

Assessment of Quality of Life among Parents with Autistic Child

ADYAN LHMOOD ABD-ALNABI¹, KAREEM RESHAK SACHET²

¹Academic Bachelor's nurse, Mohammed Al-Mosawi hospital, Dhi-Qar Health Department, Iraqi Ministry of Health

²Associate Professor Department of Psychiatric Mental Health Nursing College of Nursing University of Baghdad

Corresponding author: Adyan Lhmod Abd-Alnabi, Email adeaan.lahmood1205b@conursing.uobaghdad.edu.iq

ABSTRACT

Background: Parents caring for or living with a child diagnosed with a chronic illness such as autism are more likely to experience stress-related issues and have a lower quality of life

Aims of the study: assess the quality of life among parents with autistic children.

Methodology: A descriptive cross-sectional study conducted by a purposive sample of 120 parents of autistic children were selected through the use of a non-probability sampling approach. The reliability of the questionnaire was achieved through a pilot study and then presented to experts to prove its validity. The total number of items included in the questionnaire was 26-items for quality of life. The data was collected using the self-report method and analyzed by applying a descriptive and inferential statistical data analysis approach.

Results: The results of the study indicated that (58.3%) had a poor level of quality of life. And there is a significant association in quality of life with regard to parents' kinship ($p=0.006$), level of education ($p=0.001$), social status ($p=0.050$), monthly income ($p=0.001$), and duration of diagnosis for their children at ($p=0.011$).

Conclusions: Parents with autistic children presented a poor level of quality of life overall, with a moderate level of quality of life in the physical domain, and in the psychological domain, while the reduced level of quality of life with regard to the social relationship domain, and environment domain. Further study is needed to measure a wide population so that the findings may be generalized.

Keywords: Quality of Life, Parents, Autistic child.

INTRODUCTION

Autistic Disorder is a complicated childhood developmental disability that can have a severe impact on a child's intellectual, social, and language abilities. The number of children diagnosed with Autistic Disorder has risen dramatically, leaving a large number of children and their parents in need of comprehensive support services. Parenting a child with Autistic Disorder has been reported to disrupt the entire family's life and cause a slew of economic, social, physical, and psychological issues⁽¹⁾. Autism spectrum disorder affects as many as one in every 68 children and is a lifelong issue. According to a large amount of research, ASD can have both beneficial and harmful long-term consequences on Families of children, especially parents⁽²⁾.

According to their child's developmental issues, parents of children with autism spectrum disorders (ASD) encounter numerous hurdles. Parents' Quality of Life (QoL) has recently been identified as one of the key health problems following a lifelong challenging experience such as parenting a disabled child. Quality of life is defined as an individual's view of their position in life in relation to their objectives, expectations, standards, and concerns in the context of the culture and value systems in which they live.⁽³⁾

Caring for a child with autism can have a variety of negative effects on the caregiver's quality of life. When a child is diagnosed with autism the family is frequently burdened and family members are forced to drastically alter their everyday routines to accommodate their new reality⁽⁴⁾.

Parents of children with autism may have a higher impairment of quality of life (QOL) than other groups, posing a threat to their emotional, physical, and social well-being⁽⁵⁾. The psychological discomfort and physical health of parents are directly linked to the symptoms of autism spectrum disorder, which severely impacts the parents' sleep and comfort, as well as their eating patterns and their marital connection, resulting in a lesser quality of life than it should be⁽⁶⁾.

METHODOLOGY

Design of the Study: A descriptive study design was carried out in order to achieve the objectives of the study. The study was initiated (from January first, 2022 to 20 March 20th, 2022).

Setting of the Study: The study was carried-out at the Dhi Qar Center for Rehabilitation of Autistic Disorders

The Sample of the Study: A non-probability (purposive) sample of (120) autistic parents were selected from Dhi Qar Center for Rehabilitation of Autistic Disorders

Data collection: Data were collected through the use of a questionnaire by means of direct interviews with nurses from the January 4th, 2022, until January 20th, 2022.

The Study Instrument: The instruments underlying the study phenomenon deals with parents socio-demographic characteristics, and a Quality of life questionnaire (World Health Organization Quality of Life (WHOQOL)-BREF scale) developed and constructed to describe study phenomenon. The total number of items included in the questionnaire was 26 items.

