# Effect of Nursing Intervention Program on Psychosocial Problems among Family Caregivers of Children with Autism Spectrum Disorder

Shimaa Saied Adam $^{\rm l}$ , Hanaa Sayed Ewise $^{\rm 2}$ , Mona Mohamed Barakat $^{\rm 3}$ , Fathyea Abdallah Ahmed Shams  ${\rm Eldin}^{\rm 4}$ 

(1) Psychiatric Mental Health Nursing Department Faculty of Nursing/Ain Shams University, Egypt. (2) Psychiatric Mental Health Nursing Department Faculty of Nursing/Beni Suef University, Egypt. (3) (4) Psychiatric Mental Health Nursing Department Faculty of Nursing/Benha University, Egypt.

#### Abstract

Background: Managing a child with autism is a difficult task that must be done daily. It has a huge impact on the child's well-being, the mental state of the parent, and their capacity to provide for their children. Recognizing the difficulties that parents face will open new avenues for research and the development of interventions. Aim: Evaluate the effect of nursing intervention program on psychosocial problems among family caregivers of children with autism spectrum disorder. Design: A quasi experimental design for one group (pre/post-test) was used. Setting: This study was carried out at the outpatient clinic of El Abbassia Psychiatric and Mental Health Hospital. Sampling: The study involved 75 family caregivers of children with autism spectrum disorder. Data Collection Tools: Four tools were used: Tool (I) Structured Interview questionnaire, Tool (II) Parenting Stress Index, Tool (III) Zarit Burden interviewing questionnaire for family caregivers, and Tool (IV) Explanatory Model Interview Catalogue-Community Stigma Scale. Results: This study shows that highly statistically significant differences were found between pre/post-program implementation in total levels of parenting stress, burden, and community stigma. In addition, there was a highly statistically significant correlation between total scores of parent stress, burden, and community stigma during the pre/post-program implementation phase ( $P \le 0.001$ ). Conclusion: Nursing intervention program has a significant positive effect on reduce psychosocial problems among family caregivers of children with autism spectrum disorder. Recommendations: Generate and manage nursing care plans for caregivers of children with autism spectrum disorder should focus on their child's psychiatric mental health aspect and provide caregivers with sufficient social support

**Keywords:** Autism, Caregivers, Program, Psychosocial, Problems.

#### **Introduction:**

Autism spectrum disorder (ASD) is a type of neurodevelopmental disorder. It is characterized by persistent problems with social interaction and communication skills in various social settings, special hobbies, and sensory processing of repetitive patterns of behavior. The child requires assistance in daily life as the symptoms start in the early years of life, throughout the first two years of life (Naji, Waheeb, & Hamza, 2020).

The primary symptoms of autism spectrum disorder (ASD) in children are deficits in social communication, which include the inability to strike up a conversation, deficient eye contact, facial expressions, and gesture comprehension, abnormal voice volume

and tone, and repeating of words or phrases. An increasing number of irrelevant answers to questions are offered, and people are unable to pleasure, achievements, optimism, success stories, sentiments and reactions to others. Persistent deficiencies in social communication and social interaction skills are indicative of autism spectrum disorder (ASD). (Hyman, Levy, Scott, & Myers, 2021).

The challenges of parenting children with autism spectrum disorder have an impact on the life of those who are caregivers. Prior research has documented psychological problems that impact parents of children with ASD, such as anxiety, stress, depression, functional limitations, marital tension, burden, impaired physical health, and social stigma. (Tathgur & Kang, 2021).

Furthermore, ASD is more common in nations that are developing. While most parents and children in poor countries have access to high-quality professional intervention programs, merely a tiny percentage of children with ASD actually use them, and they are typically out of reach for them. Children have a big impact on the health of their entire family, especially if they don't receive high-quality healthcare services. Even though ASD is very expensive for both the community and the person, there hasn't been much focus on these disorders in the international arena of the health sector. (Wang et al., 2020).

The social stigma close to children with ASD is one of the challenges that parents face. which is influenced by parental attitudes, a lack of awareness and comprehension knowledge of ASD, a serious deficiency in behavioral treatments and special education programs, as well as inadequate f trained staff, and a shortage of qualified workers. (Liao et al., 2019) (Gabra et al., 2021).

The psychosocial problems, low parenting effectiveness, high-stress levels, physical and mental health problems, serious financial difficulties, time constraints, reduced support difficulties with adjustment, increased burden of care, and social stigma. The impact of ASD on the family may be higher than that of numerous other disorders. As a result, raising autistic children can be challenging for families and parents in developed as well as developing countries. (Wang et al., 2020).

Parents of children with ASD are prone to experience psychological problems because they can regularly encounter their children's symptoms profile, in particular, socially inappropriate behavior, aggressiveness, stereotypical gestures, lack of communication interaction, speech, and language impairment. We compared the parental perspectives of children with ASD with normally developing children, showing that the parents have higher parental involvement exhaustion, stress, and health issues. (Rahman et al., 2021).

