

# Research Paper: Quality of Life of Mothers of Children With Autism Spectrum Disorders and Its Relationship With Severity of Disorder and Child's Occupational Performance



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## ABSTRACT

**Introduction:** Mothers of children with Autism Spectrum Disorders (ASD) have the lowest grade of quality of life compared with mothers of children with other disorders like mental retardation, learning disorders, or physical impairments. To the best of our knowledge, there is no study on the influence of severity of disorder and occupational performance of autistic child on mother's quality of life. This study aims to determine the relationship between quality of life of these mothers with severity of disorder and occupational performance in their autistic children.

**Materials and Methods:** The participants included 35 mothers and their children with ASD (aged 3 to 7 years). They were selected by available sampling method from Tehran City, Iran. Severity of disorder and occupational performance were respectively measured by Gilliam Autism Rating Scale 2 and Canadian Occupational Performance Measure.

**Results:** The relationship between mothers' quality of life and severity of their children's ASD was significant (except for two components of physical roles [P=0.276] and bodily pains [P=0.174]). Also correlation of mothers' quality of life and occupational performance was significant (except for four dimensions of physical functioning [P=0.439], physical roles [P=0.801], bodily pains [P=0.105] and role emotional [P=0.140]).

**Conclusion:** The results show that quality of life of mothers of autistic children is significantly associated with severity of disorder and occupational performance of children, but its relationship with severity of disorder is more pronounced than occupational performance. Therefore, in order to improve mother's quality of life, the severity of symptoms of ASD should be decreased and child's occupational performance increased.

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## 1. Introduction

**A**utism Spectrum Disorders (ASD) are the range of complex developmental disorders characterized by delays or problems in cognitive, social, emotional, language, sensory and motor abilities. These defects are manifested in the early years of growth and affect the person's entire life [1]. Based on DSM-V like DSM-IV, there is no separate classification for pervasive developmental disorders. These disorders are all known as ASD, and in fact the degree and severity of disorder are considered. The degree of disorder is determined on a level and range and the severity of disorder is considered with regard to continuing deficiency in communication and social interaction, limited interests, and repetitive activities [2]. Children with ASD have many problems including attention problems, impulsivity, excessive or less responses to sensory stimuli and countless behavioral problems, like stereotyped behaviors, self-stimulatory behaviors, aggression, echolalia, sleep, nutritional problems and other so on [3, 4]. Average prevalence of ASD in Asia, Europe and North America is 1%. Symptoms commonly begin in 12 to 18 month old. Studies have shown that the prevalence of ASD in boys is nearly five times more than girls [5, 6].

ASD have multidimensional and extensive effects on the parents of these children [1]. Volkmar and Paules (2003) reported that about 85% of children with ASD, due to cognitive or adaptive constraints, have poor ability for independent living and so, parents take a lot of time to meet the needs of their children during their lifetime [7]. The mental and physical burden of taking care of children with ASD, due to primary role of mother in education and upbringing of child, is on mothers' shoulders. Therefore, they experience little marital satisfaction and experience more stress and fatigue and lower quality of life than fathers [8, 9].

The World Health Organization defines Quality of Life (QOL) as the individuals' perception of their position in life which depend on the cultural context and value systems of the community and their goals, expectations, standards and interests. It is very important to focus on QOL in difficult conditions, such as having a child with pervasive developmental disorder [9]. Haimour and Abu Hawwash (2012) showed that, among parents of children with mental retardation, cerebral palsy, learning disorder and normal children; parents of children with ASD, had the lowest degree of QOL [10]. Also, Gardiner (2015) examined the role of adaptive behavior and behavioral problems in family quality of life. The results indicated

that demographic and behavioral characteristics (child age and sex, severity of disorder, behavioral problems, and family income) and then adaptive performance in activities of daily living were considered as important predictors of family satisfaction from quality of life [11]. In addition, Rattaz (2017) showed that the effects of children with ASD on the quality of life of parents depend on their child's adaptive skills, as well as severity of disorder and presence of challenging behaviors [12].

