

Assessment of Quality of Life for Parents of Autistic Child

تقييم جودة الحياة لوالدي الطفل التوحدي

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المستخلص:

الهدف: تهدف الدراسة الى تقييم جودة الحياة لأبوي الطفل المصاب بالتوحد.

المنهجية: اجريت دراسة وصفية على والدي الطفل التوحدي في مدينة بغداد . تم اختيار عينة عمدية (غير احتمالية) مكونة من 156 والدا ووالدة، 78 أب و 78 أم ل 78 طفلا توحديا يتلقون العناية في المراكز الاهلية التخصصية لرعاية التوحد للاشتراك في الدراسة الحالية . تم استخدام استبانة الادارة الذاتية لغرض جمع العينة.

النتائج: اظهرت نتائج الدراسة ان كلا الوالدين (الاباء والامهات) قد اشتركا في هذه الدراسة و بنفس العدد (78) لكل منهما . كلا الوالدين سجلا مستوى متوسط من جودة الحياة . الامهات سجلوا مستوى اقل في الرفاه النفسي و الرفاه البدني والراحة البيئية من الاباء . هناك اختلاف ذو دلالة بين الاباء والامهات في مستوى جودة الحياة بالجانب النفسي والجانب البدني .

التوصيات: ابوي الطفل المصاب بالتوحد و خاصة الامهات يحتاجون الى الانتباه و الدعم في جميع جوانب الحياة المرتبطة بجودة الحياة.

Objectives: The study aims to assess the QOL for parents of a child with autism

Methodology: A descriptive study was conducted on parents of autistic child in Baghdad city. A purposive (non-probability) sample of (156) parents, (78) mothers and (78) fathers of (78) autistic children who are clients and receive care in the private specialization centers for autism were selected to participated in the current study. The study used a self- administrative questionnaire for data collection.

Results: The findings indicated that both parents (mothers and fathers) were participated in this study, and they comprised an equal number (78). Both parents reported a moderate level of QOL. Mothers were reported a lowest levels of psychological well-being, physical well-being and environmental comfort than fathers. There is a significant difference between mothers and fathers in psychological and physical domains of QOL level.

Recommendations: Parents with autistic child especially mothers need more attention and support in all aspects of their lives that have been correlated with their QOL.

Keywords: Quality of Life, Parents, Child, Autism.

Introduction:

Raising a child with an autism spectrum disorder can be an overwhelming experience for parents and families. ASD is associated with deficits in social and communication functions of children which cause an excess of difficulties in caregivers, including decrease parenting efficacy, increase parenting stress, and an increase in mental and physical health problems compared with parents of typical developing children ⁽¹⁾. It has been reported that limitations in functioning of children with autism spectrum disorders results in requirement for long term of care far exceeding the usual needs of children as they develop. Thus, while caregiving is a normal part of being a parent, providing the high level of care required by a child with long term functional limitations can become burdensome and may impact both physical and psychological health of caregivers⁽²⁾. Quality of life (QOL) is a multidimensional concept that includes physical, psychological and social domains of health. Caring for a child diagnosed with autism could affect the quality of life of the caregivers in various different ways ⁽³⁾. Several studies

have documented the occurrence of negative outcomes such as stress, anxiety and depression among caregivers of children with autism ⁽²⁾. Little is known about the quality of life of parents with autistic child, no previous research has assessed the (QOL) of parents in Iraq, so it is important to study the parent's quality of life in order to help those parents to take care for their children and themselves.

Methodology:

A descriptive study was conducted on parents of autistic child in Baghdad City from June 15th 2013 to October 15th 2013. The study was carried out to determine the quality of life of parents who have an autistic child. A purposive (non-probability) sample of (156) parents, (78) mothers and (78) fathers of (78) autistic children who are clients and receive care in the private specialization centers for autism were selected to participated in the current study. A self-administrative questionnaire was constructed to achieve the study objectives. The quality of life was assessed using the (WHOQOL-BREF) which contains 26 items. The researcher made some modifications and

adding new items to the original scale depending on the extensive review of literature and the (WHOQOL-100), in order to achieve the study objectives. The questionnaire comprised two sections:

(a) The socio-demographic characteristics for each parent which include: (age, occupation, housing type, family property of housing, family type, no. of children, educational level, family income, child's burden on him/her, feeling of distress, evaluation of his/her QOL).

