



## ASSESSMENT OF STRESS AND COPING STRATEGIES AMONG PARENTS HAVING CHILDREN WITH AUTISM SPECTRUM DISORDER

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### Abstract

**Background:** Autism is one of the most important developmental disorders which severely affect both parents and children; this disorder imposes great physical, mental, and social pressures on families particularly parents.

**Aim:** to assess stress and coping strategies among parents having children with autism spectrum disorder.

**Design:** descriptive design was used in carrying out the study.

**Setting:** The study was conducted at psychiatric outpatient clinic in Fayoum General Hospital.

**Subjects:** convenience sample from parents having children with autism included in the study.

**Tools:** 1st structured interview questionnaire, 2nd Parent Stress Scale and 3rd Coping Strategies Scale.

**Results:** this study represent high percentage of severe stress and low coping strategies among parents having children with autism.

**Conclusion:** the study concluded that, Parents of children with autism have severe level of stress and low coping strategies with individual differences in the way parents cope with these stresses and highly significant correlation between total stress levels, total coping strategies and total knowledge among parents having children with autism.

**Recommendation:** providing program to reduce parent stress and enhance coping strategies associated with caring of these children.

**Keywords:** Autism, Parent, Stress, Coping Strategies

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## 1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disability characterized by persistent and pervasive impairments in social understanding and communication, poor adaptive functioning, and the presence of restricted or repetitive behaviors and interests. Current epidemiological studies have revealed an increased prevalence of ASD over the previous two decades; ASD has been diagnosed more often in boys than in girls, with a sex ratio of (3boys): (1girls). According to estimates from the Autism and Developmental Disabilities Network (CDC's) the current prevalence is 1 in every 54 children in the United States, while in recent years, the prevalence in Europe has increased rapidly, due to an increased awareness of autism (Papadopoulos, 2021).

Diagnosing autism spectrum disorder (ASD) can be difficult because there is no medical test like a blood test, to diagnose the disorder. Doctors look at the child's developmental history and behavior to make a diagnosis. ASD can sometimes be detected at 18

months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. Some people are not diagnosed until they are adolescents or adults. This delay means that children with ASD might not get the early help they need. Monitoring, screening, evaluating, and diagnosing children with ASD as early as possible is important to make sure children receive the services and supports they need to reach their full potential (Alonso Esteban., et al. 2020).

Mothers of autistic children take on the responsibilities of diagnosis, advocacy, and daily care. There is evidence that this impacts upon their quality of life, had higher levels of modeling, stress, they have great difficulties in accepting the diagnosis of their children due to lack of knowledge, social stigma, and skills in establishing a healthy communication with their children to maintain their social emotional and physical development in a healthy way. Also, they tend to report more depression and greater pessimism about their child's future than other mothers of children with other developmental disabilities (Bassam, & Tork, 2019).

The most significant sources of stress for parents who have children with autism spectrum disorder are: sedentary conditions of disturbance, family and community member's disapproval of the behavior exhibited by children. Parents often also feel a sense of 'being judged' by their environment who think that parents are not able to provide good care for children so parents will then choose to withdraw from social interaction and lack of professional support. The more severe behavioral problems in children will cause difficulties for parents to get a day care or child care (Kalalo & Setiawati, 2020).

Coping mechanisms that are often demonstrated by parents when caring for their child with ASD include support from family, friends, social support groups, other parents of children with ASD, service providers, advocacy, and religion. Furthermore, a parent's ability to deal with a high-stress level depends on the effectiveness and quantity of the coping mechanism they employ in managing the demands of stressors associated with a child with ASD (Haytham, et al., 2022).

The positive coping patterns give higher chances for both autistic children and their care givers to act more smoothly with less rejection and more acceptances on the part of each other and the society. The coping response of the caregivers of autistic children towards the perceived strains depends on the situation/threat being faced, in addition to the caregivers' personality traits, health, optimistic beliefs, culture, social support networks, problem-solving capabilities and religion (Abu El-Soud, Ouda, Abdou, & Mohamed, 2020).