Generally and according to previous studies, parents of children with mentally and physically disorders, especially the parents of children with ASD have the lowest QOL. There are many factors affecting quality of life of parents of these children, especially their mothers. Until now no study has investigated the relationship between quality of life of these mothers with severity of disorder and occupational performance of children with ASD. This study was conducted to find out the answer to this relationship.

## 2. Materials and Methods

This cross-sectional study has descriptive-analytic design. After obtaining the approval of Ethics Committee of Tehran University of Medical Sciences, 35 mothers of children with ASD were selected based on inclusion criteria using convenience sampling method. At first, the study purpose and procedure were explained to mothers and then the written consent of the subjects was taken to participate in study. The inclusion criteria of this study were having children of pre-school age (3 to 7 years old) with primary diagnosis of ASD, no associated disorders in these children, such as blindness, deafness, central nervous system diseases, and receiving common intervention of rehabilitation. Mothers of these children should not have severe depression (Beck depression score  $\leq 28$ ) [13]. Exclusion criteria of this study were lack of cooperation and willingness to leave the study during evaluation. The following tools were used to collect the study information:

### Demographic questionnaire

The questionnaire consisted of two categories of information: mother's personal information included age, marital status, educational status, and job status, child's personal information comprising age, sex, educational status and being a single child or not.

### Short Form Health Survey (SF 36)

This questionnaire has 36 questions that was designed by Ware and Sherbourne in the United States in 1992

to assess individual's health in terms of physical, psychological and social status in eight different domains. In the scoring, the physical functioning has 10 phrases, the physical role has 4 phrases, the bodily pains have 2 phrases, the general health has 5 phrases, the vitality has 4 phrases, the social functioning has 2 phrases, the role emotional has 3 phrases and mental health has 5 phrases which assesses the quality of life of individuals. The reliability and validity of the Persian version of this questionnaire in Iran was confirmed by Montazeri (2005). The internal consistency (to test reliability) showed that all eight SF-36 scales have satisfied the minimum reliability standard. The Cronbach  $\alpha$  coefficient values ranged from 0.77 to 0.90 with the exception of the vitality scale ( $\alpha=0.65$ ) [14, 15].

### Gilliam Autism Rating Scale 2 (GARS 2)

The GARS 2 test is a checklist that helps to identify autistic people. GARS 2 test is suitable for diagnosis of autism in individuals aged 3 to 22 years and can be completed by parents and specialists in the school or home. The GARS 1 test consists of four subscales and each subscale consists of 14 items. The first subscale is the stereotypical behavioral, which includes items 1 to 14. This subscale describes stereotypical behaviors, motor disturbances and strange behaviors. The second subscale is the establishment of communications and includes items 15 to 28. These items describe the verbal and nonverbal behaviors that are signs of autism. Social interactions are the third subcategory, which includes items 29 to 42. The raw grades of all three subscales are converted to standard grades and the total score of standard sub-scores can be converted to percentage scores and autism rates. Gaining 52 or lower scores indicates the least possibility of having autism disorder. Gaining 53-84 scores refers to moderate possibility of having autism disorder, and finally getting 85 and more scores points to high probably of having autism disorder.

The fourth subscale is the developmental disorders, which includes items 43 to 56. This subscale asks key questions about the child's developmental pattern, which has been omitted from GARS 2. Validity and reliability of the Persian version of GARS 2 was tested by Ahmadi (2011). In order to estimate the construct validity, the Childhood Autism Rating Scale (CARS) questionnaire was used simultaneously and the correlation coefficient of these two questionnaires were obtained as 0.80. The reliability of this scale was estimated as 0.89 with using Cronbach  $\alpha$  coefficient [16].

### Canadian Occupational Performance Measure (COPM)

This scale was prepared by Department of National Health and Welfare and Canadian Occupational Therapy Society after an extensive study in 1988. The Canadian Occupational Performance Measure (COPM) is based on a specific occupational therapy model and it covers the areas of Occupational performance, including self care, productivity, and leisure as the main results. This scale is conducted in a semi-structured interview and it takes only 20 to 30 minutes by an experienced therapist. This scale is implemented by the occupational therapist. Validity and reliability of this scale was performed in Iran by Dehghan (2015) in mothers of children with cerebral palsy. The Persian version, demonstrated high content validity ( $0.95\pm 0.222$ ) [17].