Parents of children experience stressful circumstances with ASD. It is linked

to their children's therapy process and a decreased capacity for social interaction. Due to the requirement to care for and treat children with ASD, who require different therapy than other children, A few parents gave up their employment and are unable to enjoy everyday activities. (Acharya & Sharma, 2021)

On top of the regular emotions associated with raising and caring for children with ASD, parents of these children also experience a variety of other emotional problems, such as financial strain, parenting burdens, confusion from organized events, limitations when traveling, abrupt changes in plans, frustration, restlessness, surprise, helplessness, anger, sadness, annoyance, and a family focus that is more on short-term than long-term goals. (Remedios et al., 2020).

Psychoeducation is the most crucial part of a nurse's responsibility in identifying and managing autism. The nurse needs to be able to acquaint parents with the selection of symptoms related to autism to enhance their knowledge, comprehension, and assistance for both parents and children to promote socialization. facilitate learning development, and minimize maladaptive behaviors. The nurse oversees organizing therapies and interventions that satisfy the specific requirements of every child according to their needs. (Magor et al., 2021)

# Significance of the Study:

In 2010, there were 52 million autistic spectrum disorder cases reported globally, as well as a prevalence of 7.6 cases per 1000 children. (Shuid et al, 2021). According to estimates from the Centres for Disease Control and Prevention (CDC), 1 in 59 children had an ASD in 2018. In 2020, that percentage increased to one in 44 children. (Centers for Disease Control and Prevention, 2020). The latest information from the US and Europe indicates that the measured prevalence of autism has increased significantly over the previous 20 years, ranging from 0.48 to 3.13%. (Micai et al., 2021).

Approximately 40% of dads and 70% of moms have children with severe disabilities.

#### (Zhou et al., 2019).

Nursing intervention program have an advantage in reducing psychosocial problems, such as stress, burden of care, and community stigma. So, nursing intervention program can develop better skills that are important for positive outcomes for family caregivers of children with ASD.

# Aim of the Study:

Evaluate the effect of nursing intervention program on psychosocial problems among family caregivers of children with autism spectrum disorder through:

- 1-Assessing levels of psychosocial problems among family caregivers of children with autism spectrum disorder.
- 2-Developing and implementing nursing intervention program on psychosocial problems among family caregivers of children with autism spectrum disorder.
- 3-Evaluating the effect of a nursing intervention program on psychosocial problems among family caregivers of children with autism spectrum disorder.

# **Research Hypothesis:**

Nursing intervention program will have a significant positive effect on psychosocial problems among family caregivers of children with autism spectrum disorder.

# **Subjects and Methods:**

# **Research Design:**

The present study used a quasi-experimental design (pre/post-test) for a single group. An empirical study without random assignment is called a quasi-experiment, and it's employed to ascertain the intervention's causal impact as a result of an intervention on the intended target population, the design has the greatest ability to evaluate the effect of nursing intervention program to reduce psychosocial problems among family

caregivers of children with autism spectrum disorder.

# **Study Setting:**

The present research study was carried out at the outpatient clinic, which is affiliated with the Egyptian Ministry of Health, located within the premises of the El Abbassia Psychiatric and Mental Health Hospital. Outpatient clinic work on Monday and Tuesday every week from 9 AM to 2 PM. It provides services for about 800- 1000 patients per year suffering from a variety type of disorders such as autism spectrum disorder.

# **Study Subjects:**

#### Sample size:

The following equation was utilized to determine the sample size:

S is equal to X 2NP  $(1-P) \div d \ 2 \ (N-1) + X \ 2P \ (1-P)$ .

S= the amount of required sample size

x is the chi-square table value (3.841) for one degree of freedom at the selected confidence level.

N is the number of people.

P is the population proportion, which is usually set at .50 to yield the largest possible sample size.

d is the accuracy level given as a percentage (.05). (Krejcie & Morgan, 1970).

# Sample type:

A purposive sample of 75 family caregivers of children with autism spectrum disorder who had written consented to participate in the study for six consecutive months. The following criteria set forth for the research study were utilized to choose the participants.

#### **Inclusion criteria:**

- Can read and write.
- Both genders are from primary family caregivers.
- Free of any psychiatric disorders or chronic medical disease.

#### **Exclusion criteria:**

- Family caregivers with substance abuse.
- Family caregivers for children with any psychiatric disorders other than autism spectrum disorder.

#### **Tools of Data Collection:**

# **Tool I: A structured Interviewing Questionnaire Tool:**

An interview questionnaire was established by the researchers predicated on an assessment of scientific evidence for review of literature to collect data regarding the demographic characteristics of the family caregivers as age, degree of relation, educational level, occupation, residence, and income.

# Tool II: Parenting Stress Index: Short Form:

The questionnaire is self-administered; it was designed by **Abidin**, (1992) and consisted of 36 questions divided into the following three subscales.

**First subscale: Paternal Distress;** to evaluate the perceived competence of parental functions, the sense of loss of freedom in their personal lives, social support, and the presence of depression.

Second subscale: Parents-Child Dysfunctional Interaction; this subscale includes questions related to the parent's expectations and experiences regarding interaction with their children.

