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Original Research Article

Quality of life disparities among mothers of autistic children and mothers having normal children in Baghdad city-2024

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ABSTRACT

Background: Raising children with autism spectrum disorder (ASD) is well known to have a long-term negative impact on parents' quality of life (QOL). However, there is limited evidence about the QOL for parents of autistic children in Iraq. Objectives were to assess the overall QOL, general health, and the QOL domains (physical, social, psychological, and environmental) among mothers of autistic children as compared to mothers of normal children.
Methods: Respondents in this comparative cross-sectional study were mothers of children with ASD and mothers of normal children who visited the consultation clinics of the pediatric welfare teaching hospital-medical City/Baghdad-Iraq and the consultation clinic of the national center for autism. A WHO-validated questionnaire was used.
Results: The study involved five hundred forty mothers from both groups (two hundred seventy for each one). Mothers of autistic children reported significantly poorer general QOL (35.9% vs. 24.8%, p=0.01) and general health (18.2% vs. 8.1%, p=0.001) compared to mothers of normal children. Substantial disparities and significant differences with poorer physical (24% vs. 15.92%, p=0.01) and psychological well-being (22.96% vs. 18.14%, p=0.03) were observed between the two groups.
Conclusions: Given the importance of QOL for mothers and its impact on their general health and family dynamics, it is essential to establish programs that promote better resolution in this risk group.

Keywords Quality of life**,** WHOQOL-BREF, Autism spectrum disorder, Baghdad

INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong, complex neuro-developmental disorder characterized by difficulties with social and communicative interactions, the presence of limiting behaviors, and repetitive interests and activities, including sensory problems.[1]

Children with ASD may exhibit inappropriate behaviors such as unusual laughter, echolalia, fear of danger, deafness, bizarre eye contact, inappropriate attachment to objects, and tantrum crying that seem out of context. This disorder is not affected by specific race, educational level background, socioeconomic status, or life style.[2]

Autism is characterized by a complex interaction between genetics and the environment.[3] The prevalence of ASD varies between 0.02% and 3.66% worldwide. It is higher in males than in females, with 80.3% of cases occurring in males and a sex ratio of 4:1.[4,5]

The prevalence of ASD varies across continents and is 0.4% in Asia, 1% in the USA, 0.5% in Europe, 1% in Africa and 1.7% in Australia.[4]

Parental QOL has recently been recognized as one of the critical health issues of challenging experiences such as raising a child with a disability; The QOL represent a comprehensive, multidimensional measure based on a person's subjective perception of several life events.[6]

The world health organization defines QOL as follow: an individual's perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns.[7]

Measuring QOL is a major concern and become important for understanding parents' health outcomes and their determinants, particularly for women.[8] Several factors were identified as having a significant impact on the levels of parenting stress experienced by parents of ASD children. These characteristics included: (i) social support, (ii) the severity of autistic symptoms, (iii) financial problems, (iv) parents' comprehension and perceptions of ASD, (v) parents' anxiety and concerns about their child's future, and (vi) religious beliefs.[9]

In Arab countries, fathers tend to be less involved in childrearing while mothers are more likely to assume family care giving responsibilities and this may be an important factor in the relatively higher burden on mothers.[10] Furthermore, parental perceptions of ASD can be negative (e.g., the child is defective and the impairment must be treated) or positive (e.g., This is a challenge to parents to become better people), and these judgments of the concept of disability can be culturally influenced.[11] societal stigma also is one of the most significant issues for them.[12] Because of the child's challenging behaviors, parents are also too shy to take them to the homes of friends or relatives. As a result, parents might sometimes become separated from their friends, relatives, and neighborhood.[13]

Thus, understanding the QOL disparities between the two groups of mothers is essential for several reasons because it provides insight into the specific needs and challenges faced by these mothers, emphasize the importance of tailored assistance and resources and allows for a deeper understanding of maternal experiences and well-being.

