Parent's Stress and Quality of Life for Children Diagnosed with Autism

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Abstract

Background: Autism was currently one of the most prominent and widely discussed pediatric condition and was a set of neurodevelopmental disorders. **Aim of study:** The aim of this study was to assess parent's stress and quality of life for children diagnosed with autism. **Design:** A descriptive design was utilized to conduct this study. **Settings:** The study was carried out at outpatient clinics of Benha Specialized Pediatric Hospital, and Al–shohdaa Hospital at menoufia city. **Sample:** A convenient sample of (75) parents accompanied their autistic children were selected from the previously mentioned settings. **Total of data collection:** Five tools were used: **Tool (1)** A structured interviewing questionnaire. **Tool (II)** Developmental assessment for children, **Tool (III)** Childhood Autism Rating Scale (CARS) –Second Edition, **Tool (IV)** Parental stress Index-short form scale and **Tool (V)** Pediatric Quality Of Life 4.0 Generic Core Scale. **Results:** Less than half of the studied fathers were in the age groups 45 years old , and more than two fifth of the studied mothers were in the age groups less than 25 years old. More than two thirds of the studied parents have unsatisfactory knowledge regarding autism, while less than one third of them have satisfactory knowledge regarding autism. Less than half of the studied children had moderate autism less than half of the studied parent had moderate stress level and less than two thirds of studied children had low level quality of life. **Conclusion:** There was a highly statistically significant positive correlation between total parent's stress, knowledge, and total quality of life of their children. **Recommendations:** Providing training programs for parents of children diagnosed with autism, which helps them to be able to deal in the best way with their children.

Key words: Autism, Children, Parent's Stress**,** Quality of Life

Introduction

Autism is currently one of the most prominent and widely discussed pediatric conditions. Autism spectrum disorder (ASD) is a set of neurodevelopmental disorders characterized by early onset of impaired social interaction, communication, or repetitive behaviors, and restricted interests. children with autism also commonly present with atypical patterns of sensory responsiveness, such as hypo responsiveness or hyper responsiveness (**Feldman et al., 2020**).

According to Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5), ASD may occur along with other medical conditions such as; epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), intellectual disability, sleep disturbances and gastrointestinal problems. The prevalence of ASD has increased in recent years to 1 in 160 children worldwide due to genetic or environmental susceptibility. This requires simultaneous investigations of interactions between children characteristics or genetics and environmental factors for more encompassing explanations (**Leblanc et al., 2020**).

Parent's Stress and Quality of Life for Children Diagnosed with Autism

The increased prevalence of autism has intensified the demand for effective educational and therapeutic services, and intervention science is providing mounting evidence about practices that positively impact outcomes. Accurate diagnosis of developmental disorders in early childhood, and autism in particular, is vital for the obvious goal of targeting timely effective treatments to minimize symptoms, to increase probability of successful adaptive, personal, and social growth, and ultimately for achieving independent and "satisfying" function in adulthood (**Steinbrenner et al., 2020).**

Early diagnosis and interventions for children implemented before 4 years old showed significant gains in cognition, language, and adaptive behavior. Missed diagnosis, or a false-negative result, deprives the child from the benefits of early intervention and the chance to minimize clinical symptoms, early diagnosis tools incorporating observations of adaptive behaviors, prosaically play and associated communication with playmates, and interaction with family, caregivers, and peers; and long-term surveillance to verify diagnosis stability, and severity so as to adjust their treatment plan as needed (**Segal& Hus, 2021).**

Although there are health-care centers specializing in the treatment of ASD, the majority of the care is provided at home by family members. Parents of children with ASD reported stress more than parents had normal children. The challenges that affect parent's psychological well-being include lack of social support and deficiencies of health services. Caring for a child with ASD is associated with increased financial burden owing to the number of visits made to the health-care office, prescribed treatment, special education, and coordinated family services. This also affects parents' employment decisions; to accommodate their child's needs (**Alenazi et al., 2020).**

Quality Of Life refers to how an individual perceives and evaluates life experiences and can be conceptualized by domains that are universal (e.g. emotional and physical well-being). Having a good QOL is important because it is indicative of positive perceptions of overall health and well-being as well as satisfaction with life experiences. Also, QOL has been measured using generic instruments (**Gómez et al., 2020).**

Autistic children have lower Quality of life (QoL) than their neurotypical peers. The main risk factors for QoL impairment in autistic children are autism severity, behavior problems, low adaptive behavior level, and psychiatric comorbidities as anxiety disorder. Qol impairment in ASD also involves parental well-being, which may be related to the child's behavior disturbances (**Schneider et al., 2022).**