Third subscale: Difficult Child; to evaluate the parental perception of their child's temperament and behavior. The questionnaire is answered on a 5-point Likert-type scale where (5) is totally agree, (4) is agree, (3) is uncertain, (2) is disagree and (1) totally disagree. The sum of all the items indicates the total degree of parental stress (not including the stress caused by other situations).

# **Scoring system:**

Percentile scores that fall between 15 and 80 are considered typical. High-stress scores range from 81 to 84 (for P-CDI) and 89 (all other subscales). Clinically significant levels of stress that need additional follow-up are above 85 (for P-CDI) and above 90 (for all other subscales).

# Tool III: Zarit Burden interviewing questionnaire for the family caregiver.

It was designed by **Zarit, Reever, & Bach-Peterson**, (1980) and was adapted from **Seng, Luo & Lim,** (1980). It is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. It is assessed on a 5-point Likert scale, ranging from (0) never to (4) nearly always. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden.

# **Scoring system:**

The result was categorized as the following 0-21 indicates little or no burden, 21-40 indicates mild burden, 41-60 indicates moderate burden and 61-88 indicates severe burden.

# Tool IV: Explanatory Model Interview Catalogue- Community Stigma Scale (EMIC-CSS).

This scale developed by **Weiss**, (1997), contained 15 items designed to gauge perceptions of behavior and attitudes towards those who are stigmatized individuals. The EMIC-CSS handles the following aspects of life that are susceptible to stigma, namely: concealment, avoidance, pity, shame, being made fun of, respect, and marriage (prospects). Every item was scored by participants using a 3-point Likert scale that went from (0) No to (2) Yes. Higher scores indicate low stigma. The total scores ranged from 0 to 30.

# **Scoring system:**

Subjects with a total score of positive response in each item reaching 60% or more

were considered to have low stigma and those with less than 60% were considered high level of stigma.

#### Procedures:

The study was executed in multiple stages, comprising the preparatory phase, validity, and reliability of tools, pilot study, ethical and administrative considerations, and fieldwork.

# Preparatory phase:

This phase begins with an overview of previous and current national and international literature concerning the topic of the study. Textbooks, papers, publications, periodicals, research, and online searches were all used in this phase. The goal was to gain in-depth knowledge of all aspects related to the study and to set up data for gathering tools as well.

#### Validity of tools:

The tools used in this study were judged for face and content validity by three professors in psychiatric nursing at Ain Shams University to ensure their accuracy, comprehensiveness, relevance, and clarity which indicates content validity.

#### Reliability of tools:

To evaluate the internal consistency of the questionnaire, Cronbach's alpha scores were calculated. The values of Cronbach's alpha for the different tools, were as follows: 0.87 for the Parenting Stress Index, 0.85 for Zarit Burden interviewing questionnaire for the family caregiver, and 0.88 for Explanatory Model Interview Catalogue- Community Stigma Scale. These alpha values indicate strong internal consistency, suggesting that the questions within each domain of the questionnaires were reliably measuring the intended constructs.

#### **Pilot Study:**

Prior to the actual study, a pilot research study using 10% of the total sample

was conducted to ensure that the questions were clear, that the methods used to gather data were valid and relevant, and to determine whether the research process was feasible. The results of the pilot study did not require any modifications to the instruments, and every participant from the pilot sample was a part of the sample for the main research study sample.

#### **Ethical and administrative considerations:**

Before the study was initiated. permission to conduct research was given by the Ain Shams University Faculty of Nursing's Scientific Research and Ethical Committee: permission to conduct research and the approval code was (89). The Director of El Abbassia Psychiatric and Mental Health Hospital and the Faculty of Nursing at Ain Shams University both provided an official letter of authorization. This letter contained permission to collect the data and describe the goals and nature of the study. The family caregivers who were approved to participate in the study were informed about the study's purpose and objectives beforehand, and written consent was obtained. The confidentiality and privacy of the collected data were ensured, and the data was utilized exclusively for research purposes. The researcher guaranteed that the subjects' information would remain anonymous and confidential. The patients were informed that they had the option to leave the study at any moment. Consequently, the researcher was authorized to enter the hospital and execute the study on the 75 family caregivers who participated in the research.

#### Fieldwork:

The nursing intervention program was carried out for six consecutive months, which involved pre-program assessment, program planning and implementation, and post-program evaluation. The program started in October 2023 and was finished by the end of March 2024.

# **Program Implementation:**

The educational intervention for family caregivers of children with autism spectrum

disorder was executed through the following sequential phases:

# I. Assessment Phase (Pre-intervention Phase):

In August 2023, before administering the nursing intervention program aimed to evaluate the effect of program on psychosocial problems among family caregivers of children with autism spectrum disorder, all study participants underwent a baseline assessment. Each caregiver was given a data collection tool and was instructed to select a response that accurately reflected their situation. The researchers assisted participants who encountered difficulties while completing the questionnaires.