(b) Assessment of quality of life for each parent contains (39) items divided into (5) domains which include: psychological domain; contains (9) items, physical domain; contains (8) items, spiritual and religion domain; contains (6) items, social domain; contains (7) items, and environment and housing domain; contains (9) items. The response to these items is (never, sometimes, always), some items reflect a positive response while others reflect a negative response, so the scoring and rating for negative items is (never=1, sometimes=2, always=3), the scoring and rating for positive items is (never=3, sometimes=2, always=1). The levels of QoL are measured according to the cut off point for each domain of the QoL

assessment, table (1) show the levels of parent's QoL for each domain according to the range of scoring.

In order to test the validity of the questionnaire, it was presented to 14 experts in different fields. Before starting the work, a pilot study was carried out from June 15th 2013 to June 30th 2013, on 20 parents of 20 autistic children. For the purpose of measuring the reliability of the questionnaire, two methods are used:

1. Split-halve technique: it has been used to estimate homogeneity, in this approach the items on a scale was divided into two groups; odd items and even items, and scored independently, and then using the Spearman-Brown prophecy formula (r_1) which equal = (0.937) of the present study.

2. Cronbach' alpha (coefficient alpha): the Cronbach' alpha of the current study is $r = (0.946)$. The data has been analyzed by using the descriptive statistics (Frequencies, Percentages, Means and contingency table between QOL domains and levels of QOL for mothers and fathers), and inferential statistics (t-test to compare between mothers and fathers in the level of QOL).

Table (2): Parents Level of Quality of Life according to the Range of Scoring for Each Domain of Quality of Life Scale

No.	Domain	Range of scoring	Level of QoL
1	Psychological domain (9 items)	9 – 17	high
		18 – 20	moderate
		21 – 27	low
2	Physical domain (8 items)	8 – 14	high
		15 – 17	moderate
		18 – 24	low
3	Spiritual domain (6 items)	6	high
		7 – 8	moderate
		9 – 18	low
4	Social domain (7 items)	7 – 13	high
		14 – 15	moderate
		16 – 21	low
5	Environmental domain (9 items)	9 – 17	high
		18 – 20	moderate
		21 – 27	low
	Total (39 items)	39 – 67	high
		68 – 80	moderate
		81 – 117	low

Results:**Table (2): Demographic Characteristics of Parents**

Demographic characteristics		Mothers		Fathers	
		f	%	f	%
Parent's age	21 – 30	32	41.0	11	17.3
	31 – 40	32	41.0	33	40.7
	41 – 50	12	15.4	25	30.9
	51 – 60	2	2.6	8	9.9
	61 – 70	–	–	1	1.2
	Total	78	100%	78	100%
Parent's employment	Employed	30	38.4	73	93.6
	Retiree	2	2.6	3	3.8
	Not employed	46	59.0	2	2.6
	Total	78	100%	78	100%
Parent's educational level	Read and write	4	5.1	1	1.3
	Primary degree	11	14.1	7	9.0
	Intermediate degree	6	7.7	13	16.7
	Secondary degree	13	16.7	7	9.0
	Diploma degree	8	10.3	14	17.9
	Bachelor degree	35	44.9	30	38.5
	Postgraduate degree	1	1.3	6	7.7
	Total	78	100%	78	100%
Presence of chronic physical disease	Yes	10	12.8	16	20.5
	No	68	87.2	62	79.5
	Total	78	100%	78	100%
Parent's feeling burden of having a child with autism	Not at all	9	11.5	13	16.7
	A little	15	19.2	12	15.4
	A moderate amount	25	32.1	23	29.5
	Very much	16	20.5	16	20.5
	An extreme amount	13	16.7	14	17.9
	Total	78	100%	78	100%

