Quality of Life in Children with Autism Spectrum Disorder (ASD): An Assessment study

Noura A. Otefy [(1)], Safy S.E. Al-Rafay[(2)], Amina M. Thabet[(3)]
[(1)] Nursing Specialist at Technical Institute of Nursing, Sohag University
[(2)] Professor of Pediatric Nursing, Faculty of Nursing, Ain Shams University
[(3)] Assistant Professor of Pediatric Nursing, Faculty of Nursing, Sohag University

Abstract

Background: Autism spectrum disorder is a neurodevelopmental disorder associated with symptoms that include persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behavior, interests, or activities. Measuring health- related quality of life is very important for children with autism spectrum disorder. **Aim of the study:** This study aimed to assess the quality of life in children with autism spectrum disorder. **Design:** A descriptive design was utilized in carrying out this study. **Setting & Sampling**: A purposive sample of 146 children suffering from autism and their mothers were attending at Institute of Childhood Studies that affiliated to Aim Shams University and the Out-patient Child Neurology Clinic that affiliated to Sohag University Hospital. **Tool:** Interviewing questionnaire sheet composed of 3 tools; **tool I:** Child's assessment sheet, **tool II**: Mothers' reported practices, **tool III:** Quality of life questionnaire. **Results:** It was found that, there is high statistically significant positive correlation between total studied mothers' practices and their children quality of life. Also, there was statistically significant positive correlation between total studied mothers' practices and their total knowledge. In addition' there is statistically significant positive correlation between total studied mothers, knowledge and their children quality of life. **Conclusion:** Based on the findings of the present study, it was concluded that, more than two fifths of the studied mothers had average level of reported practices regarding their role towards their children. In addition, there was high statistically significant positive correlation between total studied mothers practices and their children quality of life. **Recommendation:** Encourage continuous sharing of the mothers during the care of their children with autism by specialists to identify needs and problems of ASD.

Key words: Autism Spectrum Disorder, Children, Quality of Life.

Introduction:

Autism spectrum disorder (ASD) known as autism, is a common highly heritable and heterogeneous neurodevelopmental disorder that has underlying cognitive features and commonly co-occurs with other conditions. The behaviors, strengths and challenges of children with autism have attracted the attention of scientists and clinicians for at least 500 years. Autism is a heterogeneous disorder and reflecting this heterogeneity, the term autism has been used in various ways to describe both a broader presentation as well as a specific diagnosis following its consideration as a subgroup within the general diagnostic category of 'pervasive developmental disorders' (PDDs). PDDs are a group of disorders introduced in the diagnostic and statistical manual of mental disorders **(Tistarelli et al., 2020).**

Children with autism often have co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder as well as challenging behaviors such as difficulty sleeping and self-injury. The level of intellectual functioning among autistic children varies widely, extending from profound impairment to superior levels **(Linton et al., 2016)**.

Concept of Quality of Life (QoL) serves as a conceptual and assessment framework to develop person-centered planning, as a basic principle to guide professional practice, and as a vehicle to lead the development and implementation of public policies. Most recently published systematic review found only one QoL measure designed for use with the general autism spectrum population in adulthood (the QoL1 and QoL2) highlighting the pressing need to develop robust tools for this population **(Ayres et al., 2017)**.

Societal attitudes and the level of support provided by local and national authorities are important factors determining the quality of life of children with autism. The influence of quality of life evaluation of autistic children to measure the effects of child illness, treatment, and guide the choice of treatment is of great significance from the aspects of quality of life **(Bonnin et al., 2018)**.

Nursing care to the autistic child is based on qualified listening, once that nurses are the eyes and ears of the health team and the voice for parents. The nurse becomes a link between the multiprofessional team and the caregivers of the autistic child . Assistance of the nursing team in listening to parents requires an approach of concerns that surround them with the purpose of paving the process to educate the families of children with ASD to cope with the challenges and best driving the well-being of all **(Frye, 2018).**

Significance of the study:

The prevalence of ASDs, among children is 1 in 150 individuals. Autism is four times prevalent in boys than girls in Egypt the prevalence of autistic child is 180 cases at 2017 according to National Centers at Ain Shams University **National Centers for health statistics at Ain Shams University, 2017 .**