Current treatments for autism spectrum disorder (ASD) seek to reduce symptoms that interfere with daily functioning and quality of life. ASD affects each child differently. Therefore, treatment plans usually involve multiple professionals toward the children. Treatments can be behavioral, developmental, educational, social relational, pharmacological, psychological, or a combination of settings. It is important that providers communicate with each other and the child with ASD and their family to ensure that treatment goals and progress are meeting expectations (**Hyman et al., 2020).**

The role of parents in the therapeutic program is important as that of the special educators in achieving the best possible results and is necessary. The involvement of

parents in the treatment program can play a decisive role in the outcome of treatment. The systematic training of parents helps to regain their lost confidence and reduce their stress to meet their parental role requirements. Parenting experience and knowledge may seem to be the major contributors to the successful education of children with autism, The life of a child with autism continues at home and with his or her family, so educational programs implemented to include at all stages the parents of children with autism can only be achieved with cooperation and teachers and parents (**Chaidi and Drigas, 2020).**

When nurses have knowledge about early detection of ASDs, they will be able to refer children at risk for ASD for diagnostic evaluation and intervention at the earliest possible opportunity. A lack of shared enjoyment and joint attention, limited eye contact with care takers, a lack of symbolic play, inconsistent orienting to the child's name, or restrictive, repetitive patterns of behavior are early developmental deficits that a nurse can identify in children less than 18 months of age and made referral of the child for further evaluation (**Ault et al., 2021).**

Significance of the study:

Autism spectrum disorders (ASDs) represent a group of neurodevelopmental disorders characterized by impaired socialization and communication, often accompanied with stereotyped ritualistic behavior. To date, no clear data could explain the dramatic worldwide increase in the incidence of ASD during the last two decades. It is suggested that some environmental factors besides a genetic predisposition leads to autism. In addition, it's known to be associated with other psychiatric comorbidities (**Higazi et al., 2021).**

The prevalence of ASD reached a dramatic increase worldwide and reported that an estimated 1in 68 (14.6 per 1000)of children**.** The World Health Organization (WHO) estimates the international prevalence of ASD at 0.76%; however, this only accounts for approximately 16% of the global child population. The Centers for Disease Control and Prevention, (2018) estimates about 1.68% of United States (US) children aged 8 years (or 1 in 59 children) are diagnosed with ASD (**Hodges et al., 2020).**

The prevalence of ASD in Arab countries, estimated to be 1.4 cases per 10,000 children aged 0–14 years, with the highest prevalence among 5 to 9 year old children, and in males (2.5 times the prevalence in females) . In Egypt, research suggests that there are more than 140,000 children in Egypt who are diagnosed with autism (**Alallawi et al., 2020).**

Aim of the study:

This study aimed to assess parent's stress and quality of life for children diagnosed with autism.

Research questions:

1. What are levels of stress of parent with autistic children?
2. What are levels of quality of life for autistic children?
3. Are there relationship between parent's stress and quality of life of children?
4. Are there relationship between parent's stress & quality of life of children and their characteristics?

Research design:

A descriptive design was utilized to conduct this study.

Research setting:

The current study was conducted at the out-patient clinic for children neurologic disorder in Benha Specialized Pediatric Hospital at Benha city and out-patient clinic

for children neurologic disorder in Al–Shohdaa Hospital at Menoufia. Both of Hospital affiliated to ministry of health and population. The out-patient clinic in Benha Specialized Pediatric Hospital found in the ground floor in building A and consist of one room while the out-patient clinic in Al–Shohdaa Hospital found in the ground floor in building B and consist of one room.

Research subjects

A purposive sample composed of (75) parents accompanied their autistic children who were selected from the above previously mentioned settings during the period of the study, (20 parents) from Benha Specialized Pediatric Hospital and (55 parents) from Al–Shohdaa Hospital at Menoufia after fulfilled the following criteria:

Inclusion criteria:

- Parent's having children aged from 6<12years.
- Parent's having children diagnosed with autism.
- Parents willing to participate in the study.

Exclusion criteria:

Children with any other neurological disease such as epilepsy.

Tools of data collection:

Five tools were utilized to achieve the aim of the current study:

Tool (I):- A structured interview questionnaire:-

It was designed by the researcher in an Arabic language after reviewing the related & recent literature. It included two main parts:-

Part I: It was comprised of the following:-

A): Characteristic of the studied parents: It included data related to age, occupation, educational level, and family size .

B): Characteristic of the studied children : It involved data related to age,

gender, ranking, and level of child education.