METHODS

Study design, setting and time

This study was a comparative cross-sectional. It was carried out in the consultation clinics of the pediatric welfare teaching hospital-medical city/Baghdad-Iraq and the consultation clinic of the national centre for autism during the period from April to the end of December of 2024.

Study population

Consisted of two groups of mothers- mothers of children aged two years or older who had an ASD were enrolled in the consultation clinic of the national centre for autism, and for the purpose of the study this group will be named as the first group. Mothers of children aged two years or older who did not have an ASD were enrolled in the other general consultation clinics of the paediatric welfare teaching hospital and this group will be named as the second group.

Sampling technique

A convenient sampling technique was used to include five hundred forty individuals (two hundred seventy for each group) who met the inclusion criteria.

Inclusion criteria

Mothers of children aged two and above who have previously been diagnosed with ASD before six months by a pediatric physiatrist following DSM-V criteria, or CARS.[14,15] Mothers of normal functioning children which referred as children without any other chronic disordersaschild with renal failure on dialysis, child with DM type 1, or mental disorders including learning, visual, hearing problems and intellectual disability were included.

Exclusion criteria

Mothers of children diagnosed with ASD less than six months before the data collection, mothers suffering from chronic diseases or handicaps and those having psychological insults that may affect their QOL will be excluded from the study and mothers of children having ASD associated with other chronic disorders and disabilities were excluded.

Data collection tool and process

Mothers of the children from both groups were interviewed by means of direct interview. Two sections of a structured questionnaire were filled out with the necessary information.

Research tools

Section one

The child part and the disorder specific Data which include the following: Age and the sex of the child, having ASD or not and for how long (duration). this part approved by panel of experts in the community and family medicine at college of medicine /Baghdad university.

Section two

The instrument used was "The English version of the world health organization QOL questionnaire short version (WHOQOL-BREF).[16] It demonstrates the individuals' subjective responses rather than their objective life conditions, with assessments performed during the prior two weeks, and it consists of two parts, the first one ask about demographic data which include mothers' age, educational level, martial status, and the second part which include 26 questions (2 general regarding overall/general QOL and GH and 24 questions separated into four domains).

Physical domain: Including (physical pain, daily use of medical treatment, daily life energy, sleep satisfaction. The capacity to move around {mobility}, satisfaction with daily activities and the capacity to work).

Psychological domain: Including (positive feelings as enjoying in life and feelings of meaningful life, capacity to concentrate {thinking}, self-satisfaction and body appearance, negative emotions like {anxiety and depression}).

Social relationship domain: Including (relative relationship, support from friends and others, satisfaction with personal life {sex}).

Environmental domains: Including (feeling safety in daily life, health environment, finance" enough money to meet needs", information and knowledge, leisure activities opportunity, satisfaction with their living place conditions, access to health services, and with their transport).

Scores of WHOQOL-BREF

Scoring of the domains was done according to WHOQOL-BREF manual.[17] All domain scores were scaled in a positive direction, meaning that higher scores corresponded to greater QOL ratings.

The 26 items of the questionnaire were scored as 5-Liker's scale, for all questions, a score of 1 represents the lowest result and a score of 5 represents the highest result, with the following exceptions: Questions 3, 4, and 26: For these three questions, the scoring is reversed. A score of 1 represents the highest result and a score of 5 represents the lowest result.

Items were recorded as follows:- (1=1)(2=2)(3=3)(4=4)(5=5) except three negative questions which are Q3, Q4 in the physical domain and Q26 in the psychological domain; their scores were reversed as (6 minus the score of Q3), (6 minus the score of Q4), (6 minus the score of Q26).

The procedure for manually calculating individual scores and overall raw scores is shown below:[17]

Physical domain = (6-Q3score)+(6-Q4score)+Q10+Q15+Q16+Q17+Q18.

Psychological domain= Q5+Q6+Q7+Q11+Q19+(6-Q26 score (social relationship)=Q20+Q21+Q22.

Environmental domains= Q8+Q9+Q12+Q13+Q14+Q23+Q24+Q25.