Because mothers of children with Autism Spectrum Disorder (ASD) take on responsibilities of this diagnosis, advocacy, and daily care that this impacts upon their Quality of Life (QoL) having an impact on the core features of ASD, presence of particular maladaptive behaviors such as social interactions, communication and behavior of children that can lead to; problems in school and with successful learning, inability to live independently and social isolation. In addition, the number of children diagnosed with ASD is rising which affects children of all races and nationalities; therefore, this study will be conducted to assess mothers' knowledge and reported practices on (QoL) in children with (ASD), in addition to the quality of life in children with (ASD). So, the aim of this study was to assess the quality of life in children with Autism Spectrum Disorder.

Aim of the study

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Research Questions:

1. What is the mother's level of knowledge about ASD in children?
2. What is the mother's level of reported practices during caring of children with ASD?
3. What is the relation between mother's knowledge and reported practice on QOL for children with ASD?

Subjects and Method

The study was conducted under four categories as follows:

1- Technical design.
2- Operational design.
3- Administration design.
4- Statistical design.

1-Technical design:

Research design:

A descriptive research design was utilized for this study.

Setting:

This study was conducted at Institute of Childhood Studies that affiliated to Ain Shams University and Out-patient Child Neurology Clinic that affiliated to Sohag University. As these two settings have a high census of children attending with their mothers at the outpatient clinics for ASD diagnosis or follow up according to both outpatient clinics records.

Subjects:

A purposive sample composed of 146 mothers having children with ASD attending at the previously mentioned settings (according to flow rate along 6 months) with inclusion and exclusion criteria of children as follows:

Inclusion criteria:

1- Children with both genders.
2- Children at school age (6-12) years.

Exclusion criteria:

1 -Children with Down syndrome.
2- Children with Attention Deficit Hyperactivity Disorder (ADHD).
3 -Children with mental retardation.

Sample size equation:

$$n = \frac{N\,Z^2\,\sigma^2}{Z^2\,\sigma^2 + N\,e^2}$$

Where:

$Z = 1.96$ [standard scores], $e = 0.05$ [error], $\sigma = 0.345$ [SD], $N = 720$ [population], $n = 146$ [sample]

Tool for data collection:

A structured interview sheet was used to collect the data. It was written in simple Arabic language. It composed from three parts:

Tool I: Child's assessment sheet adopted from Raslan et al., (2019):

It was a questionnaire consists of 4 parts as the following:

1: Characteristics of the studied children with ASD including: Gender, age, ranking, level of education and history of disease (degree and duration).

2: Assessment for the level of independence regarding the children's daily activities such as: Feeding, transferring, movement, clothes, showering, toileting, mouth care and communication with others.

❖ **Scoring system:**

Response was ranged using five points Likert scale as: (5) extremely agree, (4) agree, (3) neutral, (2) disagree, and (1) extremely disagree. The maximum score was (125) and minimum (25).

Total scoring:

The score of items was summed-up and the total divided by number of the items, giving a mean score of the part.

These scores were converted into a percent score was classified as the following:

- Negative effects < 50%
- Positive effects ≥ 50%

3: Characteristics of the studied mothers having autistic children. The data included: Age, level of education, job, kindship relation with father and family history of autism.

4: Mothers' knowledge about autism including: Definition (3 items), predisposing factors (4 items), warning signs (12 items), methods of treatment (10 items) and problems experienced by autistic child (10 items).

❖ **Scoring system:**

The right answer was scored "one degree" and that wrong was scored "zero". These scores was summed-up and be converted into a percent score. Regarding the knowledge of the studied mothers of children, 39 degrees allocated to all items of the questionnaire.

Total scoring:

For scoring the total level of mothers' knowledge, mothers' response checked with a key model answer and accordingly, it was categorized into three levels:

- 75% and more was considered a good level of knowledge.
- From 50% to less than 75% was considered average level of knowledge.
- Less than 50% was considered the poor level of knowledge.

Tool II: Mothers' reported practices assessment sheet adopted from Raslan et al., (2019):

It consisted of 114 items divided into 2 parts to assess the mothers' reported practices in the following aspects of care:

1-**Developmental skills consisted of 27 items regarding:** Self-care skills (9 items), social skills (6items), motor skills (6 items) and attention & concentration skills (6 items).