Rating and Scoring: The items of the questionnaire were scored as 5-Liker's Scale

Statistical data analysis: Data were analyzed through the use of IBM-Statistical Package of Social Sciences (SPSS) which included descriptive statistics

RESULTS

Table 1: Distribution of Sample according to Parents' Socio-demographic Characteristics

List	Characteristics	f	%	
1	Age M±SD= 35.38±8.880	26 – 35 year	71	59.2
		36 – 45 year	39	32.4
		46 – 55 year	5	4.2
		56 ≤ year	5	4.2
		Total	120	100
2	Kinship	Father	50	41.7
		Mother	70	58.3
		Total	120	100
3	Level of education	Doesn't read & write	36	30
		Read & write	16	13.3
		Primary school	15	12.5
		Intermediate school	0	0
		Secondary school	5	4.2
		Institute/college	48	40
Total	120	100		
4	Social status	Living together	94	78.3
		Separated	26	21.7
		Dead father	0	0
		Dead mother	0	0
		Total	120	100
5	Monthly income	Insufficient	67	55.8
		Barely sufficient	35	29.2
		Sufficient	18	15
		Total	120	100

f: Frequency, %: Percentage, M: Mean, SD: Standard deviation

This table shows that parents of autistic children are young adult with age 35.38±8.880 years that 59.2% of them are seen with age group of 26-35 year and 32.4% are with age group of 36-45 year.

The kinship degree refers that 58.3% of them are mothers and remaining are fathers (41.7%).

Regarding level of education, the highest percentage refers to institute/college graduation among 40% of parents while 30% of them are doesn't read and write. The social status variable for parents refers that more of them are with normal social status in which 78.3% of them reporting they living together but 21.7% of them reported they are separated.

Regarding monthly income, 55.8% of parents are perceived insufficient monthly income, and 29.2% of them perceive barely sufficient income while only 15% are perceive sufficient monthly income.

Table 2: Distribution of Sample according to Children' Socio-demographic Characteristics

List	Characteristics	f	%
1	Age M±SD= 5.68±3.181	1 – 3 years	31 25.8
		4 – 6 years	64 53.3
		7 – 9 years	6 5
		10 ≤ year	19 15.8
		Total	120 100
2	Gender	Male	88 73.3
		Female	32 26.7
		Total	120 100
3	Birth order	First	69 57.5
		Second	26 21.7
		Third	13 10.8
		Fourth	0 0
		Fifth +	12 10
Total	120 100		
4	Duration of diagnosis	1 – less than 2 year	62 51.7
		3 – less than 4 years	11 9.1
		4 – less than 6 years	12 10
		6 – less than 8 years	0 0
		8 – less than 10 years	35 29.2
Total	120 100		
5	Another autistic child in family	No	87 72.5
		Yes	33 27.5
		Total	120 100
6	Living with parent	No	13 10.8
		Yes	107 89.2
		Total	120 100

f: Frequency, %: Percentage, M: Mean, SD: Standard deviation

This table reveals that autistic children are with age 5.68±3.181 years in which 53.3% are with age group 4-6 years.

The gender for autistic children refers that more of them are males as seen with 73.3% and 26.7% are females. Regarding birth order for autistic children, 57.5% of children are firstborn and 21.7% are second born. The duration of diagnosis for autism among children refers that more than half of them are diagnosed since 1-less than 2 years (51.7%) which indicates are recently diagnosed. Regarding presence of another child with autism in family, only 27.5% of parents report they have another child with autism in their family. The parents report that their child is living with them as seen with 89.2% while 10.8% of parent report their child is nod live with them.

Table 3: Overall Assessment of Quality of Life among Parents with Autistic Child

Quality of life	F	%	M	SD
Poor	70	58.3	57.69	24.952
Fair	41	34.2		
Good	9	7.5		
Total	120	100		

f: Frequency, %: Percentage, M: Mean for total score, SD: Standard Deviation for total score Poor= 26 – 60.66, Fair= 60.67 – 95.33, Good= 95.34 – 130

This table indicates that parents with autistic children are associated with poor to fair quality of life (M±SD= 57.69±24.952) in which 58.3% are show poor level and 34.2% are show fair level.