# **II. Planning Phase:**

Guided by a comprehensive literature review, the characteristics of the sample, and the outcomes of the assessment phase, the researchers developed the content for the nursing intervention program. Additionally, an illustrated learning booklet was developed and reviewed for accuracy by three expert psychiatrists and psychiatric/mental health professors. This booklet subsequently distributed to family caregivers and intended to serve as a self-learning and reference after the intervention guide. The nursing intervention program sessions emphasized acquiring knowledge and skills to reduce psychosocial problems among family caregivers of children with autism spectrum disorder.

#### **III. Implementation Phase:**

From the first week of October 2023 to the last week of January 2024, the researchers visited the designated location three days/per week, to implement the nursing intervention program. The participating family caregivers were divided into 10 subgroups, each group consisting of 7 caregivers. The groups were scheduled to meet on Sundays, Mondays, and Wednesdays. Each caregiver group received 13 sessions (four theoretical sessions and nine practical sessions). The duration of each theoretical session was around one to one and a

half hours, while the practical sessions lasted for a minimum of two hours.

The researchers were the initiators of this phase; providers and teachers who motivated the family caregivers to engage in interaction and practice activity by motivating them by the offering of positive reinforcement.

theoretical The sessions implemented by using lectures, group discussions, handouts, and as well as a handout, and white paper, and PowerPoint was used as of teaching facilitate media to active participation in the conversation and request from the family caregivers who were the subject of the study to share opinions about their experiences in the real situations of work and life. The lecture was given in using an attractive PowerPoint presentation created by the researchers in simplified Arabic, the course was delivered in an easy-to-understand manner. Every session started with an overview of the one before session's material, and the objectives of the next one were discussed, taking into account the use of simple language to accommodate all family caregivers, guarantee that the family caregivers under study understood the program's content.

During the application of practical sessions. the researchers used real-life situations, and demonstrations as methods of teaching practical skills. They also used lectures. videos, and discussions. researchers allowed the family caregivers to think critically and give a wide range of responses to the different situations and analyze each one. After that, the researchers presented the most appropriate response at the end of each situation discussion and gave a rationale for each choice. At the session's conclusion, the researchers also provided them with a summary and the time of the following session.

# Contents of the Nursing Intervention Program:

Session 1; was a theoretical session that took 60 minutes. The session's objective was to assist the caregiver in identifying general information about autism spectrum disorder including meaning, symptoms, causes,

diagnostic investigation, and treatment models.

**Session 2;** was a theoretical session that took 90 minutes. The session's objective was to help the family to explain the meaning and types of stress and burdens.

**Session 3;** was a theoretical session that took 90 minutes. The session's objective was to assist family caregivers in recognizing the meaning and types of psychosocial problems related to autism spectrum disorder.

**Session 4;** was a theoretical session that lasted 90 minutes. The session's objective was to assist the family caregivers in identifying the meaning of communication skills and recognizing the importance of improving communication skills.

**Session 5**; was practical and lasted 90 minutes. The session's objective was to help the family caregivers demonstrate therapeutic communication skills in real situations by training caregivers on some skills such as accepting, active listening, encouraging descriptions of perception, focusing, and summarizing.

**During session 6;** which was practical and lasted 90 minutes, the primary goal was to assist the caregivers in demonstrating the deep breathing technique.

In session 7; which was practical and lasted 90 minutes, the primary aim was to demonstrate the progressive muscle relaxation technique to the family caregivers.

**During Session 8;** which was practical and lasted 90 minutes, the focus was on helping caregivers apply guided imagery techniques.

**Session 9;** was practical and consumed 90 minutes. The primary aim of the session was to assist caregivers in implementing a time management plan by setting short and long-term goals, determining the value of their time, keeping a time log, analyzing their time usage, and developing a plan to reduce time-wasting

activities.

**During session 10;** which was practical and lasted 90 minutes, the focus was on helping caregivers develop cognitive restructuring skills to overcome negative thoughts. This involved training caregivers in skills such as selfmonitoring and idea termination.

In session 11; which was also practical and lasted 90 minutes, the goal was to help participants design an individual plan to manage negative thoughts and emotions. This included creating a list of automatic negative emotions, practicing mindfulness, focusing on positive thinking, releasing negative thoughts and emotions, and replacing them with positive emotions.

**During session 12;** which was practical and lasted 90 minutes, the primary objective was to assist the participant in demonstrating problem-solving skills. This involved defining the problems, analyzing them, developing potential solutions, selecting the best approach, implementing it, and evaluating its effectiveness.

In Session 13; which lasted 60 minutes, the closure session involved summarizing the program's sessions and ending the intervention sessions with a post-test.

#### IV. Evaluation Phase:

The evaluation phase was conducted from the beginning of the first week of February 2024 to the end of the fourth week of March 2024. Utilizing the same tools, the researchers assessed the program's efficacy by comparing variances between pre-program and post-program test results. This evaluation enabled the researchers to gauge the effect of nursing intervention program on psychosocial problems among family caregivers of children with autism spectrum disorder as a result of the nursing intervention program.