Then these raw scores were changed to transformed scores 0-100 to be used in analyses using Table 4 of WHOQOL-BREF instructions.[17]

A mean score of±1 SD score on each domain was graded as "fair", a mean of <-1 SD as "poor", and a mean of > + 1 SD as "good".[18]

Statistical analysis

To code and analyze the data, they were firstly entered into excel sheet then they were loaded into SPSS (version 27). Categorical data summarized as frequencies and percentage. A Chi square test had been used to examine the quality-of-life domains experienced by mothers of the two groups, with a p value level of less than 0.05 indicate a significant association.

RESULTS

The study involved five hundred forty mothers whose agreed to participate the study. Of mothers who were participate; the autistic children were mainly males (61.1%), with an age distribution equal to 66.7% were aged five and younger. While nearly equal proportions of both sexes was found in normally developing children (51.5% were females and 48.5% were males. The 58.9% of them were aged five and younger. The percentage of respondents who were married exceeded 68% in the autistic child mothers versus 75% in the normal children mothers' group.

Physically, the mothers of the first group reported higher physical pain (62% vs 40%), having lower energy for daily life (28% vs 48%) and less sleep satisfaction (13% vs 47%), less daily activities performance and less working capacity than the mothers of the second group (45% vs 66%) (17% vs 36%) as shown in Figure 1.

Psychologically, they had a lower level of positive feelings in their life with frequent negative feelings such as anxiety, anger, and depression (41% vs 21%). and were less likely to report satisfaction with their body appearance and self-acceptance than the other group (35% vs 48%) (42% vs 54%) respectively Figure 2 show more details.

Socially, often they were experienced considerable challenges in maintaining social relationships than the other group (22% vs 52%) as shown Figure 3.

On environmental factors; they less satisfied with their living conditions (27% vs 36%) and less likely to report having opportunities for leisure activities (24% vs 48%) when compared to mothers from the second group, finally regarding feelings of safety, financial difficulties in meeting daily needs and access to the health services, although there were variations between the two groups, they were not as noticeable as the first two factors mentioned above in this domain as shown in Figure 4.

Of mothers of the first group, 35.9% were reported a poor impression of GQOL (general QOL), 36.6% as fair GQOL, and 27.4% As a good impression. Compared to the other group, 24,8% of mothers had a poor impression,

45.2% and 30% had fair and good impression respectively with A significant difference exists between them (p=0.01 using chi-square test), as shown in Table 2. Of mothers of the first group, 18.2% reported a negative impression as dissatisfied with their general health impression, 48.1% were reported a fair impression as neither satisfied nor dissatisfied and 33.7% as a positive impression as satisfied. Compared to the other group, only 8.1% of mothers had a negative impression, 32.3% had a neutral one, and 59.6% had a positive one. Although they show statistically differences but most of them in both groups were satisfied to their health conditions. chi-square test demonstrates a significant difference between the groups (p=0.001), as illustrated in Table 3. Concurrently mothers of the first group exhibited significantly poorer physical health and psychological well-being; with a higher proportion fell into fair and poor categories, fewer proportions were in good category conversely to mothers of the second group were most of them fell into fair and good categories with fewer of them were in poor category, while the social and the environmental domains show no significant differences between both groups. The distribution of the above findings in terms of quality-of-life domains are illustrated in Table 4.