C): Medical history of the studied parents : It involved data related to presence of genetic disease in the family, presence of chronic disease in the family, consanguinity, presence of diseases during pregnancy of mothers, presence of problems during delivery of mothers, and other sibling have autism in the family.

D): Medical history of the studied children : It included data related to the onset of autism, problems occur during child birth, symptoms appears that make mother seek medical help.

Part II: Parent's knowledge assessment: It was developed by the researcher after reviewing the related & recent literature to assess parent's knowledge regarding autism, it include 15 multiple choice questions related to definition of autism, causes, signs and symptoms of autism, parent's knowledge about the abilities and needs of their children with autism, problems of having an autistic child in the family (5questions) that includes (behavior and emotional problems, problems with understanding the world around him, problems related to teaching life skills & economic problems), treatment methods for a children with autism (3 questions) related to (behavioral therapy, educational therapy& family therapy), the role of social service centers in facing the problems arising from autism in the family &source of information.

Scoring system for knowledge:

The studied parent's answers were compared with a model key answer, correct and complete answer scored (2), correct and incomplete answer scored (1), wrong or don't know answer scored (0), the total score were ranged from (0-30) degree. According to parents answers, their total level of knowledge categorized as unsatisfactory level

of knowledge <60% (15-24degrees) of total knowledge score. Satisfactory level of knowledge ≥60% (25-30 degrees) of total knowledge.

Tool (II): Developmental assessment for children:-It was adopted from **Maguire et al.,(2015)** to assess developmental milestones for children. It include (21) statement answered by (Yes) and (No) related to cognitive development (6 items), motor development (7 items), and social & emotional development (8 items)**.**

Tool (III):- **Childhood Autism Rating Scale (CARS) –Second Edition:**

It was adopted from **Schopler & Reichler , (1980)** to assess the severity of autism for children. It contain (60 items) grouped under 15 domains including relationship to people (4 items), imitation (4 items), emotional response (4 items), body use (4 items) , using things (4 items) , adaptation to change (4 items), visual response(4 items), listening response (4items) , taste-smell-touch response (4 items), fear& nervousness(4 items), verbal communication (4 items), non-verbal communication (4 items), activity level (4 items), level & consistency of intellectual response (4 items), and general impression(4 items).

Scoring system for autism rating scale

The scoring system of the scale was classified into 4 point rating scale. (1) Normal for child, (2) mildly abnormal, (3) moderately abnormal, (4) severely abnormal. The total level of autism was categorized as mild autism >60% (15-30 degrees), moderate autism 60>85% (31-35 degrees), severe autism ≤ 85% (36- 60 degrees). A higher score are associated with severe level of impairment.

Tool (IV):- Parental stress Index-short form scale:- It was adopted from **Abidin, (1995)** to measure stress among parents of children younger than 12 years old , The PSI-

SF scale is one of the most commonly used measures across many different samples. It consisted of 36 items grouped under 3 domain such as parental distress (12items), parental-child dysfunction (12 items), and difficult child (12 items).

Scoring system for parental stress index

The score system of the scale is classified into 5 point Likert scale ranged from 1 (strongly disagree), 2 (disagree), 3(not sure), 4(agree), to 5 (strongly agree). Total score range from 36 to 180. Total level of stress are categorized as low level of stress >60% (36-90 degrees), moderate level 60>85% (91-134 degrees), high level ≤ 85% (135-180 degrees). A higher score indicate greater levels of parenting stress.

Tool (V):- Pediatric Quality Of Life 4.0 Generic Core Scale:-

It was adopted from **Varni et al., (1999)** to measure quality of life among school age children and utilized in pediatric psychiatric disorders for demonstrating any significant impairments. It consisted of 23 items included four domains physical (8 items), emotional (5 items), social (5 items), and school functioning (5 items). The Pediatric quality of life is a feasible, reliable, and valid instrument to measure QOL in children.

Scoring system for pediatric quality of life

The score system of the scale is classified in to 5-point Likert scale ranged from (0= never a problem, 1= almost never a problem, 2= sometimes a problem, 3 = often a problem,4 = almost always a problem). To further increase the ease of use for the young child self- report, the response scale is reworded and simplified to a 3-point scale ranged from (0) not at all a problem, (2) sometimes, to (4) a lot of a problem. Then, the researcher made modification on score system to become from(1) never, (2) sometimes, to (3) always. Total level of

pediatric quality of life is categorized as low level of quality >60%(23-34 degrees), moderate level 60>85%(35-50 degrees), high level ≤ 85%(51-69).