# **Statistical Analysis:**

The data from the study were entered into two computer software programs, namely

Statistical Package and Microsoft Excel for Social Science (SPSS) version 23.0. Statistical tests, such as chi-square, were utilized to calculate the discrepancy between the actual and predicted frequency of outcomes for an identified group of variables or events. Correlation coefficients were also utilized to calculate the extent to which two variables have a linear relationship. Descriptive statistics, which included presenting means and standard deviations (SD) for continuous variables and frequencies and percentages for categorical data, were used to summarize the study's results.

#### **Results:**

**Table (1):** reveals that nearly two-thirds 62.3% of the studied family caregivers' ages ranged from 20 < 30 years old with a mean age of  $64.44 \pm 3.65$  while 78.7 % of them were mothers of the child. Moreover, 42.6 % of caregivers had secondary education and 45.4 % of them had a housewife, more than half 58.6 % of the studied sample belonged to rural areas, and regarding income, 62.6% of the studied sample did not have enough income.

**Table (2):** reveals that there were highly statistically significant differences were found in parenting stress subscales among the studied family caregivers pre/post-program implementation (P<0. 001). 69.4% had a high level of paternal distress at preprogram, this percentage decreased to 42.6% during postprogram and 90.6% of studied family caregivers had a dysfunctional interaction with children at preprogram, which percentage decreased to 16 % during post-program. At the same time, 74.6 % had a high-level regarding items of difficult children, which percentage decreased to 25.4 % during post-program.

**Figure (1):** shows that there was a reduction in the total parenting stress post-program implementation as the figure represents that, 82% of studied family caregivers had a high level of parenting stress preprogram versus 37% after implementation of the program.

**Table (3):** found that there were highly statistically significant differences between pre/post-program implementation regarding the types of burden (subjective and objective) perceived by the studied family caregivers (P < 0.001). As the figure represents, 76% of family caregivers had a high subjective burden pre-program which decreased to 38.6% post-program, and 78.6% of family caregivers had a high objective burden at pre-program which decreased to 41.3 % during post-program.

**Figure (2):** reveals that there was a reduction in the total level of high burdens at post-program implementation. The figure shows that 77% of family caregivers had a high level of burdens at preprogram compared with 37% during post-program.

**Figure (3):** reveals that there was a reduction in the total level of community stigma at post-program implementation. The figure shows that 84% of family caregivers had a high level of community stigma at preprogram versus 32% after implementation of the program.

**Table (4):** denotes that there was a highly statistically significant correlation between the total score of parenting stress and their total scores of burdens and stigma pre/post program implementation ( $P \le 0.001$ ).

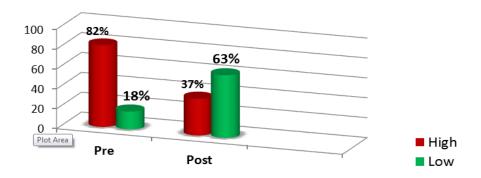
**Table (1):** Frequency and percentage distribution of the studied family caregivers sociodemographic characteristics (No =75).

Ito	ems		N	%
Age(years):				
• 20 < 30			47	62.3
• 30 to 40			18	24.2
<ul> <li>More than 40</li> </ul>			10	13.5
N	Mean ±SD	$64.44 \pm 3.65$		
Degree of relation:				
<ul> <li>Father</li> </ul>			16	21.3
<ul> <li>Mother</li> </ul>			59	78.7
Education level:				
<ul> <li>Primary</li> </ul>			14	18.7
<ul> <li>Secondary</li> </ul>			32	42.6
University			29	38.7
Occupation:				
• Employee			33	44
<ul> <li>Housewife</li> </ul>			34	45.4
<ul> <li>Farmer</li> </ul>			2	2.6
<ul> <li>Work in manual crafts</li> </ul>			6	8
Residence:				
Rural			44	58.6
Urban			31	41.4
Income:				
<ul> <li>Enough</li> </ul>			28	37.4
Not enough			47	62.6

**Table (2):** Frequency and percentage distribution of parenting stress subscales among the studied family caregivers pre/post-program (n=75).

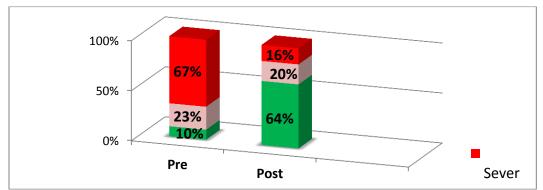
		Pre-pro	Post-program				Chi-Square			
Items of parenting stress	High		Low		High		Low			
-	N	%	N	%	N	%	N	%	$\mathbf{X}^2$	P-value
Paternal Distress	52	69.4	23	30.6	32	42.6	43	57.4	27.18	< 0.001
Parents-Child	68	90.6	7	9.4	12	16	63	84	38.22	< 0.001
Dysfunctional Interaction Difficult Child	56	74.6	19	25.4	28	37.3	47	62.7	29.15	< 0.001

**Figure (1):** Percentage distribution of total levels of parenting stress among the studied family caregivers pre/post-program (n=75).