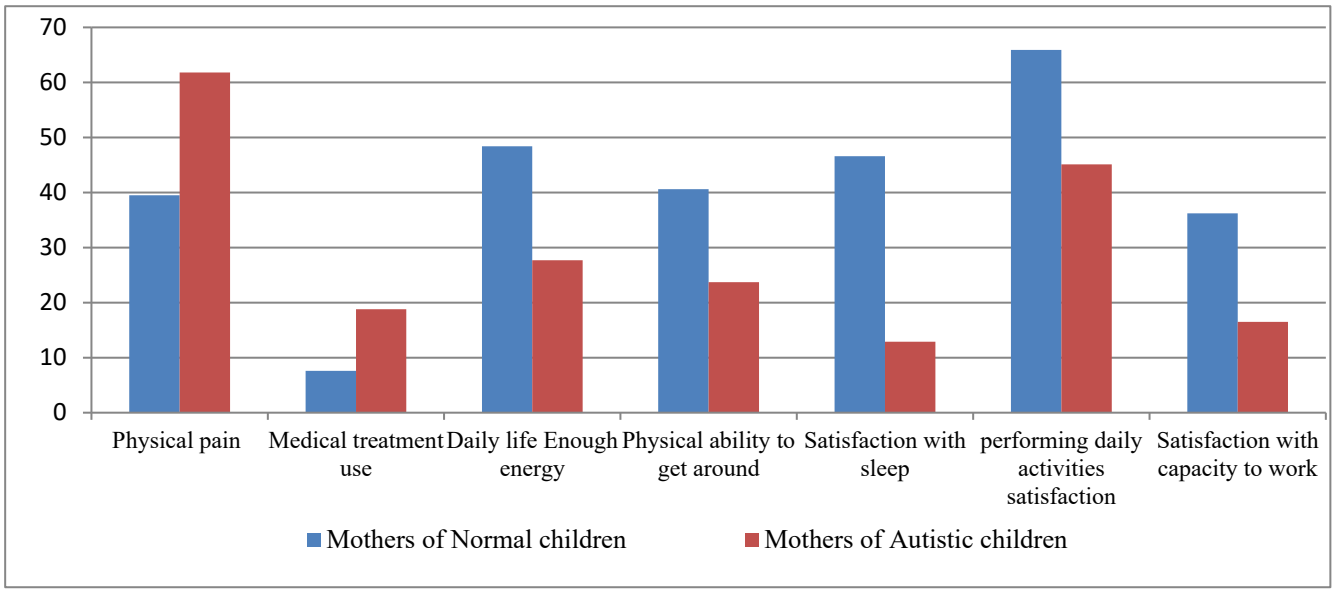

Figure 1: Mothers' percentage in response to the physical WHOQOL domain.