Response scale	Modified scoring
(0) not at all a problem	(1) never
(2) sometimes	(2) sometimes
(4)a lot of a problem	(3) always

Tools of validity and reliability:
Content validity

The data collection tools were translated into Arabic and revised by a panel of three experts (one professors and two assistant professors) in the field of pediatric nursing specialty from Faculty of Nursing at Benha University, who selected to test the content validity of the instrument. Their opinion was elicited regarding the format, layout, consistency, accuracy and relevancy of the tools, all of their remarks were taken into consideration. Some items were re-phrased to arrive the final version of the tools. The tools were regarded as valid from the expert's point of view.

Reliability

Reliability of the tools was applied by using Cornbrash's alpha coefficient test. This turned to be (0.816) for A structured interview questionnaire, (0.715) for developmental assessment of children, (0.824) for childhood autism rating scale, (0.763) for parental stress index short form scale and (0.851) for pediatric quality of life 4.0 generic core scale. These indicate a high degree of reliability for the study tools.

Ethical consideration:

Written approval was obtained from the Ethical Committee at the Faculty of Nursing, Benha University. The researcher clarified the aim of the study and expected outcomes to all

the studied parents participated in the study. Verbal approval was prerequisite to participate in the study. The studied parents were assured that all gathered data were used in research purpose only and the study was harmless. Additionally, the studied parents were allowed to withdraw from the study at any time without giving the reason. Confidentiality and anonymity of the gathered data and results were secured.

Pilot study:

A pilot study was conducted on 10% of the expected sample size (4 mothers,4 fathers accompanied their children) from the previously mentioned settings to test the applicability, clarity, efficiency of the tools and time needed. In the light of pilot study analysis, no modification was made, parents were included to the total sample of the study. This phase was carried out from the beginning to the end of march, (2021).

Field work:

Data collection was carried out in the period from the beginning of April (2021) to the end of September (2021), covering 6 months. The researcher was available in the study settings two days per week (Sunday and Wednesday) in the specialized Pediatric Hospital at Benha. and two days per week (Monday and Thursday) in Al–shohdaa Hospital at Menoufia. at the morning shift from (9 A.M to1 P.M) to implement this study and collect data in each study setting. The average numbers of interviewed parents was 3 parents per week. At the beginning of interview; the researcher welcomes each parent and their children. Then the researcher explained the title, objectives, tools and the study technique for each parent to obtain their oral approval and cooperation which is needed for conducting this study.

Each parent was individually interviewed using Arabic structured

interviewing questionnaire and the time needed for filling this tools was about 15- 30 minute, Autism Rating Scale (ARS) took nearly 15- 20 minute, Parent Stress Scale (PSS) took nearly 10- 15 minute, and Pediatric Quality Of Life scale (Peds QOL) took nearly 10- 15 minute . The researcher was present all the time during filling the study tools to explain & illustrate everything to the parents.

Precautionary measures are taken into consideration during data collection including; personnel protective materials such as, face mask, gloves, antiseptic solution for hand hygiene. Also, personal distancing to maintain a minimum 1.5 M distance, avoiding shaking hands or hugging, always cover the mouth while sneezing or coughing to prevent droplet transmission, avoid touching one`s mouth, nose or eyes to prevent the spread of infection. Motivation and reinforcement were used to enhance sharing in the study. Motivation of parent and their children was done by encouraging words , giving sweets and gifts to their children.

Statistical analysis:

The collected data were organized, categorized, analyzed and tabulated by using the Statistical Package for Social Science (SPSS) version 22 for windows, running on IBM compatible computer. Quantitative data was expressed as; mean scores and standard deviation. While Qualitative data was expressed as frequencies and percentages. Statistical test as Chi-square was used to measure significant of qualitative variables. correlation coefficient (r) was used for correlation analysis and degree of significance was identified. Reliability of the study tools was done using Cronbach's Alpha. Data were presented in the form of tables and graphs. A significant relation was considered when (p< 0.05). A highly statistical significant relation when (p < 0.001), meanwhile, No statistical

significance difference was considered when (p > 0.05).

Results:

Table (1): In relation to parent's characteristic's it reveals that, less than half (48%) of the studied fathers are in the age groups 45 years old and more, with mean age 38.80±6.34 years, and more than two fifth (44%) of the studied mothers are in the age groups less than 25 years old with mean age 32.28±7.68 years. Regarding their occupation it's found that, less than two third (64%) of studied fathers are employee. Also, more than two thirds (68%) of the studied mothers are un- employed. Regarding educational level of the studied fathers, it's found that, slightly less than one third (32%) of them has preparatory and secondary school. Also, less than half (48.0%) of studied mothers have primary school. Regarding consanguinity of the studied parents, more than half (56%) of the studied parents reports negative consanguinity, and more than two fifth (44%) of the studied parents reports positive consanguinity.

