship between physical and mental health domains of HRQOL and parents' job, income status, and educational level. The findings were consistent with the results of the study by Dadras and Ahmad in 2014 in terms of education and inconsistent in terms of income status (3). Moreover, according to the literature, socioeconomic status and availability of resources influenced one's health and wellbeing (22). In fact, socioeconomic status acted as a moderating variable between QOL of caregivers of disabled children and behavioral problems among children (22, 23). However, the effect of this variable on QOL might be influenced by the presence of a disabled child in the family.

In addition, the results demonstrated no significant

difference between fathers and mothers in terms of depression; nevertheless, the scores of depression among men were slightly higher than women. Analysis of depression level demonstrated that 43.3% of the respondents suffered from moderate and severe depression. Similarly, two-thirds of the participants in a study by Bitsika et al. in 2004 had some levels of depression (24); therefore, the present finding was consistent with the results of the study by Bitsika et al. in 2004 (24). In their study, 11.4% and 21% of the parents suffered from severe and mild depression, respectively, which were reported to be 28.8% and 21% in the present study. It should be noted that in the current study, the mean score of depression among men was insignificantly higher than women.

In the present study, detailed examination showed that 21 out of 25 patients with severe depression were women. This finding was in line with some common assumptions about the prevalence of depression in the majority of women. In a previous study, the prevalence of major depression among parents of autistic children was higher than groups such as nurses (2.6%) (25). Compared to the present study in which the prevalence of depressive symptoms was 68%, a previous study reported depressive symptoms in only 21% of the general population (26). These findings indicate that having an autistic child reinforces the symptoms of depression and mental disorders among parents.

In 2007, Motamedi et al. showed that 73% of mothers of disabled children experienced a small degree of depression, while 21% suffered from severe depression. In the present study, the rate of severe depression was 4% higher than that reported in the mentioned study (27). In general, it should be noted that previous studies have indicated a higher prevalence of depression and other mental health problems among parents of autistic children, compared to parents of disabled children (8). Similarly, other studies have shown that the prevalence of stress among families of autistic children is higher than that among families of children with Down's syndrome or IDD (28).

In conclusion, considering the viewpoints of Skevington et al. (2004), who considered a score of 60 out of 100 on the WHOQOL-BREF questionnaire as average (29), and generalization of this criterion to SF-36 scale, it can be stated that the respondents' general scores in the physical and mental health domains were lower than average. Accordingly, it was concluded that HRQOL (mental and physical health) was lower than average among parents of autistic children. Regarding depression among parents of autistic children, the results showed that 68% had depressive symptoms, while 25.8% had symptoms of major depression according to Beck's depression inventory.

The limitations of the present study included lack of ac-

cess to both parents of autistic children to compare their conditions. Moreover, since the data were collected in form of self-reports (based on parental responses), more objective data based on field observations should be reported. Another limitation of this study was the lack of a control group. Therefore, we could only compare the results of the current study with previous research on the general population.

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Footnotes

Authors' Contribution: Hoshang Amirian and Nader Rajabi Gilan designed and conducted the study and drafted the manuscript. Fatemeh Maleki participated in the acquisition of data. Syed Ramin Ghasemi participated in the analysis and interpretation of data. Siavash Solimani participated in the study design and drafting the manuscript. Sohyla Reshadat participated in the critical revision of the manuscript. All authors read and approved the final manuscript.

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