2- Problems of autistic child consisted of 87 items regarding: Meals time difficulties (11 items), toilet time problems (8 items), sleep disorders (15 items), fear of risks and accidents (6 items), self-harm tantrums (9 items), isolation behavior (9 items), loss of self-esteem (7 items), typical movements & repetitive talking (7 items), verbal communication problems (9 items) and resistant of change (6 items).

❖ **Scoring system:**

The scoring system for mothers' response was evaluated upon fulfillment of the reported practices assessment sheet. Therefore, a score (1) was given in the item done completely and score (0) was given in the item not done or wrong.

Total scoring:

These scores were summed-up and were converted into percent scores that were categorized into three levels:

- 75% and more considered a good level of reported practices.
- From 50% to less than 75% considered average level of reported practices.
- Less than 50% considered the poor level of reported practices.

Tool III: Quality of life questionnaire adopted from El-gazzar et al., (2018):

It consisted of 63 items 5 parts to assess quality of life by asking questions regarding the following: Quality of school life (18 items), quality of social environment (8 items), quality of life in daily activities (13 items), quality of health & surrounding environment (10 items) and quality of psychological life (14 items).

❖ **Scoring system:**

Each response took a score, never=1, sometimes=2 and always=3. Quality of life questionnaire consists of 63 sentences.

Total scoring:

Score of total quality of life were categorized into three levels:

- Less than 50% was considered as good total quality of life.
- From 50% to less than 75% was considered as average.
- From 75% to 100% was considered as poor total quality of life.

2- Operational design:

Preparatory phase:

The current and international related literature using books, periodicals journals, magazines and internet was reviewed by the researcher to be more acquainted with the topic and with the process of tool designing.

Content validity:

Tools of the study were reviewed by 5 panel experts, the Jury consisted of 5 professors of Pediatric Nursing to test the content validity. Modifications of the tools were done according to the panel judgment on clarity of sentences, appropriateness of content and sequence of items with no change in the core of minor questions in the used tools.

Reliability:

The internal consistency was measured to identify the extent to which the items of tools measure the same concept and correlate with each other. Reliability was assessed using Cronbach's Alpha test coefficient test and was estimated as (0.78) for knowledge, (0.82) for practice and (0.85) for quality of life.

Pilot study:

A pilot study was conducted on 10% of the study participants (15 mothers having children with ASD) to evaluate the study tools applicability, clarity and time required for data collection and then the necessary modification was done as revealed from the results of pilot study, so it was excluded.

Field work:

- Data were collected through 6 months from beginning of December 2021 to the end of May 2022. The researcher was available at the previously mentioned settings by rotation 2 days per week on Saturday and Sunday for Out-patient Child Neurology Clinic that affiliated to Sohag University Hospitals and on Wedndes day and Thursday for Institute of Childhood Studies that affiliated to Ain Shams University Hospitals in each study setting from 10 a.m. to 12 p.m. by scheduled rotation. Data collection from mothers who accepted to be included in the study after explaining the aim of the study.

- Data collected from Child Neurology Clinic that affiliated to Sohag University Hospitals were (100 sheets) and data collected from Institute of Childhood Studies that affiliated to Ain Shams University Hospitals were (46 sheets).

• Mothers were interviewed to fulfill the questionnaire sheet according to their free time throughout the speech session time of their children. As regards the reported practices assessment sheet, it demands the suitable time throughout the session time for the mothers to be fulfilled.

• Each mother took about 45 minutes to answer the all items of the questionnaire sheet. Time needed for **Tool I** was ranged from (10-15) minutes. Also**, Tool II** needed (15-20) minutes and **Tool III** ranged from (10- 15) minutes.

Ethical considerations:

The research approval was obtained from scientific research Ethical committee Faculty of Nursing, Ain Shams University before starting the study. An informed consent was obtained from each mother before inclusion in the study sample. There was clear and simple clarification of the study nature and its expected outcomes was explained. They was secured that all data collected was treated in confidentiality and anonymity. All the study subjects have the right to withdraw at any time from the study.

3 - Administration design:

An official permission was obtained by submission of a formal letter issued from the Dean of Faculty of Nursing, Ain Shams University to the director of each of the previously mentioned setting to collect the necessary data for current study after a brief explanation of the purpose of study and its expected outcomes.