In order to analyze the obtained data, SPSS version 22 was used. To assess relationship between quality of life of mothers of children with ASD with severity of disorder and occupational performance of the child, the Pearson correlation coefficient was used.

### 3. Results

The demographic variables of mothers and children are presented in Tables 1 and 2. The relationship between variables of study are shown in Tables 3 and 4. The results showed that the relationship between physical functioning, general health, vitality, social functioning, role emotional, and mental health with child's severity of disorder was significant but there was no significant correlation between physical role and bodily pains with child's severity of disorder.

The results indicate that the relationship between general health, vitality, social functioning, mental health with child's occupational performance was significant but there was no significantly correlation between physical functioning, physical roles, bodily pains, role emotional with child's occupational performance.

### 4. Discussion

As parents influence children's development, the children's characteristics also impact parents' functions and their QOL [18]. Therefore, the relationship between child disorder and parents' functions is a two-way relationship. Therefore, besides children's needs, parents' functions must be considered, too [19]. So far many studies examined the effects of various factors (severity of disorder, child's challenging behaviors, mother's

**Table 1.** Demographic characteristics of mothers

| Variables          | Age Group           | No. (%)   | Mean (SD) |
|--------------------|---------------------|-----------|-----------|
| Age, y             | 24-30               | 11(31.42) | 32.8±4.97 |
|                    | 31-35               | 12(34.28) |           |
|                    | 36-40               | 11(31.42) |           |
|                    | 41≤                 | 1( 2.85)  |           |
| Marital status     | Married             | 35(100)   | -         |
|                    | Divorced or widowed | 0(0)      |           |
| Educational status | Eighth grade        | 5(14.28)  | -         |
|                    | High school         | 2(5.71)   |           |
|                    | Diploma             | 17(48.57) |           |
|                    | Bachelor            | 8(22.85)  |           |
|                    | Master              | 3(8.57)   |           |
| Job status         | Employed            | 2(5.71)   | -         |
|                    | Housewife           | 33(94.29) |           |

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age, child's sex and age, environmental and social needs, presence of comorbid disorders, mother's depression, mother's demographic characteristics, etc.) on QOL of mothers of children with ASD [8, 20-26].

This study was conducted to determine the relationship between QOL of mothers of children with ASD with the

severity of disorder and occupational performance of affected children.

This study showed that QOL of mothers of children with ASD was significantly associated with severity of disorder of child. There are similar articles supporting our present study results, Zablotzky (2013) reported that

**Table 2.** Demographic characteristics of children

| Variables                | Age Group                              | No. (%)   | Mean (SD) |
|--------------------------|--|-----------|-----------|
| Age, mon                 | 36-47                                  | 4(11.43)  | 58±10.75  |
|                          | 48-59                                  | 13(37.14) |           |
|                          | 60-71                                  | 14(40)    |           |
|                          | 72-84                                  | 4(11.43)  |           |
| Sex                      | Boy                                    | 30(85.72) | -         |
|                          | Girl                                   | 5(14.28)  |           |
| Educational status       | Going to kindergarten or preschool     | 8(22.85)  | -         |
|                          | Not going to kindergarten or preschool | 27(77.15) |           |
| Being or no single child | Single child                           | 21(60)    | -         |
|                          | Not being single child                 | 14(40)    |           |

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**Table 3.** The relationship between mother's quality of life with child's severity of disorder

|                              |                         | Mother's Quality of Life |               |              |                |          |                    |                |               |
|------------------------------|-------------------------|--------------------------|---------------|--------------|----------------|----------|--------------------|----------------|---------------|
|                              |                         | Physical Functioning     | Physical role | Bodily Pains | General Health | Vitality | Social Functioning | Role Emotional | Mental Health |
| Child's Severity of disorder | Correlation coefficient | -0.339                   | -0.189        | -0.235       | -0.565         | -0.537   | -0.401             | -0.339         | -0.498        |
|                              | Sig.                    | 0.047*                   | 0.276         | 0.174        | 0.000**        | 0.001**  | 0.017*             | 0.046*         | 0.002**       |