Continues

Table (2): To be Continued

Parent's feeling embarrassment of having a child with autism	Not at all	21	26.9	21	26.9
	A little	14	17.9	19	24.4
	A moderate amount	28	35.9	23	29.5
	Very much	8	10.3	8	10.3
	An extreme amount	7	9.0	7	9.0
	Total	78	100%	78	100%
Parent's evaluation to their QOL	Very good	3	3.8	4	5.1
	good	10	12.8	9	11.5
	fair	35	45.0	41	52.6
	poor	21	26.9	18	23.1
	Very poor	9	11.5	6	7.7
	Total	78	100%	78	100%

f=frequency, %=percentage

Table (2) indicates that 41% of mothers were aged between (31-40) years with mean = (32.4) and 40.7% of fathers were aged between (31-40) years with mean = (39.65).

More than the half of mothers were not employed (59%) while (93.6%) of fathers were employed.

Concerning the parent's educational level (44.9%) of mothers and (38.5%) of fathers were at bachelor degree. (87.2%) of mothers and (79.5%) of fathers were did not suffered from any chronic disease.

In regard to the parent's feeling burden of having a child with autism, (32.1%) of mothers and (29.5%) of fathers rated themselves a moderate amount of burden. 35.9% of mothers and (29.5%) of fathers rated themselves a moderate amount of feeling embarrassment of having a child with autism. (45%) of mothers and (52.6%) of fathers reported a fair levels when they evaluate the QOL from their point of view.

Table (3): Family Socioeconomic status

Demographics		f	%
Family housing	Urban	78	100
	Total	78	100%
Property of housing	Property	59	75.6
	Rent	19	24.4
	Total	78	100%
Family type	Solitary	52	67.5
	Extended	26	32.5
	Total	78	100%
Monthly income	Insufficient	13	16.7
	Barely sufficient	35	44.8
	Sufficient	30	38.5
	Total	78	100%
Number of children	1-3 children	63	80.8%
	4-6 children and more	15	19.2%
	Total	78	100%

f=frequency, %=percentage

Table (3) reveals that all families were from urban (100%). 75.6% of families lived in their own house. More than the half of families was a solitary family type (67.5%). Regards to family income (44.8%) of families reported barely sufficient monthly income. 80.8% of families have between one to three children.

Table (4): Distribution of Parents According to their Quality of Life Levels for Each Domains of Quality of Life

Quality of Life Domains	Levels of Quality of Life											
	Mothers (n=78)						Fathers (n=78)					
	Low		moderate		High		Low		moderate		High	
	f	%	f	%	f	%	f	%	f	%	f	%
Psychological well-being	22	28.2	34	43.6	22	28.2	14	17.9	28	35.9	36	46.2
Physical well-being	24	30.8	30	38.5	24	30.8	15	19.3	26	33.3	37	47.4
Spirituality	15	19.2	33	42.3	30	38.5	24	30.8	29	37.2	25	32.1
Social interaction	32	41.0	18	23.1	28	35.9	20	25.6	17	21.8	41	52.6
Environmental comfort	30	38.5	20	25.6	28	35.9	25	32.1	20	25.6	33	42.3
Total Level of Quality of Life	24	30.8	34	43.6	20	25.6	19	24.4	32	41.0	27	34.6

f=frequency, %=percentage, n= number of cases

Table (4) depicts that the highest percentage (43.6%) of mothers were reported a moderate level of the psychological well-being, and (38.5%) of them were also reported a moderate level of physical well-being. While the highest percentage (46.2%) of fathers reported a high level of psychological well-being, and (47.4%) of them are also have high level of physical well-being.

Concerning the spirituality (42.3%) of mothers has a moderate level. And the highest percentage was (37.2%) of fathers have a moderate level of spirituality.

As regards to social interaction domain 41% of mothers reported a low levels. And 52.6% of fathers reported a high level of social interaction.