4- Statistical design:

The obtained data was organized, tabulated, analyzed, represented in tables and graphs a required, mean and stander deviation as well as percentages, suitable statistical test was used to test the significance of results obtained.

Significance of results was considered as follows:

Significant (S) at $p< 0.05$

Highly significant (HS) at $P<0.01$

Results:

Table (1): illustrated that, nearly two thirds (65.8%) of the studied children were male, more than half (56.2%) of them had 6< 8 years of age, less than two thirds (62.3%) of them were second in the child's ranking, all (100%) of them were in primary level of education, more than two fifths (45.9%) of them had medium degree of disorder and nearly half (49.3%) of them were 1<5 years of duration.

Table (2): revealed that, nearly one third (32.3%) of the studied mothers had 35 < 40 years of age, more than two fifths (41 .8%) of them read and write, more than half (55.5%) of them didn't have work, less than two thirds (58.2%) of them had degree of kinship between the father and the mother and most (81.5%) of them hadn't genetic history of autism in the family.

Figure (1): demonstrated that, less than two thirds (61.6%) of the studied mothers had poor level of knowledge regarding autism, in addition (26%) of them had average level and (12.3%) of them had high level of knowledge regarding autism.

Figure (2): showed that about two fifths (40.4%) and more than two fifths (43.2%) of the studied mothers had good and average level of practices regarding their role toward the children respectively, while, less than one fifth (16.4%) of them had poor level of practices.

Figure (3): indicated that, more than two thirds (67.1%) of the studied children had poor level of quality of life and more than one quarter (28 .8%) of them had average level. On other hand, minority (4.1%) of them had good level of quality of life.

Table (3): showed that, there was high statistically significant positive correlation between total mothers' practices and their children quality of life (r 1.374 & p .002*). Also, there were statistically significant positive correlation between total mothers' practices and their total knowledge (r .324 & p .231*). In addition, there were statistically significant positive correlation between total mothers' knowledge and their children to quality of life.

Table (1): Distribution of the studied children according to their characteristics (n=146).

Characteristics of child		No	%
Gender	Male	96	65.8
	Female	50	34.2
Age in years	6< 8	66	45.2
	8 < 10	37	25.3
	10 ≤12	26	17.8
Child's ranking	First	41	28.1
	Second	91	62.3
	Third	14	9.6
	Fourth & more	0.0	0.0
Educational level	Primary education	146	100
Degree of disorder	Mild	58	39.7
	Moderate	67	45.9
	Severe	21	14.4
Duration of disorder	>1 year	40	27.4
	1<5 years	72	49.3
	5:10 years	17	11.6
	<15 years	17	11.6

Table (2): Distribution of studied mothers according to their characteristics (n=146).

Characteristics of mother		No	%
Age in years	< 30	30	20.5
	30: 35	43	29.5
	35: 40	47	32.2
	≥ 40	26	17.8
Educational level	Illiterate	37	25.3
	Read and write	61	41.8
	Moderate level of education	33	22.6
	Bachelor degree	15	10.3
Occupation	Work	65	44.5
	Not work	81	55.5
Degree of kindship between the father and the mother	Yes	85	58.2
	No	61	41.8
Family history of autism	Yes	27	18.5
	No	119	81.5