Table (2): Shows that, more than two fifth (44%) of the studied children were in the age groups 10>12years, and their mean age was 8.11±0.879 years. More than two thirds (68%) of the studied children are males, and more than one third (36%) of the studied children are the first children in their family. Also, all (100%) of the studied children are in primary education.

Table (3): Illustrates that, more than one third (38.6%) of the studied parents report that the onset of autism at in the age (3 - 6) months. Also, more than two third (69.3%) of the studied children have problems during child birth, and less than one quarter (16.0%) of those children have birth asphyxia**.** The majority (88%) of the studied children have delay in speaking and language, the vast majority (92%) of them have lack in

understanding social relationship that make mother seek medical help, and the majority (86.6%) of those children complain repetitive movement for a long time.

Figure (1): Regarding total level of knowledge of the studied parent. This figure illustrates that, more than two thirds (68%) of the studied parents have unsatisfactory knowledge regarding autism, while less than one third (32.0%) of them have satisfactory knowledge regarding autism.

Figure (2): Regarding source of knowledge among the studied parents. This figure Portrays that, the majority (86.7%) of the studied parent have knowledge about autism from health team. More than two third (68.0%) of them have knowledge about autism from family/ friends, and slightly more than two fifth (41.3%) of the studied parent have knowledge about autism from self-learning. While, only (4.0%) of them have knowledge about autism from their work place.

Figure (3): Regarding Total level of autism of the studied children . This figure illustrates that, less than half (48.0%) of the studied children had moderate autism, and more than one quarter (28.0%) of them had mild autism. While, less than one quarter (24.0%) of them had severe autism.

Figure (4): Regarding total level of stress of the studied parent. This figure illustrates that, less than half (45.4%) of studied parent have moderate stress level, and one third (33.3%) of them have high stress level. While, slightly more than one fifth (21.3%) of them have low stress level.

Figure (5): Regarding percentage distribution of the studied children regarding their total level of quality of life. This figure illustrates that, less than two thirds (65.3%) of the studied children have low level quality of life, and less than one quarter (22.7%) of them have moderate level quality of life. While, only (12.0%) of the studied children have high quality of life.

Table (4): Illustrates that, there was a highly statistical significant positive correlation between total parent stress, total parent knowledge, and total quality of life of their children.

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Table (1): Distribution of the studied parents regarding their characteristics (no=75).

Parents characteristics	Father (n=75)		Mother (n=75)	
	No	%	No	%
Age in years				
>25	0	0.0	33	**44.0**
30>25	15	20.0	15	20.0
40>35	24	32.0	9	12.0
≤ 45	36	**48.0**	18	24.0
Min -max	30-47		23-46	
Mean ±sd	38.80±6.34		32.28±7.68	
Occupation				
Employee	27	**64.0**	24	32.0
Unemployed	48	36.0	51	**68.0**
Educational level				
Primary	9	12.0	36	**48.0**
Preparatory	24	**32.0**	12	16.0
Secondary	24	**32.0**	6	8.0
University	12	16.0	15	20.0
Other mentioned	6	8.0	6	8.0
Consanguinity				
Yes	33	44.0		
No	42	56.0		

Table (2): Distribution of the studied children regarding their characteristics (no=75).

Children characteristics	No	%
Age in years		
6>8	25	33.3
8>10	17	22.7
10>12	33	**44.0**
Mean ±SD 8.11±0.879		
Gender		
Male	51	**68.0**
Female	24	32.0
Child ranking		
First	27	**36.0**
Second	24	32.0
Third	21	28.0
Fourth and more	3	4.0
Level of child education		
Primary	75	**100.0**

Table (3): Distribution of the studied children regarding their medical history (no=75).