Regards to environmental comfort (38.5%) of mothers reported low levels and (42.3%) of fathers reported high level in the environmental domain of QOL.

Table (5): Comparison between Mothers and Fathers Relative to the Level of Quality of Life

Variables	Group				Independent t-test	
	Mothers		Fathers		t	p
	mean	SD	mean	SD		
Psychological well-being	19.53	3.621	17.65	3.569	-3.240	0.001
Physical well-being	15.85	3.195	14.73	3.402	-2.111	0.036
Spirituality	7.56	1.991	7.94	2.229	1.099	0.274
Social interaction	14.77	3.445	13.68	3.301	-2.017	0.045
Environmental comfort	18.65	4.102	18.28	3.996	-0.573	0.567
Total Level of Quality of Life	76.36	12.688	71.54	14.035	-2.250	0.026

SD= standard deviation, t= t-test, p= p-value

Table (5) indicated that there is a significant difference between mothers and fathers when $p\text{-value} \geq 0.05$ in psychological well-being, physical well-being and the total level of QOL.

Discussion:

Discussion of the demographic characteristics of parents:

The study findings show that both parents (mothers and fathers) were participated in this study, and they comprised an equal number (78), the highest percentage of them aged between (31-40) years. More than half of mothers were unemployed, this may due to caring for their autistic child and other members in the family, and majority of fathers were employed, this result was consistent with Kheir et al. (2012) who reported that the majority of the respondents held professional jobs⁽³⁾.

Table (2) indicates that the highest percentage of parents for those who have Bachelor's degree as their educational level, this result is congruent with that who found that the majority of participants had Bachelor's degree⁽³⁾.

The highest percentage of mothers and fathers are rated themselves a moderate amount of feeling burden from their autistic children. Parents of children with autism rated themselves higher frequency of burden⁽⁴⁾. The difference between the current study and the other studies may be due to that the Iraqi families have a strong interrelation

between their members and there is cooperation between them.

The highest percentage 35.9% of mothers and 29.5% of fathers rated themselves a moderate amount of embarrassment feeling from having a child with autism. This finding is due to the nature of autism and the behavioral problems that the autistic child was displayed. It has been reported that parents may become embarrassed at their child's behavior, particularly as many people do not understand ASD and feel the parents should control their child⁽⁵⁾.

In this study 45% of mothers and 52.6% of fathers evaluated their QOL as fair, this followed by 26.9% of mothers and 23.1% of fathers rated themselves a poor QOL level. Many studies suggested that parents of children with autism have a lower QOL. It has been documented that there is a marked QOL decrement in families of children with autism when compared with families of typically developed children⁽⁶⁾.

Discussion of the demographic characteristics of the family:

The demographic characteristics of families in table (3) shows that all families participated in this study were

from urban 100%. This may be explained by the study was conducted in Baghdad city, and the centers for autism care were located in the center of city. This result is consistent with those who reported that all their participants were belonging to urban domicile⁽²⁾.

In this study, 75.6% of families resided in their own house, and 67.5% had a solitary family type. This result may be due to these families are consist of both parents who lived together and have somewhat a steady life.

Table (3) shows that 44.8% of families were reported barely sufficient monthly income. This result may be due to that the child with autism needs for special education services, and a medical intervention which cause a financial burden on the family. Also may be the inability of mothers to work increases the financial stressors on families. It has been reported that families caring for autistic child face a particular demand include significant financial burden⁽¹⁾.

80.8% of families of this study were having 1-3 children. Most of Iraqi families' have (1-3) children.

Discussion of the parent's Quality of Life levels:

Table (4) shows that the highest percentage (43.6%) of mothers reported a moderate level of psychological well-being. The highest percentage (46.2%) of fathers reported a high level of psychological well-being. Studies have consistently found higher levels of psychological distress in parents of children with autism when compared to parents of typically developing children or children with other disabilities ⁽⁷⁾. Many parents of children with autism showed lower QoL in the psychological domain ⁽⁸⁾. The result of the current study is congruent with Mungo et al. (2007) who found that the impairment of psychological well-being was higher in mothers than in fathers ⁽⁹⁾.