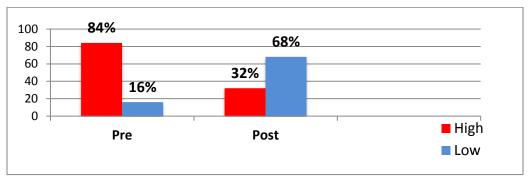


**Table (3):** Frequency and percentage distribution of types of burdens among the studied family caregivers pre/post-program (n=75).

		Pre						Post						Chi-Square	
Types	M	ild	Mod	lerate	Se	ever	N	Iild	Mod	lerate	S	ever		_	
of burdens	N	%	N	%	N	%	N	%	N	%			$\mathbf{X}^2$	P-	
														value	
Subjective	9	12	21	28	45	60	44	58.7	20	26.7	11	14.6	27.18	<	
Burden														0.001	
Objective	6	8	28	37.4	41	54.6	49	65.4	11	14.6	15	20	38.22	<	
Burden														0.001	



**Figure (2):** Percentage distribution of total levels of burdens among the studied family caregivers pre/post-program (n=75).



**Figure (3):** Percentage distribution of total levels of community stigma among the studied family caregivers pre/post-program (n=75).

**Table (4):** Correlation between total scores of parenting stress, burdens, and stigma pre/post program (n=75).

	Total score of parenting stress								
Correlations	Pre-	program	Post-program						
	r	P-value	r	P-value					
Total score of burden	0.517	< 0.001	0.833	< 0.001					
The total score of stigma	0.492	< 0.001	0.772	< 0.001					

#### Discussion:

A child with autism may present several obstacles and issues for their family, including lowered parenting efficacy stress levels, issues with mental and physical health, significant financial difficulties, time constraints, struggles with sibling integration, diminished social support, and conflict within family. (Gabra et al., 2021).

According to the current study, most of the caregivers were males and the majority of participants' kin relationship to the patient, were mothers, these findings can be explained according to Egyptian culture mothers typically have disabled childcare and are often required to leave their careers or jobs to remain at home and take over the majority of childcare tasks, while fathers assume the provider role. This finding conformed with the findings of the research study conducted by Sau et al., (2021) about Potential Factors of Parenting Stress in Chinese Parents of Children with Autism Spectrum Disorder, which found that most of the caregivers were females.

Regarding the total levels of parenting stress among family caregivers, the finding of the current study represented a reduction in the level of stress at post-program implementation. This stress preprogram may result from caregiving to a child with autism spectrum disorder (ASD), which might present additional stresses such as the child's inability to communicate well, unpredictable behaviors, challenges with self-care, social isolation, and a lack of understanding in the community. The improvement of stress after the implementation intervention program may be due to, the including program stress management techniques, problem-solving skills, thought management, and meditation to help caregivers with their stress while improving their emotional and coping skills to handle the frustration and anger of the caregivers. Also, this may be due to post-program implementation, the parent's level of knowledge improved and became more knowledgeable regarding How to cope with the child's issues and meet their needs which led to decreased levels of parent stress.

These results agree with the study by Khatua, (2021) entitled "Effects of Father-Based Intervention on Parental Style, Stress, Sense of Coherence, and Coping in Parents of Children with Autism" which shows that the stress scores reduced after one-month intervention in both parents after intervention and stress come down significantly in them. Also, finding agreement with the study of Karaman, (2018) who studied "Effect of Stress-Response Psycho-Training on the Stress

Levels of Mothers with Autistic Children" found significantly reduced parent stress levels after program implementation. This result was also supported by the study additionally provided by Al-Oran et al., (2019) about The Effectiveness of Educational Programs on Parenting Stress and Coping Mechanisms among Parents of Children with Autism Spectrum Disorder: A Systematic Review discovered that parents of children with ASD may discover that educational programs may be essential in minimizing the stress accompanying with parenting.

Regarding the level of burden encountered by family caregivers, the findings of the current study revealed that statistical difference between pre- and post-program implementation regarding level of burden. The result of the present study may be because the program educated participants about autism spectrum disorder, how to handle the emotional aspects of family caregivers, how to maintain family relationships, how to communicate with families, how to parent, and how to discover resources and make transitions into a meaningful life. Therefore, the program we established in place improved the caregivers' opinions about the family's ability to handle day-to-day matters. Through concentrating on family demands, such as knowledge needs and emotional support, the program educated participants on how to better intervene and cope with their children's challenging behaviors. which can lead to a reduction in the level of burden.

This result is supported by the study developed by **Pacia et al.**, (2021) they studied the systematic review of family-mediated social communication interventions for young children with autism, and the program highlighted the beneficial effects of enhancing family quality of life and caregiver burden among children with autism.

Concerning to level of community sigma, the present study reveals that, Following the program's implementation, there was a decrease in the total level of community stigma; this result could be attributable to, the lack of information about autism spectrum disorder in society might cause parents of autistic children

to become face stigmas, which are affected by cultural beliefs. Therefore, educating parents and providing them with the necessary information about autism spectrum disorders, ensures that parents maintain an essential role in educating the surrounding community and providing them with information that helps correct misconceptions about the disease.