Nurses are the eyes and ears of the health care team and the voice for the parents, thus creating a critical connection between the parents and health care team. The nurse in a generalist role may work with child with autism in a variety of settings. Nurses working in mental health clinics, paediatrician's office, and schools have the most contact with these children. Understanding the disorder, its etiology, symptoms, and types of treatment enables the nurse to work with the child and family and identify their specific need (Ahmed, 2017).

#### **Aim of the Study:**

The study was aimed at to assess stress and coping strategies among parents having children with autism spectrum disorder.

#### **This aim was attained through:**

- 1- Assess stress of parent having children with autism.
- 2- Assess coping strategies of parents having children with autism.
- 3- Assessing the relationship between knowledge of parents about autism with their stress and coping strategies.

#### **Research Questions:**

- What is the stress facing the parents having children with autism?
- What are the coping strategies used by parents having children with autism?
- Is there any relationship between knowledge of parents about autism with their stress and coping strategies?

## **2. SUBJECTS AND METHODS**

### **1) The technical design:**

#### **A) Research design:**

A descriptive research design was used to achieve the objective of the study.

#### **B) Setting:**

The study was conducted at psychiatric outpatient clinic in Fayoum General Hospital.

#### **C) Subject:**

Sample types and size:

Convenience sample from parents having children with autism. The sample size was 60 from the studied parent.

#### **D) Tools for data Collection:**

##### **I. Tool I:** Self-administered questionnaire sheet.

A structured Arabic self-administered questionnaire sheet was designed by the researcher, after reviewing the related current and previous literature, to collect data which cover the aim of the study, and which consists of three parts as follows:

The first part: about parent: name, age, level of education, occupation, relation to child, family mental history

The Second part: about the child which includes: child's name, age, sex, degree of autism, child's birth order, presence of any mental illness besides autism and does the child participate in any of the behavior modification programs?

**The Third part:** Knowledge assessment questionnaire: to assess the knowledge of parents about autism such as definition of autism, causes and clinical features of autism, What are the factors that occur during pregnancy and child birth lead to autism, what are the warning signs and symptoms of autism, treatment methods and how to deal with child problems.

##### **Scoring System:**

The parent knowledge was given scores 0 mark to incorrect answer and one to the incomplete answer and 2 to complete answer. The scores of the items were summed-up and the total divided by the number of the items, these scores were converted into a percent score.

**Tool II:** Parent stress scale (PSS) (Hosny, 2006): The parent stress scale was developed by (Hosny, 2006). The scale was designed to assess level of stress directly associated with parenting role, The PSS consists of 72 items divided into six subscales: which include: somatic symptoms, psychological symptoms associated with child disability, psychological stress resulting from child communication problems,

psychological stress resulting from child behavioral disturbance, psychological stress resulting from child social skills deficit and psychological stress resulting from financial aspects.

**Scoring system of parent stress:**

The sales rated on a 5-point Likert scale format, ranged from (0-4), (0) = Never occurs, (1) = rarely occur, (2) = sometimes occurs, (3) = often occurs, (4) = always occurs. The total score of the scale is (0-288).

Mild stress	0:69
Moderate stress	70 : 192
Severe stress	193 : 288

**Tool III: Coping Strategies Scale:** This scale was developed by (Bustami, 2013). This scale used to assess the coping strategies that used by the parent having children with autism. It consists of 64 questions (Arabic version). All items were answered by using a 5-point Likert scale.

**Scoring system:**

The scoring ranged from (1-5), always = (5), often= (4), sometimes = (3), rarely = (2), never= (1). The total score of the scale is (64-320). The cutoff point is (160) the higher the score the higher the frequency of using the coping strategies.

High coping	≥75%
Low coping	<75

**Ethical consideration**

Ethical approval was obtained from a scientific, ethical committee in the faculty of nursing, Helwan University before starting the study. The researcher obtain oral consent from each participant in the prementioned setting. The researcher clarified the objectives of the study to parents included in the study. The researcher assure anonymity and confidentiality of subject's data. Parents informed that they are allowed to choose to participate or not in the study and that they have the right to withdraw from the study at any time.