The highest percentage (38.5%) of mothers reported a moderate level of physical well-being, and (47.4%) of fathers reported a high level of physical well-being. This result is consistent with those who have found that the impairment of physical well-being was higher in mothers than in fathers ⁽⁹⁾. Malhotra et al. (2012) founded that the impairment in physical well-being is

more pronounced in mothers than in fathers ⁽²⁾.

The table (4) shows that the highest percentage of mothers and fathers reported a moderate level of spirituality. This result may due to the religious faith of Iraqi families' as Muslims which helped them to accept their disabled child and deal with his disorder. It has been reported that the Islamic teaching emphasized virtues of endurance, resilience, and acceptance of ill health, just like good health and good fortune. Islamic faith enabled Muslims to accept disability as an expression of God's will. The religious faith may help parents having a child with autism to cope with the challenges of having a child with autism ⁽³⁾.

41% of mothers reported a low level of social interaction, and more than half of fathers reported a high level of social interaction. It has been reported that parents having a child with autism tend to avoid social situations ⁽²⁾. The result of the current study was congruent with Mungo et al. (2007) who reported that mothers showing lower scores in social relationships than fathers ⁽⁹⁾.

In regard to the environmental domain the highest percentage (38.5%)

of mothers reported a low level, and the highest percentage (42.3%) of fathers reported a high level. Because parents of children with developmental disabilities such as autism experience feelings of anxiety, danger, and constant worry toward the physical security of their child, this could have attribute to their lower scores on the environment domain⁽²⁾.

The result of the current study was congruent with Mungo et al. (2007) who found that mothers reported lower scores than fathers in the environmental domain of Quality of Life⁽⁹⁾.

Table (4) shows that both parents reported a moderate level of the total score of Quality of Life. This result may due to that both parents are lived together and sharing the responsibilities of caring for their autistic child.

Discussion of the comparison between mothers and fathers in the level of QOL:

Table (4) shows that there is a significant difference between mothers and fathers in psychological ($p=0.001$) and physical ($p=0.036$) well-being and in total level of QOL ($p=0.026$). Mothers reported lower QOL. This result was consistent with Yamada et al. (2012) and

Kheir and his colleagues (2012) who found that mothers reported a lower QoL scores than fathers, especially in the psychological well-being domain⁽¹⁰⁾⁽³⁾. Mungo and his colleagues (2007) mentioned that the level of impairment of physical and psychological well-being was higher in mothers than in fathers⁽⁹⁾. The results of the current study is due to those mothers were more concerned with caring for their children and family and this cause more strain, fatigue and stress for them. May be mothers were more embarrassed by their child's behavior and this lead to withdrawal from social interactions.

The study concluded that both mothers and fathers were participated in this study, and they comprised an equal number (78). Most of them were aged between (31-40) years. The highest percentage of mothers and more than half of fathers evaluated their Quality of Life as fair.

All families were lived in urban area; most of them resided in their own house, and had a solitary family type. The highest percentage of families reported barely sufficient monthly income, and most of them were having 1-3 children.

Both parents reported a moderate level of the total score of Quality of Life. Mothers were reported a lowest levels of psychological well-being, physical well-being and environmental comfort than fathers. There is a significant difference between mothers and fathers in psychological and physical well-being and in total level of Quality of Life.

Recommendations:

1. The health and the social affairs policy should give the autistic children and their caregivers support and high quality of services to help them to coping with this disorder.

2. Parents with autistic child especially mothers need more attention and support in all aspects of their lives that have been correlated with their Quality of Life.

3. Enlightenment the general population especially parents with autistic child through mass media about autism and the effective methods to deal with the child with autism.

4. Increase and improve the governmental schools for children with special needs especially the autistic children in order to lightening the financial burden on parents.

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