\*P≤0.05; \*\*P≤0.01

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To investigate the relationship between the study variables, the Pearson correlation was used at the significant level of P≤0.05.

more severe autism symptoms and a greater number of comorbid psychiatric disorders in a child with ASD were associated with increasing the probability of depression in the mother and decreasing mother's QOL [20]. In addition, Pozo (2014) reported from parents' views that the severity of disorder and behavioral problems in children with ASD have a negative and direct impact on family QOL and mental health. The correlation between child's severity of disorder and parent's QOL was closer than other measured variables in this study. This study also supports that children whose severity of disorder was higher, had less independence in doing daily living activities and therefore more dependence to their mothers [27]. Also, Piovesan (2015) by referring to higher depression symptoms and lower QOL in mothers of children with ASD reported more severe disorder with comorbid disorders [23].

Likewise and Øien (2016) reported that QOL of mothers of children with severe ASD, i.e. with problems in communication, behavior, and interests, have been affected [8]. In addition, Schlebusch (2017) clearly showed that family income, family class, and severity of symptoms of ASD were associated with family satisfaction and their

QOL. In other words, the child's severity of disorder had negative relationship with family QOL [28].

The results of this study indicated that QOL of mothers of children with ASD was significantly associated with occupational performance of child. There are similar studies with the same results of ours. According to Fairthorne (2014), mothers of children with ASD reported that challenging behaviors of children, adaptation to increasing needs of children and consequently isolation, were factors responsible for decreasing their QOL [24]. Also, Baghdadli (2014) concluded that lower function level and higher aberrant behaviors in children with ASD were the main risk factors of lower QOL of their mothers [29].

Generally, the results indicate that mother's QOL in significancy and number of components is more correlated with child's severity of disorder than child's occupational performance. These results may have several possible causes. For a start, severity of disorder was assessed by therapists with collaboration of mothers, but children's occupational performance was reported only by mothers. Therefore, the assessment of severity of disorder may be more objective and accurate than the

**Table 4.** The relationship between mother's quality of life with child's occupational performance

|                                  |                         | Mother's Quality of Life |                |              |                |          |                    |                |               |
|----------------------------------|-------------------------|--------------------------|----------------|--------------|----------------|----------|--------------------|----------------|---------------|
|                                  |                         | Physical Functioning     | Physical Roles | Bodily Pains | General Health | Vitality | Social Functioning | Role Emotional | Mental Health |
| Child's occupational performance | Correlation coefficient | 0.135                    | 0.044          | 0.279        | 0.433          | 0.361    | 0.402              | 0.255          | 0.352         |
|                                  | Sig.                    | 0.439                    | 0.801          | 0.105        | 0.009**        | 0.033*   | 0.017*             | 0.140          | 0.038*        |

\*P≤0.05; \*\*P≤0.01

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assessment of the child's occupational performance. Similarly, the mothers evaluated their children's occupational performance by COPM scale, in three areas of self care, productivity and leisure, but GARS 2 test examines the social, behavioral, and communication problems of these children. Probably due to the bias and attitude of the society, social and behavioral and communication problems of children with ASD are more effective than other problems of these children on mental health and quality of life of their mothers.

On the whole, authors of this study believe that, in order to improve QOL of mothers of children with ASD, severity of symptoms of ASD should be decreased and their occupational performance be increased. Paying attention to this point in rehabilitation programs of ASD, can help increase QOL of family, especially mothers.

One of the limitations of this study was poor cooperation of rehabilitation centers and mothers in the research. Another problem of this study was time consuming completion of the questionnaires. For future studies, we suggest evaluation of performance impairments of children with ASD using standard instruments and then evaluating its relationship with mothers' QOL and comparing the results with ours.

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### Conflict of Interest

The authors declared no conflicts of interest.

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