

Original Article

Perceived Social Support and Quality of Life of Parents of Children with Autism

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ABSTRACT

Background: When examining the incidence of autism, however, children should not be considered independent of their parents, as this collection of disorders also affects the life of their family members. Having a disabled child affects the relationships with the family and friends, and the social and work life of families. The quality of life of these families is discussed in terms of financial aspects, health, support of family members, values, occupation, family relations, and individual support dimensions of developmental disabilities. However, there are very limited studies on the relationship between perceived social support and quality of life of parents of children with autism, and none of these has been conducted in Turkey. **Aim:** This study aimed to identify the perceived social support and quality of life of the parents of children with autism and to investigate the related factors. **Study Design:** The sample of the study consists of 90 parents who accepted to join the research studies. The participants enrolled in the study included 90 biological parents (31 mothers; 59 fathers). Eighteen children had both mother and father participate (all participants subsequently will be referred to as “parents”). **Methods:** This was a descriptive cross-sectional study. A socio-demographic form, the EUROHIS Quality of Life Scale (EUROHIS QOL-8) and the Multi-Dimensional Scale of Perceived Social Support (MSPSS) were used for data collection. **Results:** The mean score on the EUROHIS QOL-8 was 26.17 ± 4.91 and that on the MSPSS was 51.06 ± 20.6 . A statistically significant relationship was found between the EUROHIS QOL-8 and MSPSS scores ($r = 0.524$, $P = 0.000$). There were significant differences on the average score on the EUROHIS QOL-8 and MSPSS based on fathers’ job status. **Conclusion:** Our results provide important insights into the family experiences of parents of children with autism, and may aid the development of appropriate interventions to further support them. Providing support and understanding families of children with autism and their experiences, nurses, doctors and health professionals can positively affect their health outcomes. Healthcare professionals should focus on determining the needs of families to accordingly plan and implement appropriate programs.

KEYWORDS: *Autism, perceived social support, quality of life, Turkish parents*

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INTRODUCTION

Autism is a neuropsychiatric developmental syndrome that develops before the age of 3 years. The conceptualization process of this syndrome is based on the observations of Kanner.^[1] Kanner assessed children with autism in terms of socialization,

communication disorder, and repetitive restrictive behaviors. Autism, Asperger syndrome, Rett

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syndrome, childhood disintegrative disorder, pervasive developmental disorder, and any other condition that is not otherwise specified are examined under the framework of autism spectrum disorder (ASD) by the World Health Organization (WHO).^[2] In addition, the common features of these disorders are difficulties in acquiring cognitive, linguistic, social, and motor skills.^[2] According to the data obtained by the Centers for Disease Control and Prevention, autism affects 1 in 68 children.^[3] In different studies, the proportion of children with autism ranged from 1.2% to 4.3% in Canada and from 14.7% to 24.6% in the UK, and this rate is determined to be 26.4% in South Korea and 2.9% in Taiwan.^[3-6] It is known that the prevalence of ASDs varies between 1% and 2% in Asia, Europe, and South America.^[4] According to Turkish Statistical Institute, the rate of incidence of mental retardation, learning disabilities, cerebral palsy, autism, and congenital dislocation of the hip was 1.7% in 2008, 2% in 2010, and 3.1% in 2012 in Turkey. However, the rate of incidence of autism is unknown in Turkey.^[7]

When examining the incidence of autism, children should not be considered independent of their parents, as this collection of disorders also affects the life of their family members. Having a disabled child affects the relationships with the family and friends, and the social and business life of families.^[8] Some studies showed that families of children with disabilities have a high level of depression and anxiety.^[9-11] In addition, one study revealed that most families of children with disabilities never receive social support.^[12] According to the results of a qualitative study on the perceptions of perceived social support of parents of children with autism, the number of people they interact within their social environment, the frequency of close family visits, and the social support provided to them are at the beginning of the effects on social life.^[13] Social support has been identified as a critical factor that reduces the negative psychological effects of raising a child with ASD as well as other disabilities.^[14] Social support is crucial for the health of parents of children with disabilities. Regardless of the age of children with autism, families may need social support at all times. Effective social support is beneficial both for the health of mothers and for the development of the children with disabilities.^[15]

A study found that the social support provided to families of children with autism was the most important predictor of perceived quality of life (QoL) and that the perceived social support was positively affected by QoL.^[16] In other words, it is emphasized that optimal social support is also a sign of QoL.

Studies on the QoL of families seem to focus on families of persons with developmental disabilities. The QoL of these families is discussed in terms of financial aspects, health, support of family members, values, occupation, family relations, and individual support dimensions of developmental disabilities.^[17] However, there are very limited studies on the relationship between perceived social support and QoL of parents of children with autism, and none of these have been conducted in Turkey.^[16,18] Therefore, the purpose of this descriptive study was to determine the status of perceived social support and QoL of parents of children with autism and to examine the related factors.