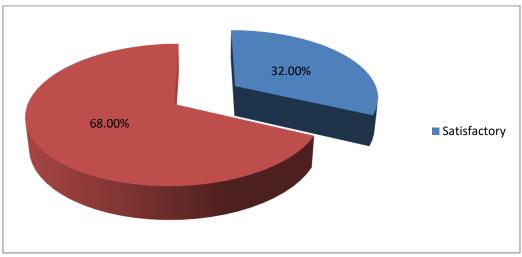| Medical history	No	%
The onset of autism		
1 <3 months	19	25.3
3< 6 months	29	**38.6**
≥6 months	27	36.0
Presences of problems occur during child birth		
Yes	23	30.6
No	52	**69.3**
Types of problems occur during child birth		
Birth asphyxia	12	**16.0**
Abnormal fetal presentation	8	10.6
Fetal dystocia/abnormal size	10	13.3
Symptoms appear that make mother seek medical help		
Delay in movement	12	16.0
Delay in speaking and language	66	**88.0**
Lack in verbal and non-verbal communication	60	80.0
Lack in understanding social relationship	69	**92.0**
Insufficiency in emotional expressions	42	56.0
Repetitive movement for a long time	65	**86.6**

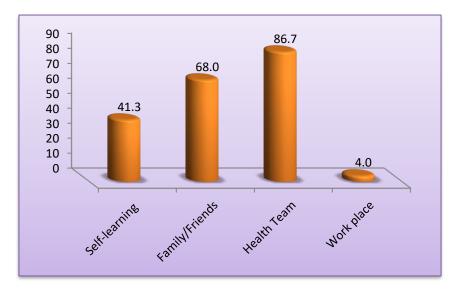**Figure (1): Total knowledge level about autism among the studied Parents.**

Figure (2): Source of knowledge among the studied parents.

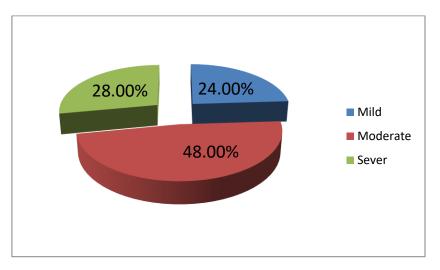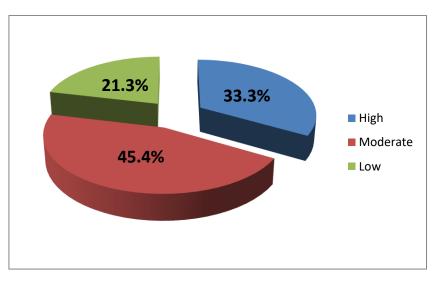**Figure (3): Total level of autism among the studied children.**

Figure (4): Total level of stress among the studied parents.

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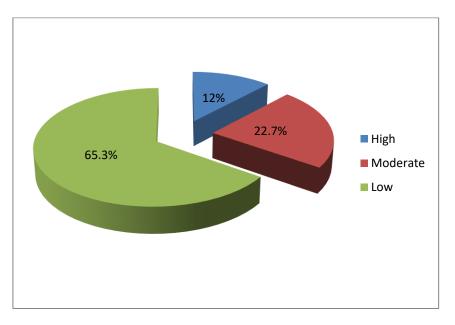

Figure (5): Total level of quality of life among the studied children.

Table (4): Correlation between total severity of autism, total parent knowledge, total parent stress and total quality of life among studied sample (n=75).

Variables		Total severity of autism	Total parent knowledge	Total parent stress	Total quality of life
Total autism	r	1	.321	.891	-.611
	p-value		.021	.004*	.016*
	n	75	75	75	75
Total knowledge	r	.321	1	.737	.533
	p-value	.021		.000**	.000**
	n	75	75	75	75
Total parent stress	r	.891	.737	1	-.403
	p-value	.004*	.000**		.000**
	n	75	75	75	75
Total child quality of life	r	-.611	.533	-.403	1
	p-value	.016*	.000**	.000**	
	n	75	75	75	75

** A highly statistical significant at p value ≤ 0.001. *A statistical significant at p value <0.05 .

Discussion:

Autism had a lifelong neuro developmental condition. It's characterized by differences in behavior, social interaction, communication, special interests and sensory processing. These differences can present children on the autism spectrum with challenges in how they interact with their environment and may behave in non-typical ways, often in response to the different ways in which they experience their environment. Such behaviors are generally a way to communicate their feelings or to adapt to a situation, or may result from their heightened sensitivity to a sound or something they have seen or felt **(Malik et al., 2021).**

Autism spectrum disorders (ASD) widely common, can be diagnosed as young as 18 months of age, and has evidenced-based interventions that may improve function. Parents should be familiar with the diagnostic criteria for ASD, appropriate etiologic evaluation, medical and behavioral conditions such as disorders of sleep and feeding, gastrointestinal tract symptoms, obesity, seizures, and attention-deficit/hyperactivity disorder, anxiety, and wandering that affect the child's function and quality of life. Children with ASD have service needs in behavioral, educational, health, leisure, family support, and other areas **(Hyman et al., 2020).** So, the present study aimed to assess parents' stress and quality of life for their children diagnosed with autism.