**II. Administrative design:**

Official letters, including the title and purpose of the study were issued from the faculty of Nursing Helwan University and Written informed consent was obtained from Fayoum General Hospital manager and head of psychiatric department and oral permission was obtained from each parent..

**III. Operational design:**

The study, to be completed,has passed through different phases as follows: the preparatory phase, then the pilot study phase and lastly the field of work phase.

**Preparatory phase:**

During this phase the researcher reviewed the current, local and international related literature using books, periodicals journals, magazines and internet.

This helped the researcher to be more acquainted with the study.

**Pilot study:**

A pilot study was carried out on 10% of parents (6 parent) under the study to test the applicability, clarity and the efficiency of the tools according to the criteria of selection. Pilot study is excluded from the sample.

**Field work:**

The researcher collected data over period of 6 months starting at (October 2021 till the end of March 2022) through interviewing parents of children with autism comes to outpatient clinic at El- Fayoum General Hospital, Saturday, Tuesday and Thursday each weak from 9:00am to 12 pm, 2:3 parent interviewed/day. The time needed by each participant to complete the questionnaire ranged between 40-50 min, the total number 60 from the parent.The researcher introduced herself to parent of children with autism and the approval of parents was obtained orally after explaining the purpose of the study and try to establish a trustful relationship.

**IV. STATISTICAL DESIGN:**

A Statistical Package for Social Science (SPSS) version 20 was used for statistical analysis of data. Number and percent was calculated for all variables of the study. Frequency tables were done for all variables. Chi-square was used for detection of correlation between stress and coping strategies. Linear.

The observed difference and associations were considered as follows: P > 0.05 non significance (No difference (P<0.05 (Significance difference ( P< 0.001 highly significance difference.

**3. RESULTS**

**Table (1):** Reveals that about (43.3%) of studied parent aged between 35 or more and (50.0%) at secondary education level,while (65%) of them doesn't work, but (70%) of them living in rural area, plus (40%) the monthly income of the family were insufficient and (73.3%) of them doesn't have any family history of mental/psychiatric illness.

**Table (2):** this table show that (83.3%)of the studied autistic children were males and (61.7%) of them were in the age category 5<10y while, (53.3%) have moderate degree of autism, and (36.7%) of them were the second child, while (50.0%) of them participate in behavior modification programs, (60.0%) of them report presence of mental / mental illness besides autism and (56.7%) of them "autism disorder discovered at age 3: <6.

**Table (3):** this table show that (66.7%) of studied parent had correct incomplete knowledge regarding how to deal with tantrums and screaming and only

(10%) had correct complete knowledge regarding the concept of autism.

**Figure (1):** This figure reveal that (43.3%) of studied parent have average levels of knowledge, (35%) had poor levels of knowledge and (21.7%) had good levels of knowledge.

**Figure (2):** This figure illustrates that, (65%) of parent of children with autism suffering from severe stress level, and (25%) had moderate stress, (10%) had mild stress.

**Figure (3):** this figure reveal that (63.3%) of parent had low level of coping strategies, (36.7%) had high level of coping strategies.

**Table (1):** Distribution of the socio-demographics of the studied parent (N=60)

Items	N	%
<b>Age (years)</b>		
<30	12	20.0
30- <35	22	36.7
35 or more	26	43.3
Mean±SD	32.98±4.53	
<b>Education Level</b>		
Illiteracy	7	11.7
Primary education	9	15.0
Secondary / middle education	30	50.0
university level	14	23.3
<b>Job</b>		
Work	21	35.0
does not work	39	65.0
<b>Housing</b>		
Urban	18	30.0
Rural	42	70.0
<b>The monthly income of the family</b>		
Adequate	22	36.7
insufficient	24	40.0
Somewhat sufficient	14	23.3
<b>Any family history of mental/psychiatric illness</b>		
Yes	16	26.7
No	44	73.3