This study is matched with the study accomplished by Tsujita et al., (2023) That incorporates comprehensive intervention for reducing the stigma of autism spectrum disorders: which involves the experience of simulated autistic perception and social contact, They discovered that a two-pronged strategy can help reduce the stigma associated with ASD. This result is consistent with other research showing that an intervention that participants with a simulated perceptual or social contact encounter decreased the stigma associated with mental illness. Additionally, it aligns with a related study that demonstrated the efficacy of an intervention including simulated perception in reducing stigma associated with ASD.

In terms of the correlation between the total score of parenting stress and their total score of burdens, the current study denotes that, there was a highly statistically significant correlation between the total score of parenting stress and their total score of burdens score during pre/post-program implementation. The viewpoints of the researchers suggest a correlation with each other between the stress and burdens of care. A higher level of burden result from cycles of grief and dissatisfaction experienced by family caregivers with high levels of worry, tension, negative emotions, and stress, as well as from their perception of their caring position.

This result is in line with the research carried out by **Pandey & Sharma**, (2018) titled "Perceived Burden in Caregivers of Children with Autism Spectrum Disorder" According to the study, there is a statistically significant correlation between family caregivers' stress levels and the level of burden.

With respect to the correlation between the total parenting stress score and the

total community stigma score, the current study demonstrated a highly statistically significant correlation between the two variables. during pre/post-program implementation. According to the viewpoints of researchers, as a result of society's constant criticism of the autistic child and his behavior, the parents feel that society is constantly rejecting their child, and this increases the intensity of anxiety and depression and increases the psychological stress among the parents.

This result depends on the study research that was done by Papadopoulos et al., (2018) entitled "Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health the study stated that, a statistical relationship between the level of stress and the level of social stigma among family caregivers.

#### **Conclusion:**

Nursing intervention program have a significant positive effect on reduce psychosocial problems among family caregivers of children with autism spectrum disorder.

#### **Recommendations:**

# The present study recommended that:

- Generate and manage nursing care plans for caregivers of children with autism spectrum disorder should focus on their child's psychiatric mental health aspect and provide caregivers with sufficient social support to ensure that their children take the best care achievable.
- The public's understanding of autism and the knowledge that is required for child health care should be greatly enhanced by the mass media. Including parents of Early intervention programs for disabled children may have an ongoing impact on them, helping them comprehend how the intervention fits with their specific requirements, explaining expectations about the program's content, procedure content, as well as anticipated accomplishments outcomes, or resolving practical problems and barriers.

- As soon as an autism diagnosis is made, It is best for parents to enroll children in early intervention programs. continuous counseling and health education services are also required to help them use coping mechanisms.
- Develop locally based formal centers that offer education and treatment services, these institutions should offer social support to families of disabled children whose children experience A variety of emotions from the first period of diagnosis, which necessitates the need to focus on the daily routine.
- Design strategies that can assist parents in dealing with the challenges of having a disabled child and reduce their stress levels, such as engaging in social activities.
- Family orientation programs to enhance parents' perceptions of care for their challenged child, as well as their ability to respond to stressors.

# **References:**

- **Abidin, R.** (1992): Parenting Stress Index, (3<sup>rd</sup>ed), Charlosteville, VA: Pediatric Psychology.
- Acharya, S., & Sharma, K. (2021): Lived Experiences of Mothers Raising Children with Autism in Chitwan District, Nepal; Hindawi Autism Research and Treatment Volume 2021, Article ID 6614490, 12 pages <a href="https://doi.org/10.1155/2021/6614490">https://doi.org/10.1155/2021/6614490</a>.
- Al-Oran,M., Khuan ,L., Kit, A., Poh Ying, L,.(2019): The Effectiveness of Educational Programs on Parenting Stress and Coping Mechanism among Parents of Children with Autism Spectrum Disorder: A Systematic Review; Mal J Med Health Sci 15(3): 135-141.
- Centers for Disease Control and Prevention, (2020): Data and Statistics on Autism Spectrum Disorder. Atlanta, Georgia, United States: Center for Disease Control and Prevention: 4781-4792.
- Gabra, R.H., Hashem D.F., & Ahmed, G.K. (2021): The Possible Relation between Stigma, Parent Psychiatric Symptoms, Quality of Life, and the Disease Burden in

- Families of Children with Autism Spectrum Disorder in Egypt: a multicenter study; The Egyptian Journal of Neurology, Psychiatry and Neurosurgery volume.57:170
- Hyman, S., Levy, S., Scott, M., & Myers, S. (2021): Identification, Evaluation, and Management of Children with Autism Spectrum Disorder Clinical Report. Pediatric Collections: Autism Spectrum Disorder; 145 (1): 6 -74. Available at: <a href="https://doi.org/10.1542/9781610024716-part01-ch002">https://doi.org/10.1542/9781610024716-part01-ch002</a>.
- **Karaman, Ö. (2018):** Effect of Stress-Response Psycho-Training on the Stress Levels of Mothers with Autistic Children. Universal Journal of Educational Research, 6(3), 571-575.
- **Khatua, C. (2021):** Effects of Father-Based Intervention on Parental Style, Stress, Sense of Coherence, and Coping in Parents of Children with Autism (Doctoral dissertation, Central Institute of Psychiatry (India).Publishing.2021.28862366.
- Krejcie, R.V., & Morgan, D.W., (1970).