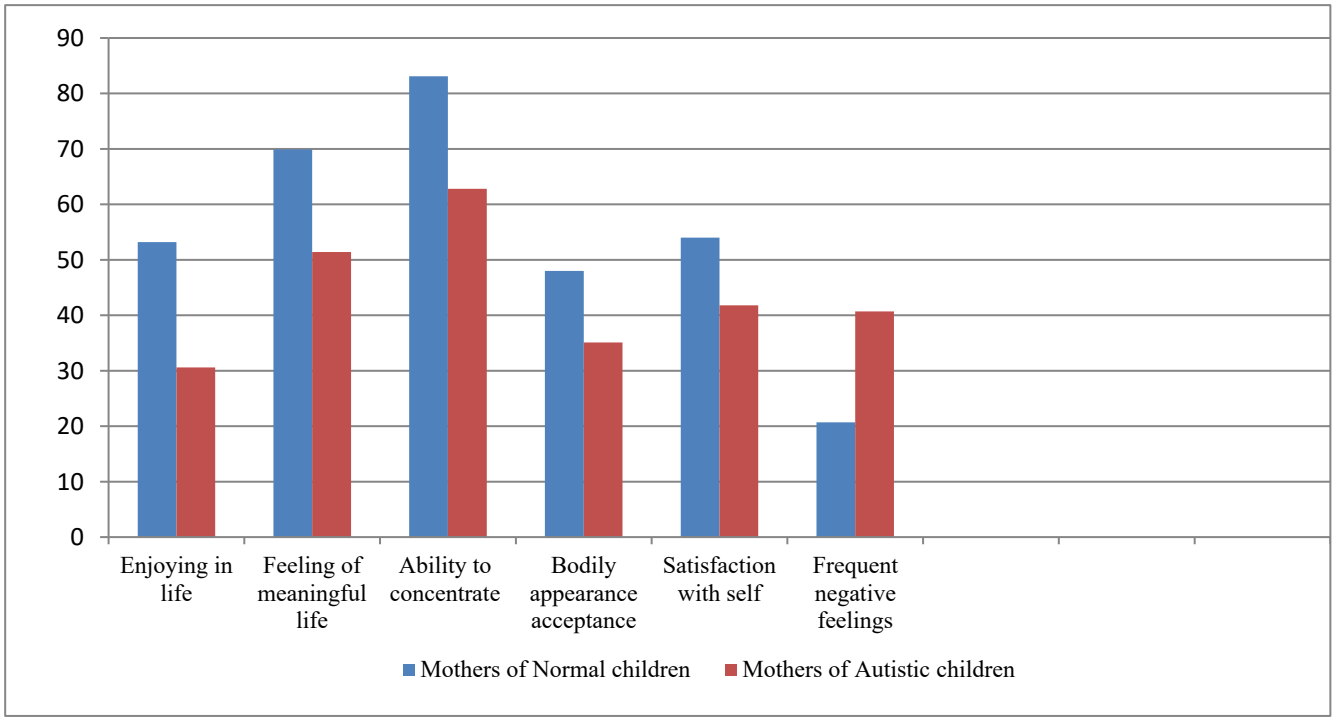

Figure 2: Mothers' percentage in response to the psychological WHOQOL domain.

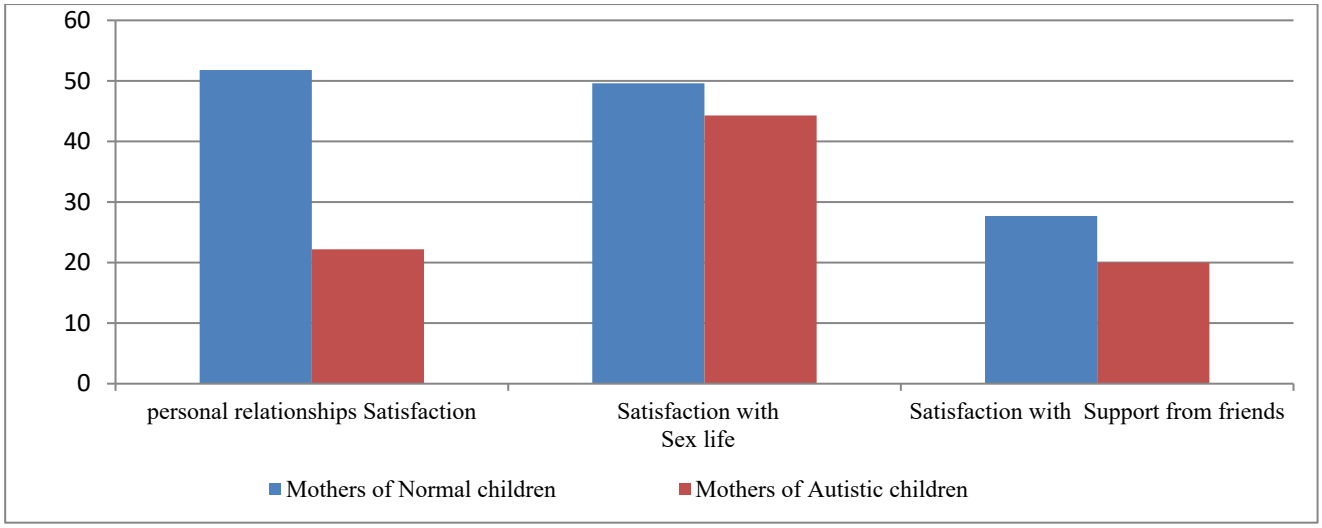

Figure 3: Mothers' percentage in response to the social WHOQOL domain.