Concerning parent's characteristics, the finding of the present study revealed that, less than half of the studied fathers aged 45 years old and more. This finding goes on the same context with **Lyall et al., (2020),** who conducted a study of "The association between parental age and autism related outcomes in children at high familial risk for autism " and found that older parents have a greater likelihood of having a child with autism, and increases risk when paternal age above 40years.

Regarding parent's occupation, the present study clarified that, all of studied fathers are employee. this finding agreed with **Hamid et al., (2020),** who conducted a study of "Socioeconomic characteristics of autistic children: a comparative study " and found that the majority of children with ASD had working fathers. Also, more than two thirds of the studied mothers were housewife, these findings goes on the same context with **Hurley-Hanson et al., (2020),** who conducted a study of "The Costs of Autism " and found that two thirds of studied mothers were unemployed. This may due to place of residence can have contributing factors with the child/parents and family coping with disease.

In addition, the present study revealed that, more than half had no consanguinity between father and mother, this finding goes on the same context with **Green et al., (2021),** who conducted a study of " Differential predictors of well-being versus mental health among parents of preschoolers' with autism" and found that, less than two third of studied sample had no consanguinity between father and mother.

Regarding children characteristics, the current study illustrated that, more than two fifth of the studied children were 10 >12 years, this finding goes on the same context with **Howells et al., (2020),** who conducted a study of " Can participation in a community organized football program improve social, behavioral functioning and communication in children with autism spectrum disorder? A pilot study", and found that nearly than half of the studied children were 10 >12years.

Regarding gender of the studied children, the current study revealed that, more than two thirds of studied children were males, this finding was compatible with

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Nordahl et al., (2020), who conduct a study of " High psychopathology subgroup in young children with autism: associations with biological sex and amygdala volume ", and found that more than two thirds of studied children were males. This may be because of hormonal causes , environmental and genetic factors. Genetic studies demonstrate that females are protected from the effects of heritable and de novo ASD risk variants, and compelling work suggests that sex chromosomal genes and/or sex hormones, especially testosterone, may modulate the effects of genetic variation on the presentation of an autistic phenotype **(Margari et al., 2021).**

The current study showed that, more than two thirds of the studied parents have unsatisfactory knowledge regarding autism, this result was supported with **Kandice,(2019)**. Who conducted a study of " parents knowledge of autism spectrum disorder" and found that, more than two fifth of parents had a relatively low knowledge base of autism, that agree with **(Ahmed et al., 2020)** who stated that, parents can't recognize early symptoms. In fact, the behavior of children younger than two years may not certify for a diagnosis, as it is very difficult to evaluate their verbal communication and Social interactions. Consequently, it may be difficult to notice impairments in social interactions before children are exposed to a different social setup.

The current study showed that, less than one third of the studied parents have satisfactory knowledge regarding autism this result was in accordance with **Crane et al., (2021).** Who conducted a study of " Autistic parents' views and experiences of talking about autism with their autistic children" and found that, one third of the studied parents have knowledge regarding autism, this might

be because of those parents had updated data and awareness about current diseases like autism.

Regarding parents source of knowledge` about autism , the current study revealed that, the majority of the studied parent had knowledge about autism from health team, This may be due to the health team members have an effective roles in sharing recent knowledge with parents about autism, and parents are viewing the doctors are the primary caregiver and trusted in doctors' information this finding was disagree with **Mansour, (2021)**, who conduct a study of "The information-seeking behavior of Egyptian parents of children with Autism Spectrum Disorder (ASD)" and found that more than three-quarters of Egyptian parents used informal sources, such as mobile/smartphones, the Web, social media and social networking sites.

Regarding total level of autism, the current study revealed that, less than half of the studied children had moderate autism, and less than one third of them had mild autism. While, less than one quarter of them had severe autism, this finding was in the same direction with **Waizbard et al., (2021),** who conduct study about " trajectories of autism symptom severity change during early childhood" and states that, the largest group of children 54.4% of the sample showed stable severity over time , the second largest group of participants 28.8% of the sample had decreased in severity over time and the smallest group 16.8% of the sample increased in severity.

The current study indicated that, less than one quarter of the studied parents have low stress level regarding total parental distress subscale, this finding was disagree with **Kim et al., (2020),** who conducted a study of " The influence of race and ethnicity

on the relationship between family resilience and parenting stress in caregivers of children with autism" and found that, than two fifth of the studied parents have low stress level regarding total parental distress subscale.