  Determining Sample Size for Research Activities. Educational and Psychological Measurement. Small-Sample Techniques. The NEA Research Bulletin, Vol. 38.
- **Liao, X., Lei, X., & Li, Y. (2019):** Stigma among parents of children with autism: a literature review. Asian J Psychiatric.;45:88–94.
- Magor, E., El-Sayed, M., Thabet, S., Hassan, H., Abd Elnaser, M., & Ahmed, M. (2021): Effect of Parent Training Regarding Coping Strategies on Reducing Stress among Parents of Children with Autism Spectrum Disorder; Egyptian Journal of Health Care, Vol. 12. no.4.
- Micai, M., Ciaramella, A., Salvitti, T., Fulceri, F., Fatta, L., Poustka, L. & et al. (2021): Autistic Adult Health and Professional Perceptions of it: Evidence from the ASDEU project. Front Psychiatry, 12, 614102. Published online 2021 May 28. Available at: https://doi.org/10.3389/fpsyt.2021.614102, PMCID: PMC8193054.
- Naji, W., Waheeb, M., & Hamza, D. (2020): Autism Spectrum Disorder: Review article. Medico Legal, 20(2): 320-325. Available at:

# https://doi.org/10.37506/mlu.v20i2.1123.

- Pacia, C., Holloway, J., Gunning, C., & Lee H. A (2021): Systematic Review of Familymediated Social Communication Interventions for Young Children with Autism. Rev J Autism Developmental Disorder. 2021;1:1-27. doi: 10.1007/s40489-021-00249-8.
- Pandey, S., & Sharma, C. (2018): Perceived Burden in Caregivers of Children with Autism Spectrum Disorder. J Nepal Heal Res Counc.; 16(2):184–9
- Papadopoulos, C. Annemarie, G. Constantinou, R. (2019): Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health; J Autism Dev Disorder. 2019 Apr; 49(4):1665-1685.
- Rahman, A.A., Zainal, A., & Ibrahim., S. (2021): Anxiety, Depression, and Quality of Life among Mothers of Autism Spectrum Disorder Children; Volume 44, Issue 6.PP 2849-2865.
- Remedios, L., Estela, V., José, M., David, P., Miguel, A., Mañas, R., & Patricia, R. (2020): Effectiveness of a Training Program in the Management of Stress for Parents of Disabled Children. Journal of Child and Family Studies, 29:964–977. Available at: https://doi.org/10.1007/s10826-019-01665-5, ORIGINAL PAPER
- Sau, C., Ng, M., Fang, Y., Wang, Z., & Zhang,
  M. (2021): Potential Factors of Parenting
  Stress in Chinese Parents of Children with
  Autism Spectrum Disorder: A Systematic
  Review. Focus Autism Other Dev Disabl.
  0:1–12
- Seng, B., Luo, N., Ng, W., & Lim, J. (2010): Validity and reliability of the Zarit Burden Interview in Assessing Caregiver Burden, Annals of the Academy of Medicine, 39(10):

- 758-763.
- Shuid, A., Jayusman, P., Shuid, N., Ismail, J., Nor, N., & Mohamed., I. (2021): Association between Viral Infections and Risk of Autistic Disorder: an overview. Int J Environ Res Public Health. 18(6):2817.
- Tathgur. M.K., & Kang, H.K. (2021): Challenges of the Caregivers in Managing a Child with Autism Spectrum Disorder- A Qualitative Analysis; Indian J Psychol Med. 43(5): 416–421.
- Tsujita, M., Miho, H., Yukie, N., Miho, H., Shin-ichiro, K. (2023): Comprehensive Intervention for Reducing the Stigma of Autism Spectrum Disorders: Incorporating the experience of simulated autistic perception and social contact. Available at: https://doi.org/10.1371/journal.pone.0288586
- Wang, H., Hu, X., & Han, ZR. (2020): Parental Stress, Involvement, and Family Quality of Life in Mothers and Fathers of Children with Autism Spectrum Disorder in Mainland China: A dyadic analysis. Res Dev Disab.;107:103791.
- Weiss, M. Explanatory Model Interview Catalogue (EMIC) (1997). Framework for comparative study of illness. Transcultural psychiatry; 34:235-263.
- Zarit, S., Reever, K., & Bach-Peterson, J. (1980): Zarit Caregiver Burden Interview. Psyc TESTS Dataset [Preprint] Available at: https://doi.org/10.1037/t41877-000. 19.
- Zhou, W., Liu, D., Xiong, X., & Xu, H. (2019): Emotional Problems in Mothers of Autistic Children and Their Correlation with Socioeconomic Status and the Children's Core Symptoms. Medicine (United States); 98(32).