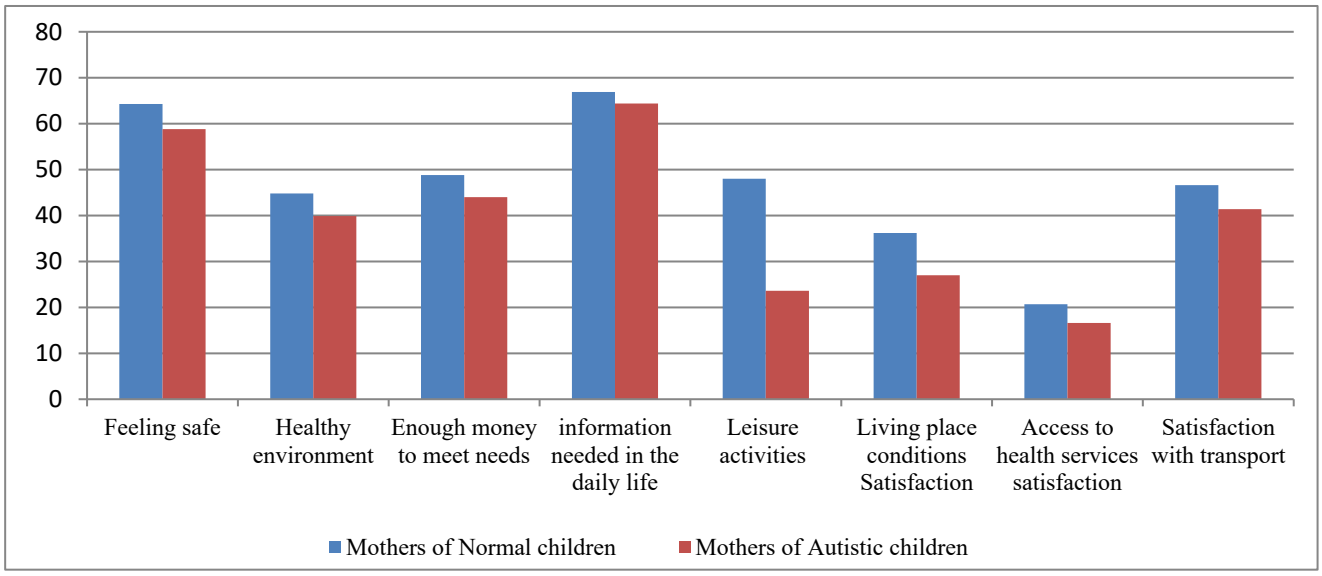

Figure 4: Mothers' percentage in response to the environmental WHOQOL domain.

Table 1: Demographic characteristics and the socioeconomic status of the mothers and their children.

Characteristics		Mothers of autistic children, n=270		Mothers of normal children, n=270	
		N	%	N	%
Child part					
Child gender	Male	165	61.1	131	48.5
	Female	105	38.9	139	51.5
Child age (in years)	≤5	180	66.7	159	58.9
	>5	90	33.3	111	41.1
Mothers part					
Mothers age (in years)	<30	143	53.0	124	46.0
	30-39	120	44,4	133	49.2
	≥40	7	2.6	13	4.8
Marital status	Married	186	68.9	203	75.1
	Divorced	78	28.8	59	21.9
	Widowed	6	2.3	8	3.1

Table 2: Comparing of the studied mothers samples according to their GQOL distribution.

Characteristics	Mother of autistic children, N (%)	Mother of normal children, N (%)	P value
Poor	97 (35.9)	67 (24.8)	0.01
Neither poor nor good	99 (36.6)	122 (45.2)	
Good	74 (27.4)	81 (30)	

Table 3: Distribution of the studied mothers sample according to their GH.

Characteristics	Mothers of autistic children, N (%)	Mothers of normal children, N (%)	P value
Fairly dissatisfied	49 (18.2)	22 (8.1)	0.001
Neither satisfied nor dissatisfied	130 (48.1)	87 (32.3)	
Satisfied	91 (33.7)	161 (59.6)	

Table 4: Distribution of the studied mothers according to domains of QOL.