MATERIALS AND METHODS

Study population

There is only one autism foundation in the capital of Turkey. The foundation, in collaboration with a public university, has set up a sports center for children with autism, to provide them opportunities to engage in training activities every weekend, from 16.00 to 18.00 pm. In total, 72 children with autism attend the training. The sample is not selected, it is aimed to reach at least one person from each child's family; if both parents are present, we suggested both to participate in the study. The sample of the study consists of ninety parents who accepted to join the research studies. The participants enrolled in the study included 90 biological parents (31 mothers and 59 fathers). There was a participation of both mother and father in 18 children (all participants subsequently will be referred to as "parents").

The study protocol was reviewed and approved by a Public University Ethics Committee. The directors of autism foundation and a public university faculty of sports sciences were informed about the study. A cover letter containing significant information about the study was attached with each questionnaire and was distributed to the respondents. The study participants were informed that if they did not want to continue, they could withdraw from the study at any time without stating a reason. Separate written consent was solicited from the parents before they answered the questionnaire. Throughout the study period, confidentiality was strictly observed.

Data collection

The data were collected privately from the children's parents while they were waiting for their children. Data were collected from May 4 to 26, 2013, between 16.00 and 18.00 pm, using face-to-face interviews. The completion of the descriptive information form and scale took 10–15 min. No sampling method was used as we

attempted to select at least one individual from each child's family.

Description of the forms

Sociodemographic form

This form comprised questions regarding demographic information (parents, educational background, and job status of parents and age, gender, and age at diagnosis of the children with autism). It was developed by the researchers.

Multi-Dimensional Scale of Perceived Social Support

Developed in 1988 by Zimet *et al.*,^[19] the Multi-Dimensional Scale of Perceived Social Support (MSPSS) consists of 12-point Likert-type items ranging from “very strongly disagree” to “very strongly agree.” The total score of the scale varies between 12 and 84. It is an easy and short measure for the subjective assessment of perceived social support. The Turkish adaptation and determination of the validity and reliability of the scale were done by Eker and Arkar^[20] and Çakır and Palabıyık.^[21] According to the results of a study that examined the psychometric properties of the MSPSS, Meral and Cavkaytar^[22] observed that the factor loadings on the exploratory factor analysis were high, and the 3-factorial MSPSS had a good level of compliant indices according to the confirmatory factor analysis. This inventory was tested for validity and reliability within the Turkish population and was found that the Cronbach's alpha reliability coefficient for the inventory was 0.91. In the present study, the Cronbach's alpha reliability coefficient for the inventory was 0.83. Therefore, the MSPSS was deemed as an appropriate tool to assess the social support resources of families of children with autism. It was found that the reliability scores of the total and subdomains of the MSPSS were as high as they were in the previous studies, and the split-half reliability of the scale was optimal.^[18]

EUROHIS Quality of Life Scale

EUROHIS QOL-8 consists of eight questions selected on the basis of a particular methodology. Two of these questions are related to WHO's concepts of overall health and overall QoL, and the other six questions are related to physical, mental, social, and environmental dimensions.^[23] Eser *et al.*^[24] stated that the Turkish version of EUROHIS QOL-8-TR can be used as a one-dimensional tool (index criterion) due to the large percentile of the first factor. The two-factor structure can be used in the confirmatory resolution because it gives better results. It consists of 8 items with a 5-point response format on a Likert scale, ranging from “not at all satisfied,” “slightly satisfied,”

“moderately satisfied,” “very satisfied” to “completely satisfied.” Based on these findings, it is suggested that the Turkish version of the EUROHIS QOL-8 is statistically sensitive for medical and socioeconomic variables and can be used for the development of policies, especially for determining priority groups, to ensure health in the Turkish society and its Cronbach's alpha value is higher than 0.70.^[25] In the present study, the Cronbach's alpha reliability coefficient for the inventory was 0.73.

Statistical analysis

The obtained data were analyzed using Statistical Package for the Social Sciences (version 22, IBM Corp., Armonk, NY, US). Means, standard deviations (SDs), frequencies, percentages, medians, minimums, and maximums were calculated. The correlations between two independent categorical variables were examined using a Chi-square test, and the Kruskal–Wallis test was used to analyze the differences between more than two independent groups. $P > 0.05$ was regarded statistically nonsignificant.