**Table (2):** Distribution of socio-demographics data of the children with autism (N=60)

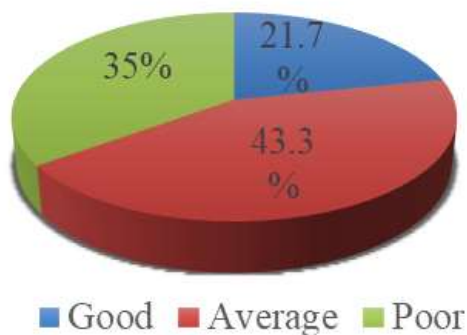
Items	N	%
<b>Age (years)</b>		
<5	18	30.0
5- <10	37	61.7
10 or more	5	8.3
Mean±SD	5.87±2.22	
<b>Gender</b>		
Male	50	83.3
Female	10	16.7
<b>The degree of autism</b>		
Mild	24	40.0
Moderate	32	53.3
Severe	4	6.7
<b>Child's birth order</b>		
First	18	30.0
Second	22	36.7
Third	2	3.3
last only	18	30.0
<b>Does the child participate in any of the behavior modification programs</b>		

Yes	30	50.0
No	30	50.0
<b>The presence of any mental / mental illness besides autism</b>		
Yes	40	60.0
No	20	40.0
<b>When was autism disorder discovered</b>		
<3	24	40.0
3- <6	34	56.7
6 or more	2	3.3

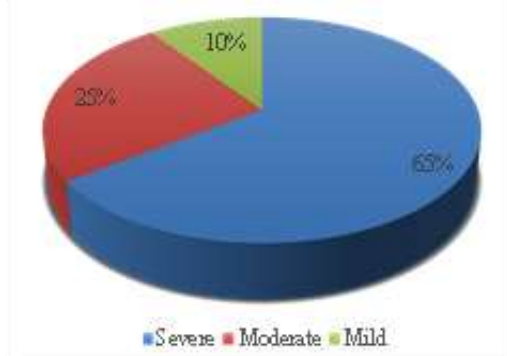
**Table (3):** Distribution of the studied parent according to their knowledge about autism: (N:60)

Items of knowledge	correct& complete		correct& incomplete		Incorrect	
	N	%	N	%	N	%
What is the concept of autism	6	10.0	19	31.7	35	58.3
What are the factors that occur during pregnancy and lead to autism	16	26.7	24	40.0	20	33.3
What are the factors that occur during childbirth and lead to autism disability	11	18.3	25	41.7	24	40.0
What are the warning signs and symptoms of autism	23	38.3	34	56.7	3	5.0
What are the treatment methods for a child with autism	19	31.7	26	43.3	15	25.0
How to deal with tantrums and screaming	11	18.3	40	66.7	9	15.0
How to deal with vandalism	24	40.0	19	31.7	17	28.3
How to deal with socially embarrassing behavior	15	25.0	15	25.0	30	50.0
How to deal with isolation and sitting alone all the time	18	30.0	23	38.3	19	31.7
How to deal with refusal to eat and malnutrition	8	13.3	38	63.4	14	23.3
How to deal with child sleeping disorder	9	15.0	40	66.7	11	18.3

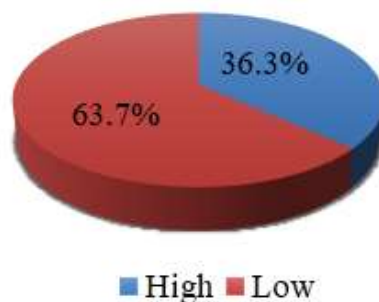
**Figure (1):** Total levels of knowledge among parents having children with autism



**Figure (2):** Total stress level among parents having children with autism



**Figure (3):** Total levels of Coping strategies among parents having children with autism



#### 4. DISCUSSION

Regarding the studied parent socio-demographic data the present study result clarified that more than one third of parent were aged 30-35 years with Mean±SD 32.98±4.53. Moreover, regarding parent occupation, more than two third of studied parent doesn't work and more than two third of them live in rural area. This may be due to parents of autistic children especially mothers had difficulty in pursuing their professional careers, due to excessive time demand for

caring the child. This finding in agreement with study of (Bassam, Tork, 2019) who entitled (Education Program for Mothers of Children with Autism Spectrum Disorder) reported that the mean age of the parents was thirty two years. Also, the study of (Mohamed, Mohammed & Hassan, 2020) who entitled "Knowledge Assessment among Autistic Children's Parents Regarding Autism Spectrum Disorder" who found the majority of mothers were housewives but disagree with them regarding housing where report the majority of families living in urban area.