QoL domain scores	Poor, N (%)	Fair, N (%)	Good, N (%)	P value
Physical health				
mother of autistic children	65 (24.07)	143 (52.96)	62 (22.96)	0.01
mother of normal children	43 (15.92)	150 (55.55)	77 (28.51)	
Psychological wellbeing				
mother of autistic children	62 (22.96)	163 (60.37)	45 (16.66)	0.03
mother of normal children	49 (18.14)	155 (57.40)	66 (24.44)	
Social relationships				
mother of autistic children	63 (23.3)	178 (65.9)	29 (10.7)	0.66
mother of normal children	59 (21.8)	177 (65.5)	34 (12.5)	
Environmental health				
mother of autistic children	56 (20.74)	172 (63.7)	42 (15.55)	0.72
mother of normal children	36 (13.33)	188 (69.62)	46 (17.01)	

DISCUSSION

Having a child with autism places a huge lifelong burden on the family. This burden has negative unfavorable effects on parents' health and QOL and reduces their ability to care for other children and families. Understanding the QOL of women with autistic children and the characteristics that contribute to their QOL can help guide interventions to reduce this burden.[19]

The current study's findings support the hypothesis that behaviors associated with ASD will negatively impact QOL. Where 35.9% of mothers of autistic children reported poor scores for general QOL. Agreed to the results of other studies discussing the association between low QOL of parents and the presence of chronically ill sons or daughters like that found by Gilbertson in 2019 revealed the overall health perception and QOL were poor among parents of children with autism or in at least one QOL measure in contrast to the parents of normally developing children or the general population.[20-22]

A survey by Kawther Dawood and Ali Khudhair in 2016 conducted in Iraq comparing families of children with autism to those of children who are normally developed, it has been shown that there is a noticeable decline in QOL.[23] A previous reviews in Arab and other countries showed that these parents had poorer QOL, a high caregiver burden, low level of hope and life satisfaction, experience substantial impairments in QOL highlighting the unique challenges posed by autism.[22,24-26]

Possible explanations for maternal QOL deficits in the setting of these mothers' problems. Mothers of children with ASD have been linked to stress even though it is a normal part of life, but families with autistic children may experience it at a higher level, more sleep deprivation, and exhaustion, which are likely to impair their mental and physical function.

Although in this study, mothers of autistic children expressed inferior satisfaction with their general health 18.2% compared to 8.1% mothers of normal children, mothers of both groups demonstrated that 33.7% and 59.6% respectively better general health satisfaction than dissatisfaction, these findings may be related maternal self-efficacy is mothers' belief in their ability to be successful mothers to their children. This belief includes the ability to understand the needs of their children, respond to these needs, and reach a desired result to promote their development. Mothers of the two groups demonstrated significant difference in their physical health, similarly a study conducted in Egypt found that caregivers of autistic children had a considerably lower

QOL in terms of physical functioning, energy, and exhaustion than the control group.[27]

Also, significant impairment was found in their psychological well being than other groups. This findings have been approved by a Previous research that linked it to worries about the child's future may have had a detrimental effect on the parents' psychological well-being and caused stress, anger, feelings of guilt, and sadness.[26]

Socially, the two groups do not differ much from one another, controversy to our study, participants in a Saudi Arabian survey showed that the parents' relationships and the family's social life were negatively impacted by their autistic child.[28] This could be explained according to the nature of Iraqi's community culture and the social family system that had been found as an important role for the social support that they needed to deal with different life stressors. The environment domain assessed living conditions, financial resources, access to social and health services, and feeling of safety. In this study, the two groups had poor environmental domain with no statistically differences between them. This may be explained by referring to the socioeconomic background of the families of the two groups, it seems that may be due to most patients seen at governmental hospitals in Baghdad are from low-income and middle-income backgrounds**.** this result is consistent with previous studies conducted in and South Africa, where the Lower income, and lack of accessibilities to the caring schools were the main causes that affecting this domain.[29]

CONCLUSION

This review highlighted the complexities of raising a child with ASD, as well as the possible negative impact on mothers' QOL. Three main significant conclusions were revealed: Mothers of ASD children reported poorer overall QOL and GH in comparison with mothers of the normal children. The two groups had been shown a significantly differences in their physical and psychological well-beings.

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