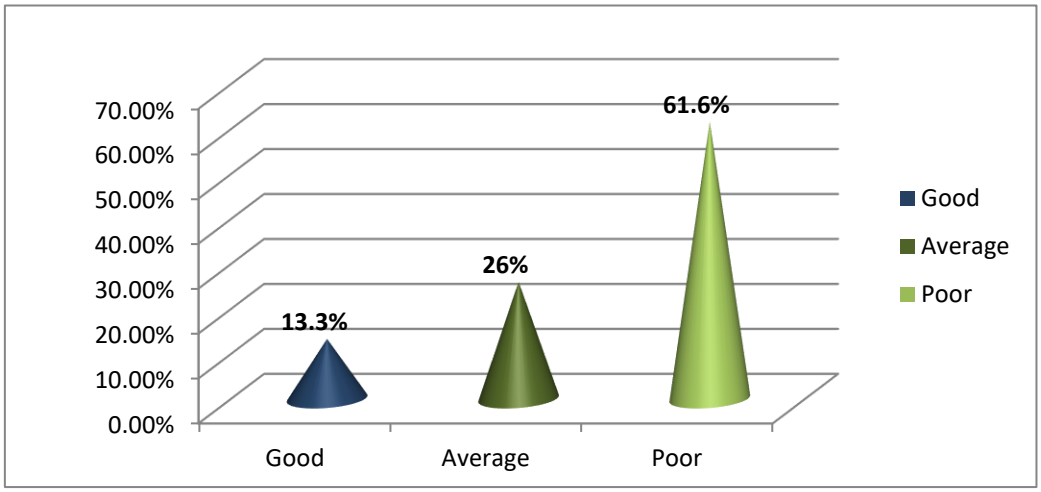

Figure (1): Distribution of the studied mothers according to total level of knowledge regarding children's autism (n=146).

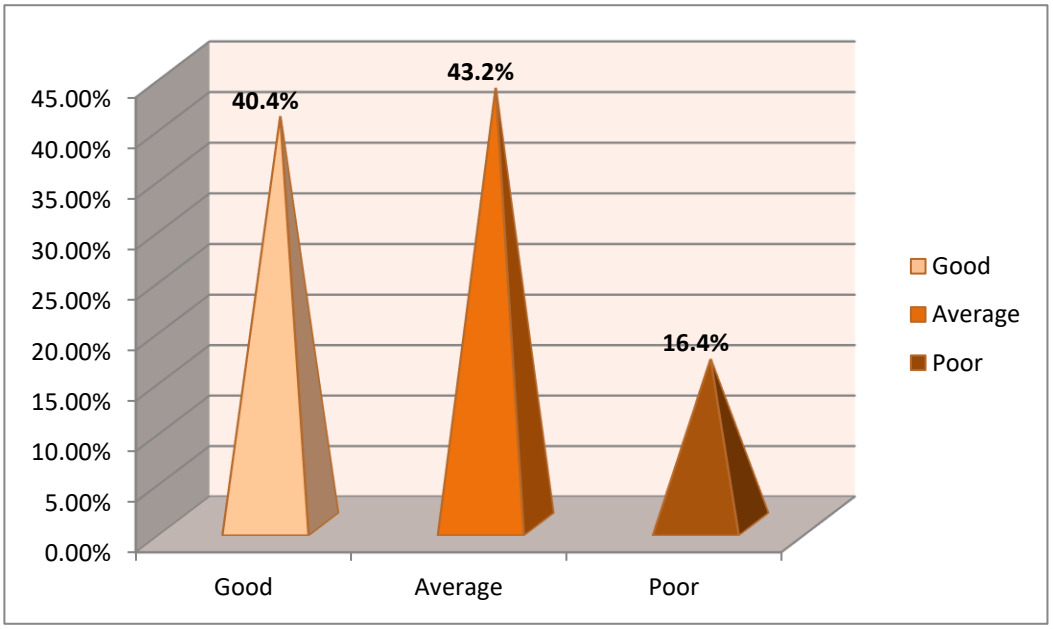

Figure (2): Distribution of the studied mothers according to total level of practices regarding their autistic children (n=146).