RESULTS

The demographic characteristics of the children with autism are presented in Table 1. Half of the children with autism were aged between 2 and 10 years (69%). Further, 19 of them were male (26.4%) and 53 were female (73.6%). Majority of the children were diagnosed with autism at the age of 13–35 months.

Table 2 presents the descriptive statistics related to the demographic characteristics of the study population. The study population consisted of 31 mothers (34.4%) and 59 fathers (65.6%). Most of the mothers ($n = 54$, 60%) and fathers ($n = 70$, 77.8%) of children with autism were university graduates. Further, most of the mothers ($n = 39$, 43.3%) and fathers ($n = 49$, 54.5%) were working as an official officer.

Table 3 shows the mean scores and correlations between the EUROHIS QOL-8 and MSPSS. The mean score on the EUROHIS QOL-8 was 26.17 (SD = 4.91) and that on MSPSS was 51.06 (SD = 20.6). There was a significant positive relationship between EUROHIS QOL-8 and MSPSS scores ($r = 0.524$, $P = 0.00$).

Table 4 presents the findings of the analysis of the relationship between some characteristics of the study population and EUROHIS QOL-8 scores. The results showed a statistically significant effect of “parents” and “fathers' job status” on EUROHIS QOL-8 scores ($P < 0.005$).

Table 1: Descriptive characteristics of children with autism (n=72)

Characteristics	n (%)
Age (years)	
2-10	50 (69)
11-20	18 (25)
21-29	4 (6)
Gender	
Male	19 (26.4)
Female	53 (73.6)
Month at diagnosis	
13-35	41 (57.0)
36-59	15 (21.0)
60-84	16 (22.0)
Total	72 (100)

Table 2: Descriptive characteristics of the study population

Characteristics	n (%)
Parents	
Mother	31 (34.4)
Father	59 (65.6)
Education of mothers	
Primary-secondary school	15 (16.7)
High school	21 (23.3)
University	54 (60.0)
Education of fathers	
Illiterate	2 (2.2)
Primary-secondary school	4 (4.4)
High school	14 (15.6)
University	70 (77.8)
Job status of mothers	
Employer is highly educated	2 (2.2)
Small businesses	2 (2.2)
Highly educated	21 (23.3)
Official officer	39 (43.3)
Unemployed	26 (29.0)
Job status of fathers	
Employer is highly educated	6 (6.7)
Small businesses	3 (3.3)
Highly educated	29 (32.3)
Official officer	49 (54.5)
Unemployed	2 (2.2)
Unskilled worker	1 (1.1)
Total	90 (100)

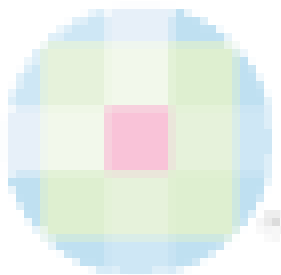


Table 3: Distribution of scale point averages of the study group and the results of correlation analysis

Scales	Minimum	Maximum	Mean±SD	r	P
EUROHIS QOL-8	12	39	26.17±4.91	0.524	0.000*
MSPSS	12	84	51.06±20.6		

*P<0.05. MSPSS=Multi-Dimensional Scale of Perceived Social Support; SD=Standard deviation; EUROHIS QOL-8=EUROHIS Quality of Life Scale

Table 5 shows the findings of the analysis of the relationship between some characteristics of the participants and MSPSS scores. There was a statistically significant difference between MSPSS and “fathers’ job status” (P < 0.005).

Table 4: EUROHIS Quality of Life Scale scores according to some characteristic of study populations

Characteristics	<i>n</i>	Mean±SD	Test value	<i>P</i>
Parents				
Mother	31	30.07±0.490	<i>F</i> : 2.55	0.021*
Father	59	33.38±0.648		
Education of mothers			χ^2 : 0.290	0.290
Primary-secondary school	15	52.35±0.614		
High school	21	36.93±0.681		
University	54	46.87±0.961		
Education of fathers			<i>F</i> : 0.851	0.497
Illiterate	2	30.87±0.176		
Primary-secondary school	4	30.00±0.060		
High school	14	31.11±0.580		
University	70	30.29±0.635		
Job status of mothers			<i>F</i> : 0.274	0.142
Employer is highly educated	2	30.63±0.353		
Small businesses	2	30.00±0.000		
Highly educated	21	30.30±0.604		
Official officer	39	31.25±0.690		
Unemployed	26	30.27±0.551		
Job status of fathers			<i>F</i> : 2.366	0.046*
Employer is highly educated	6	30.50±0.440		
Small businesses	3	30.50±0.250		
Highly educated	29	31.37±0.604		
Official officer	49	32.21±0.613		
Unemployed	2	30.13±0.000		
Unskilled worker	1	±0.231		