Table 4: Mean and Standard Deviation for Items related to Physical Domain of Quality of Life among Parents (N=120)

No	Physical domain	Mean	SD	Assessment
1	To what extent do you feel that physical pain prevents you from Doing what you need to do?	2.13	1.178	Poor
2	How much do you need any medical treatment to functionin your daily life?	2.01	1.220	Poor
3	Do you have enough energy for everyday life?	2.39	1.190	Fair
4	How well are you able to get around?	2.19	1.298	Poor
5	How satisfied are you with your sleep?	2.02	1.270	Poor
6	How satisfied are you with your ability to perform yourdaily living activities?	2.20	1.370	Poor
7	How satisfied are you withyour capacity for work?	2.38	1.583	Fair

No: Number, SD: Standard Deviation for total score, Poor= 1 – 2.33, Fair= 2.34 – 3.67, Good = 3.68 - 5

This table reveals that mean scores indicate poor among all items of physical domain except items 3 and 4 that show fair level.

Table 5: Mean and Standard Deviation for Items related to Psychological Domain of Quality of Life among Parents (N=120)

No	Psychological domain	Mean	SD	Assessment
1	How much do you enjoy life?	2.26	1.111	Poor
2	To what extent do you feel your life to be meaningful?	2.45	1.173	Fair
3	How well are you able to concentrate?	2.45	1.269	Fair
4	Are you able to accept your bodily appearance?	2.74	1.423	Fair
5	How satisfied are you with yourself?	2.39	1.530	Fair
6	How often do you have negative feelings such as bluemoor, despair, anxiety, depression?	2.35	1.537	Fair

No: Number, SD: Standard Deviation for total score, Poor= 1 – 2.33, Fair= 2.34 – 3.67, Good = 3.68 - 5

This table reveals that mean scores indicates fair level among all items of psychological domain except item 1 that show poor which is (How much do you enjoy life?).

Table 6: Mean and Standard Deviation for Items related to Social Relationship Domain of Quality of Life among Parents (N=120)

No	Social Relationship domain	Mean	SD	Assessment
1	How satisfied are you with your personal relationships?	2.36	1.500	Fair
2	How satisfied are you withyour sex life?	1.97	1.378	Poor
3	How satisfied are you with the support you get from your friends?	2.13	1.322	Poor

No: Number, SD: Standard Deviation for total score, Poor= 1 – 2.33, Fair= 2.34 – 3.67, Good = 3.68 - 5

This table reveals that mean scores indicates fair level in item 1 and poor level in items 2 and 3 that indicate poor social relationship among parents.

Table 7: Mean and Standard Deviation for Items related to Environmental Domain of Quality of Life among Parents (N=120)

No	Environmental domain	Mean	SD	Assessment
1	How safe do you feel in your daily life?	2.24	1.130	Poor
2	How healthy is your physical environment?	2.13	1.115	Poor

3	Have you enough money to meet your needs?	2.21	1.084	Poor
4	How available to you is the information that you need in your day-to-day life?	2.42	1.186	Fair
5	To what extent do you have the opportunity for leisure activities?	1.83	.974	Poor
6	How satisfied are you with the conditions of your living place?	1.68	1.047	Poor
7	How satisfied are you with your access to health services?	1.85	1.034	Poor
8	How satisfied are you with your transport?	1.66	1.008	Poor

No: Number, SD: Standard Deviation for total score, Poor= 1 – 2.33, Fair= 2.34 – 3.67, Good = 3.68 – 5

This table reveals that mean scores indicates poor among all items of environmental domain except item 4 that show fair level.

DISCUSSION

Demographic Characteristics: The finding of data analysis for 120 samples of parents with the autistic child according to Table (4-1) show (50) fathers and (70) mothers were (59.2%) The majority of the participants in the study were between the ages of (26-35 years) and (4.2%) of them were with age group (56 ≤ years). Females were participants more than males because most men are probably at work at that time or maybe The presence of mothers the most time with their children, makes them more aware of the condition of the child, in addition to gaining more flexibility in dealing with him. Supportive evidence has been found by the study conducted on 320 parents with autistic children to assess the burden among them, found about (57) males and (259) females⁽⁷⁾. regarding the level of education, the highest percentage refers to institute/college graduation among 40% of parents while 30% of them are doesn't read and write this result similar to the result of a study conducted in Iraq to Assess "Quality of Life for Parents of Autistic Child" showed advanced percentage of contributor within the age group (21-30) years old and more than half institute/college graduation was (10.2%) diploma and (44.9%) bachelor degree⁽⁸⁾. The current study also found The social status variable for parents refers that more of them are with normal social status in which 78.3% of them reported they alive together but 21.7% of them reported they are separated.