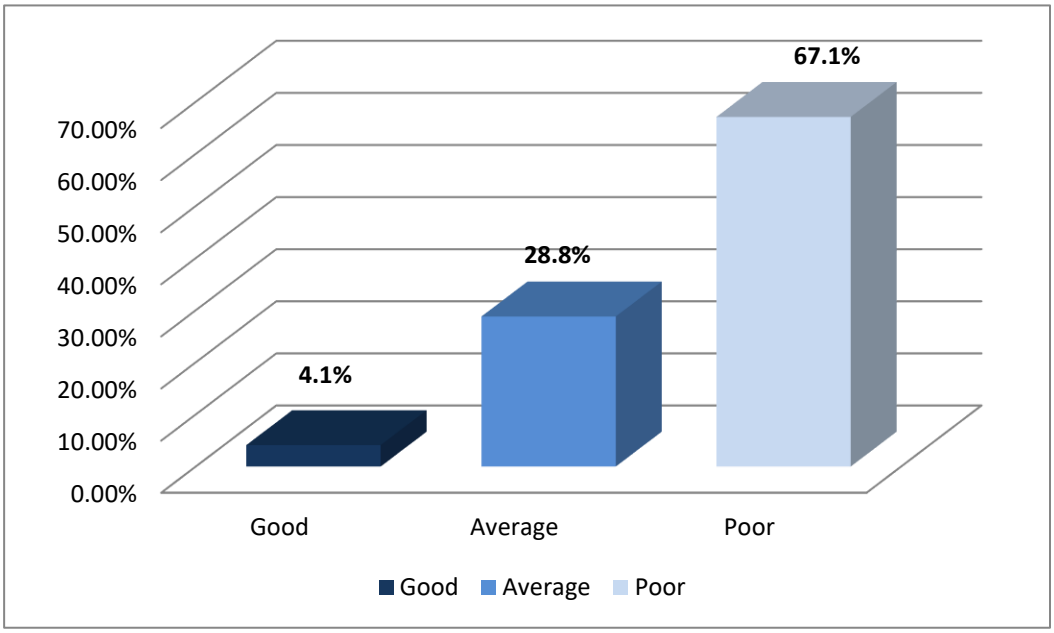

Figure (3): Distribution of the studied children regarding their total level of quality of life (n=146).

Table (3): Correlations matrix between total mothers' knowledge, practices and their children quality of life (n=146).

Studied variables	Total knowledge		Total practices		Total quality of life	
	R	P	R	P	R	P
Total knowledge	--	----	.324	.0231*	.725	.0151*
Total practices	.324	.0231*	----	---	1.374	.002**
Total quality of life	.725	.0151*	1.374	.002**	----	---

(*) Statistically significant at p < 0.05. (**) highly statistically significant at p<0.01

Discussion

Autism is neurodevelopment disorder characterized by impairments in social interactions, communication and restricted, repetitive and stereotyped patterns of behavior that typically emerge in the first few years of life. Typically, autism is manifested by the time a child is three years of age and is life-long. There is variability in the pattern and severity of symptoms and in the timing of diagnosis. Even if the parents often noticed that something is wrong during infancy it is very difficult to diagnose autism before the age of 3 years, this is because the behavioral symptoms used to establish the diagnosis have not clearly emerged developmentally until that age **(Levy et al., 2020).**

Quality of life (QoL) is a multidimensional concept that reflects on the individual's perception of his or her life and daily participation. QoL is closely related to children's rights and comprises health, well-being, living conditions, family relations, play, social life, education and leisure **(Egilson et al., 2017).** So, the aim of this study was to assess the quality of life in children with autism spectrum disorder.

Regarding characteristics of the studied children, the findings of the current study revealed that, nearly two thirds of the studied children were male, less than half of them were in the age group 6 < 8 years old and less than two thirds of them were second in the child's ranking. This finding wasn't supported by the finding of **Mohamed et al., (2020)** who carried

out a study entitled "Knowledge assessment among autistic children's parents regarding Autism Spectrum Disorder", who reported that, more than half of children were in the age group from 4 to less than 5 years old. In relation to gender, majority of studied children were boys and concerning the birth order, it was found that less than two thirds of children were the first child.

Regarding the child's ranking. The current study showed that, less than two fifths of them were in the second order. This result was in the same line with a study carried by **Khudhair and Jassim, (2018),** which entitled under "The knowledge of autistic children's mothers regarding autism in Basra city" and found that, less than two fifths of the children in the second child order.

As regards to studied mothers' personal characteristics, it was found that, nearly one third of studied mother their age 35 < 40 years, more than half of them not have work and more than two fifths of them read and write. These findings disagreed with study finding conducted by **Ebrahim and Alothman, (2021)**, which entitled" Evaluation of Mothers' Knowledge about Autism", and reported that, more than half of the studied mothers were aged between 26–30 years. Also, less than half of the participants varied as to educational qualifications with secondary school being the most common. Among all of the respondents more than half were employed.

Regarding mothers' occupation, the present study showed that more than half of them not have work. This finding in was the same line with a study carried by **Khudhair and Jassim, (2018),** who showed that, more than two thirds of them were house wife.