Concerning total parents stress level, the current study indicated that, less than half of the studied parents had moderate stress level, this finding was in agreement with **Harris et al., (2020),** who conducted a study of "Technology-assisted parenting interventions for families experiencing social disadvantage: A meta-analysis" and found that, less than half of the studied parents had moderate stress level. And also agree with **Ishtiaq et al., (2020)** who stated that, child's inability to understand speech, and undeveloped verbal communication of the child can lead to greater parental stress. Parents live in a heightened state of stress due to additional responsibilities of care of their disabled children in daily living. It is critical to study parental stress in such situations because the increased stress level may affect their health, relation and interactions**.**

The current study indicated that, one third of the studied parents have high stress level , this finding was in agreement with **Rovane et al ., (2020),** who conducted a study of "Adherence to behavioral treatments and parent stress in families of children with ASD and found that, more than third of the studied parents have high stress level.

The current study indicated that, slightly more than one fifth of them have low stress level, this finding was in agreement with **Clauser et al., (2021)**, who conducted a study of "Parenting styles, parenting stress, and behavioral outcomes in children with autism" and found that, one third of them have low stress level.

The current study illustrated that, less than two thirds of studied children had low level quality of life, this finding was

disagreed with **Günal et al., (2020),** who conducted a study of " The effects of motor and cognitive impairments on daily living activities and quality of life in children with autism" and found that less than one fifth of studied children had low score quality of life.

Regarding Correlation between total severity of autism, total parent knowledge, total parent stress and total quality of life , the present study illustrated that, there was a highly statistical significant positive correlation between total parent stress , total parent , and total quality of life of their children, this finding was in agreement with **Lichtle et al., (2020),** who conduct a study of "The effects of parent training programs on the quality of life and stress levels of parents raising a child with autism spectrum disorder: A systematic review of the literature" and found that there was a highly statistical significant positive correlation between total parent stress , total parent , and total quality of life of their children.

Conclusion

There was a highly statistical significant positive correlation between total parent knowledge, total parent stress and total quality of life of their children.

Recommendations:

Providing training programs for parents of children with autism, which helps them to be able to deal in the best way with their children.

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الضغوط النفسية للوالدين وجودة حياة اطفالهم المصابين بالتوحد.

علياء على عبد الستار   – امال غريب سباق – راوية عبد الغنى محمد

التوحد هو اضطراب النمو العصبي ويتصف بضعف التفاعل الاجتماعي والتواصل اللفظي وغير اللفظي وأنماط سلوكية مقيدة ومتكررة للأطفال، ويؤثر على عملية معالجة البيانات في المخ وذلك بتغييره لكيفية ارتباط وانتظام الخلايا العصبية ونقاط اشتباكها، إلا أن كيفية حدوث ذلك غير مفهومة تماماً حتى الآن . وللتوحد أسس وراثية قوية، وتتطلب معايير التشخيص ضرورة أن تصبح الأعراض واضحة قبل بلوغ الطفل ثلاث سنوات من العمر . تم اجراء هذه الدراسة في العيادات الخارجية للاضطراب العصبي للأطفال بمستشفى الأطفال التخصصي بمدينة بنها, ومستشفى الشهداء بالمنوفية التابعتين لوزارة الصحة والسكان.واشتملت عينة البحث على (75) من الاباء واطفالهم الذين يعانون من التوحد.(20) من الآباء من مستشفى الاطفال التخصصي و(55) من الآباء من مستشفى الشهداء المركزي. . واظهرت النتائج أن كان أقل من نصف الآباء المدروسين في الفئات العمرية 45 سنة ، وأكثر من خمس الأمهات المدروسات في الفئات العمرية أقل من 25 سنة .أكثر من ثلثي الآباء المدروسين لديهم مستوي المعرفة غير مرضية فيما يتعلق بالتوحد ، بينما أقل من ثلثهم لديهم مستوي المعرفة مرضية فيما يتعلق بالتوحد .كان أقل من نصف الأطفال الخاضعين للدراسة لديهم توحد معتدل ، وكان أقل من نصف الوالد الذي شملته الدراسة يعاني من مستوى متوسط من الضغوط النفسية وأقل من ثلثي الأطفال الذين خضعوا للدراسة لديهم مستوى منخفض من جودة الحياة واوضحت الدراسة إلى وجود علاقة ارتباط موجبة ذات دلالة إحصائية عالية بين إجهاد الوالدين الكلي ، ومعرفة الوالدين الكلية ، والجودة الكلية لحياة أطفالهم .أوصت الدراسة بأهمية توفير برامج تدريبية لأولياء أمور الأطفال مما يساعدهم على التعامل بأفضل طريقة مع أبنائهم.