Regarding level of education, the study revealed that about half of studied parents educated to secondary level of education and the minority of them had university education. This agrees with the study of (Mohammadi, Rakhshan, Molazem, & Zareh, 2018) who studied "Parental competence among parents with autistic children" who report that about half of parents had a secondary diploma. But disagree with (Pandey & Sharma, 2018) who entitled "Perceived Burden in Caregivers of Children with Autism Spectrum Disorder" report that more than half of the caregivers had attained education of above higher secondary level.

Regarding monthly income of the family, two fifth of studied parent had insufficient income and nearly three quarter doesn't have any family history of mental or psychiatric illness. This agree with study of (Bassam, Tork, 2019) clarified that the majority of parents had insufficient income and more than two third of the families had no history of autism. Also, the study of (Abu El-Soud, et al., 2020) who entitled "Assessment of Knowledge, Strains and

Coping of the Family Care Givers Having Autistic Children" revealed that the majority of the studied caregivers had negative family history of autism but disagree with them regard monthly income of the family revealed that less than two thirds of the studied children's parents had enough income.

Regarding socio-demographic characteristics of autistic children, the study result clarified that slightly more than two thirds of studied children aged between 5 to 10 years and majority of them were males. These finding were congruent with study of (Schwartzman, 2020) who studied Resilience Training for Parents of Children with Autism reported the average age of children was 6 years and the majority of children were males which is consistent with elevated rates of ASD in males in the general population.

Regarding degree of autism, the study result indicated that slightly more than half of children have moderate degree of autism and more than one third of them are second child in the family according to birth order, while about half of them participate in behavioral modification behavior and nearly two third of them diagnosed with autism at age 3 years. Age of diagnosis may be due to that parent might be not enough oriented to growth and development of normal children due to lack of experience. Regarding birth order may be interpreted as there is little proved evidence that autism can arise purely from social factors or child rearing behavior. This finding agrees with the study of (Mostafa, AbdElkader, AbdElsalam, 2017), who studied Life Adaptation Program & Its Effect on Daily Living Skills of Autistic Children and Their Parents Stress found more than half of the studied children had moderate degree of autism, the majority of children were diagnosed with autism disability from the third year of age and more than one third of the studied children were ranked the second child in their families.

Regarding comorbidity, the current study result illustrated that more than two third of studied children, their parent reported presence of mental illness beside autism. This finding study agree with study of (Cassell, 2019) who entitled "Predictors of Stress in Parents of Children Receiving Applied Behavior Analysis for Autism Spectrum Disorder"

reported the majority of participants reported that their child had at least one comorbid psychiatric or developmental diagnosis as Intellectual Disability (ID), Comorbid Anxiety Disorder, Disruptive Disorder, Attention-Deficit/Hyperactivity Disorder (ADHD).

As regarding to total level of knowledge among parents of children with autism, this study revealed that only one fifth of studied parents had good levels of knowledge about the disease. This could be attributed to poor awareness, low educational level and lack of attending any training program about autism and the nature of their children with autism not makes the mother to seek more information about the care of autistic children. This supported by the study of (**Kavita Garg., 2019**) who entitled " Study to Assess the Knowledge and Attitude regarding Care of Autistic Children among Parents of Autistic Children" implies that majority of the sample had moderate knowledge regarding care of autistic children.

In relation to level of stress on parents of children with autism, this study revealed that more than two third of parents had severe level of stress. This may be due to that autism is a long term disability and parent's reported feeling exhausted and stressed in regard to the huge responsibilities associated with caring of a child with disability to the challenging characteristics of the child. This agree with **Sim et al, (2018)**, who carried out the study entitled "Factors associated with stress in families of children with autism spectrum disorder" reported that the majority of parent reported severe family stress related to raising a child with ASD.