Regarding kinship between the father and the mother, the findings of the current study illustrated that, less than two thirds of them had degree of kinship between the father and the mother. These findings was in the same line with **El-Baz et al., (2011),** who carried out a study about risk factor of autism was consistent with the present study finding which reported the most sample had positive consanguinity degree. Moreover, this study disagreed nmwith the study results of autism in Saudi Arabia: Presentation on Clinical Correlates and Comorbidity that conducted by **Al-Salehi et al., (2012)** and reported that, studied sample represents more than one quarter were consanguineous marriages.

As regards total level of knowledge, the current study illustrated that, less than two thirds of the studied mothers had poor level of knowledge regarding autism. In addition, more than one quarter of them had average level and less than one fifth of them had high level of knowledge regarding autism. These results were compatible with **Ebrahim and Alothman, (2021)** who reported that, more than two thirds of all respondents had a low or insufficient level of knowledge about ASD, less than one third had a medium level of knowledge and none of the respondents exhibited a high level of knowledge. Also, another study carried by **Abirami et al., (2018)**, about" A Study to Assess the Knowledge on Autism among Parents Attending at SRM General Hospital, Kattankulathur", who reported that, less than half of parent had inadequate knowledge. While, more than half of them had moderately adequate knowledge and the least had adequate knowledge.

Concerning the studied mothers' total practices level. The present study indicated that, less than half of the studied mothers had good level of practices related to sleep disorders, more than two fifths of them had average level of practices related to isolation behavior, while more than three quarters of them had poor practices related to verbal communication problems. These results were supported by **Keshk et al., (2019),** who showed that, more than two fifths of mothers had satisfactory level of practices regarding sleep disorders. On the other hand, more than three quarters of them had dissatisfaction level regarding behavior, stereotypes and frequent talk of the child. Also, a another study carried by **Raslan et al., (2019),** found that, more than two fifths of the studied mothers had good role to overcome meal time difficulties, while more than two fifths of them had average role to prevent fear and accidents and less than two fifths of them had poor role to

overcome types of behavior and the typical movements and frequent talk.

In relation to the studied mothers' total practice level, the present study showed that more than two fifths of the studied mothers had average and good level of reported practices regarding their role toward the children, while less than one fifth of them had poor level of practices. These findings were inconsistent with **Bassam and Tork, (2019)** who conducted a study entitled "Education Program for Mothers of Children with Autism Spectrum Disorder: Mothers and Child Outcomes" and indicated that, more than three quarters of mothers had a low level of practices toward care provided to their autistic children. Another study carried out by **Keshk et al., (2019),** found that, less than two thirds of mothers had inadequate practice level and more than one third had adequate practices level regarding care of their autistic child.

Regarding distribution total quality of life of autistic child, the present study illustrated that, more than two thirds of the studied children had poor level of total quality of life. This finding was in the same context with **El-Gazzar et al., (2018),** who conducted a study about "Quality of life for children with attention deficit hyperactivity disorder" and found that more than half of the ADHD children under study had poor total quality of life. On the other hand, this finding not parallel to **Dawood and Khudhair**, **(2015)**, who carried out a study about " Assessment of the Quality of Life of Mothers having a Child with Autism" and found that, more than two fifths of mothers reported a moderate level in the total level of quality of life. From the researcher point of view, this may be due to the fact that, Autism is associated with broad impairment in many health quality of life parameters, including academic performance, behavior at school, peer relations and family function.

Conclusion:

Based on the findings of the present study, it was concluded that, less than two thirds of the studied mothers had poor level of knowledge. Also, more two fifths of them had average level of reported practices regarding their role towards their children. In addition, there was high statistically significant positive correlation between total studied mothers practices and their children quality of life. Also, there was statistically significant positive correlation between total studied mothers practices and their total knowledge. In addition, there was statistically significant positive correlation between total studied mothers, knowledge and their children quality of life.

Recommendations:

Based upon the results of the current study the following recommendations suggested:

- Developing educational programs about autism for mothers at home , teachers and children at school in addition to health settings to improve knowledge and attitude of the community towards the autistic children.
- Encourage continuous sharing of the mothers during the care of their children with autism by specialists to identify needs and problems of ASD.
- Conduct further studies related to children with ASD.

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