these findings agree with the study "Quality of life among parents of South African children with autism spectrum disorder" that showed higher percentage married, and according to Table (4-1) Regarding monthly income, 55.8% of parents are perceived insufficient monthly income, and 29.2% of them perceive barely sufficient income while only 15% are perceived sufficient monthly income⁽⁹⁾. According to the researcher's perspective on monthly income, the monthly income is insufficient due to the financial load of medicines and specific needs of the child, as well as transportation costs when visiting a rehabilitation center.

Children's Socio-demographic :Table (2) reveals that autistic children are with age 5.68±3.181 years of which 53.3% are with age group 4-6 years. This result is comparable to that obtained by Fayyadh and Faraj who included (31%) children aged five to six years old in their sample⁽¹⁰⁾. The gender for autistic children refers that more of them are males as seen with 73.3% and 26.7% are females this result is close to study which found that 67% of their sample were males and only 33% were females⁽¹¹⁾.

Also, another study stated that more than half (53.9 percent) of their sample were males⁽¹¹⁾. Regarding birth order for autistic children, 57.5% of children are firstborn and 21.7% are second-born. the finding was in agreement to the study confirmed by study done in Riyadh, who demonstrate more than half about 78 (47.9) were forth or more order of children with autism in family⁽¹²⁾.

The duration of diagnosis for autism among children refers that more than half of them are diagnosed since 1-less than 2

years (51.7%) which indicates are recently diagnosed this finding disagrees with a study which noted that twenty-one percent of children in their sample were having a duration of diagnosis between four to five years old⁽¹³⁾.

Regarding the presence of another child with autism in the family, only 27.5% of parents report they have another child with autism in their family. This result agrees with the result of a study that showed only 22.2 percent of parents had more than one child with autism and 77.8 had not another child with autism⁽¹⁴⁾. Another study come in line of current study demonstrated by 189 case of parents have one child with autism, while only 18 family has more than one child with autism out of a total of 207 participants⁽¹⁵⁾.

Analysis of Overall Assessment of Quality of Life among Parents with Autistic Child showed about more than half of participants (58.3%) had the poor level quality of life and less than half (34.2%) had a good quality of life (Table 3). This finding provides an indication that the presence of a child with autism in the family effects on life function of parents including quality of life and was considered as important part that lead to inability of parents to dong daily role such as at working, relationship with family member or friends and spouse. This finding of current study supported the result of previous study conducted in India to "assess quality of life in families of children with autism spectrum disorder" that showed impaired quality of life⁽¹⁶⁾.

The level of quality of life- about the physical domain showed that 50.8% of parents have moderate level of quality of life while 61.7% of parents had fair level of quality of life regarding psychological domain, 60.8% of parents had impaired level of quality of life regarding social relationship domain, and 60 % of parents show poor level of quality of life regarding environmental domain. (Tables 4,5,6,and 7). This result is in line with the study "Quality of life among parents of South African children with autism spectrum disorder" Parents of autistic children have worse quality of life scores in four QOL dimensions⁽¹⁷⁾. Parents of children with Autism also report worse quality of life scores in the WHOQOL-BREF domains than other parents, according to earlier study⁽¹⁸⁾⁽¹⁹⁾⁽²⁰⁾.

This finding provides an indication that the presence of a child with autism in the family effects on life function of parents including quality of life and was considered as significant part that lead to incapability of parents to dong daily role such as at working, connection with family member or friends and spouse

CONCLUSION

The study concluded Quality of life is significantly higher and influenced by gender, level of education, social status, monthly income of parents, and age of the child.

Recommendation: The study recommended to accomplish future studies on a large population to evaluate quality of life among autistic parents in Iraq to be able to generalize results. Mental health counseling is set up in an autistic center and provides professional counselors to prevent serious psychological problems.

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