Also, the study of (**Demšar & Bakracevic, 2021**) who studied Depression, anxiety, stress, and coping mechanisms among parents of children with autism spectrum disorder reported that behavioral issues in children with ASD are mostly responsible for higher levels of stress related symptoms amongst the parents. And, the study of (**Shepherd, Landon, Taylor & Goedeke, 2018**) who entitled "Coping and care-related stress in parents of a child with autism spectrum disorder" report that Parenting stress increased with severity of the child's ASD symptoms. Moreover, the parents report the requirements for taking care of the child far exceed financial capabilities, child's treatment is expensive, the family sacrifices different things because of the costs of taking care of child and the money spend on the child is more than what spend on other children. This may be due to cost of treatment is high, high cost of regular follow-up, cost of education and rehabilitation programs that the child need, decreased parent income because one parent may need to stay at home to care for the child and large proportion of mothers were housewives, in addition, the worker mother may leave the job to take care of child. This finding supported by the study of (**Ntre, et al, 2018**), who entitled "Psychosocial and financial needs,

burdens and support, and major concerns among families with children with autism spectrum disorder" reported that families raising children with ASD face a reduction of the family income, high costs and financial difficulties because of the increased health and educational needs of their children.

Regarding parent coping strategies, the study result indicated slightly more than two third of studied parent had low level of coping strategies, This may be due to child behavior may lead to parental exhaustion, which may result in the use of inadequate coping strategies and increased stressors and demands of managing child autistic symptoms may threaten parents' coping resources, resulting in increased stress and strain.

Also, the study result showed that about two third of parents were using avoidance and denial as a coping strategies style. While more than one third of them were using seeking information and social support as a coping strategies style, this agree with the study of (**Mostafa, 2019**) who entitled "Stress And Coping Strategies Among Parents Of Children With Autism Spectrum Disorder" illustrated that 59% of parents were using avoidance and denial as a coping strategies style. While 55% of them were using seeking information and social support.

Also, most of parents suffering from low social support and this agree with the study of (**Ntre, et al., 2018**) who suggested that families raising children with ASD are characterized by low social support and adapt avoidant coping strategies to manage their problems and handle their stress. But disagree with (**Demšar & Bakracevic, 2021**) report that the majority of parents reported that they received enough support and were satisfied with it.

The finding of study revealed that there was statistically significant relation between total levels of knowledge and age of studied parent and with educational level of parent, this agree with the study of (**Kavita Garg., 2019**) who report that age of parents had a statistical significant association with the level of knowledge. But disagree with the study of (**Abu El-Soud et al., 2020**) found that there was no statistically significant relationship regarding the studied parent level of education and their total knowledge mean scores.

The finding of study revealed there was highly significant negative correlation between coping strategies and level of stress of the studied parent's that high levels of parenting stress resulted in low levels of positive coping; this reveals that the parents of autistic children are having high level of stress due to poor coping strategies. This agree with (**Suen et al., 2021**) who entitled " The Association between Parenting Stress, Positive Reappraisal Coping, and Quality of Life in Parents with Autism Spectrum Disorder" found a significant negative correlation between parenting stress and positive reappraisal coping in parents with ASD children that a high

degree of parenting stress could be related to inefficient coping strategies.

Also, the finding of study revealed that was highly significant correlation between total stress levels, total coping strategies and total knowledge among parents having children with autism, this agree with (Suen et al., 2021) reported that high stress level in parents with ASD children was significantly connected to a lack of knowledge and coping strategies (i.e., active avoidance, escape avoidance, maladaptive/emotion-focused coping).

## 5. CONCLUSION

The result of the current study pointed to, parents of children of autism had severe level of stress ,average levels of knowledge and had low level of coping strategies. There was a highly statistically significant relation between stress, knowledge and coping strategies, and highly negative significant correlation between stress level and coping strategies of the studied parent's. The finding of the study answered the research question.

## 6. RECOMMENDATIONS:

On the light of the finding of the study the following recommendations outlined:

1)Emphasize the importance of availability and distributions of pamphlets and booklet containing the basic knowledge for parents about disease of their children.

2)Conduct awareness raising program to improve knowledge and attitude of the community towards the autistic children and their families through mass media.

### Further studies: -

Recommended program to reduce the family stress of autistic children and further comprehensive study to explore their stress and coping strategies and proper program should be applied to help them managing stress.

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