P*<0.05. SD=Standard deviationTable 5: Multi-Dimensional Scale of Perceived Social Support scores according to some characteristics of the study populations**

Characteristics	<i>n</i>	Mean±SD	Test value	<i>P</i>
Parents				
Mother	31	48.80±20.863	<i>F</i> : 0.051	0.469
Father	59	52.16±20.624		
Education of mothers			<i>F</i> : 0.944	0.423
Primary-secondary school	15	51.25±17.19		
High school	21	53.33±18.82		
University	54	50.66±21.73		
Education of fathers			<i>F</i> : 1.950	0.111
Illiterate	2	72.00±14.142		
Primary-secondary school	4	43.00±4.242		
High school	14	54.07±20.360		
University	70	49.17±20.652		
Job status of mothers			<i>F</i> : 0.563	0.690
Employer is highly educated	2	54.50±41.719		
Small businesses	2	43.00±0.000		
Highly educated	21	56.57±23.215		
Official officer	39	49.33±18.395		
Unemployed	26	49.38±21.542		
Job status of fathers			<i>F</i> : 2.347	0.048*
Employer is highly educated	6	56.50±23.636		
Small businesses	3	73.33±14.153		
Highly educated	29	54.75±22.038		
Official officer	49	47.00±18.548		
Unemployed	2	64.00±0.000		
Unskilled worker	1	±14.124		

**P*<0.05. SD=Standard deviation

DISCUSSION

In this study, we investigated perceived social support and QoL in the parents of children with autism. We observed a positive relationship between perceived social support and QoL values in our sample. Furthermore, both social support and QoL were significantly correlated with father's job status. Official officer and highly educated fathers have high QoL and perceived social support. These findings provide new insight into the effects of perceived social support of parents of children with autism and how this might interact with their QoL. Findings show that social support perception levels of families who have child with autism are above the average (51.06 ± 20.6). This finding was similar to those reported by Coşkun and Akkaş,^[25] who explored the perceived social support (52.22 ± 16.21) of mothers of children with disabilities. These findings indicate that the social environment of families of children with disabilities is not insensitive and that they support such families. Studies have found that social support is a very important factor related to the coping of families of children with autism and it helps reduce their stress levels.^[15,26] In this regard, the autism foundation can be considered as a social support system for families. The foundation was established to provide free and safe living spaces, to prepare appropriate social environments based on different needs, to provide educational intervention, and to tackle the cultural and legal issues of children with autism.^[27] On the other hand, while it is a positive outcome for families of children with autism to have above-average perceived social support, several studies have reported low perceived social support.^[28]

EUROHIS QOL-8 scores range between 8 and 40. The present study found that the QoL of families of children with autism was average (26.17 ± 4.91). While some studies have reported low QoL in families of children with autism,^[29,30] others have reported average or high QoL.^[31,32] In addition, a statistically significant relationship was found between QoL and perceived social support, suggesting that, the higher the perceived social support of families of children with autism is, the higher is their QoL.^[33]

A statistically significant relationship was found between the level of QoL and genders of the participants. We found that women had lower QoL than men did, which is similar to the findings of other studies.^[34,35] This is probably because stressful life events affect women more than they do men^[36] and caregivers of children with ASDs predominantly were mostly mothers,^[37] so these factors may affect the results.

Another important finding of this study was that the job status of the fathers positively affected both perceived

social support and QoL. Family income may be an important factor affecting the care provided to children with autism. This finding is consistent with the logical interpretation that a father with a good job may have a higher income, which would help the family seek support services more easily. This, in turn, would improve their QoL. This finding is also supported by those of the studies conducted by Hatton and Emerson^[38] and Dardas and Ahmad.^[32] However, the impact of the job status of fathers was ignored in most of the previous studies on parents of children with autism.

CONCLUSION

We observed above-average levels of perceived social support in the study group families of children with autism. High perceived social support improves the QoL of parents of children with autism. In addition, the job status of fathers had a significant impact on the perceived social support and QoL of the families. Our results provide important insights into the family experiences of parents of children with autism and may aid in the development of appropriate interventions to further support them. If nurses, doctors, and health professionals provide support and understand families and experiences, they can positively affect their health outcomes. Health-care professionals should focus on determining the needs of families to accordingly plan and implement appropriate programs.

Limitations

The small sample size and descriptive research design limit the generalizability of the findings. This study was undertaken in families of children with autism in Turkey so the results may not be generalizable to all families of children with autism. Nonetheless, there are very limited studies on the relationship between perceived social support and QoL of parents of children with autism, and none of these has been conducted in Turkey. Therefore results should be interpreted with caution.

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Conflicts of interest

There are no conflicts of interest.

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