

The Effect of Psychosocial Program on Stress and Coping Strategies among Parents Having Children with Autism Spectrum Disorder

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ABSTRACT

Back ground: Autism is an early neurodevelopmental disorder, which severely affects both parents and children, this disorder imposes great physical, mental, and social pressures on families, particularly parents, and affects various dimensions of their lives. **Aim:** This study aimed to evaluate the effect of psychosocial program on stress and coping strategies among parents having children with autism spectrum disorder. **Design:** Quasi experimental design (pre - post-test) was utilized in the study. **Setting:** The study was conducted at psychiatry outpatient clinic in Fayoum General Hospital. **Sample:** convenience sample of (60) from parents having children with autism included in the study. **Data collection tools:** Data were obtained through three tools; I: A Structured Questionnaire sheet consists of three parts: socio-demographic characteristics about parent, socio-demographic data about child, and Knowledge assessment questionnaire, II: Parent stress scale (PSS). III: Coping Strategies Scale. **Results:** the study result revealed that there was highly statistically significant improvement after program implementation regarding levels of knowledge, levels of stress and levels of Coping Strategies among parents having children with autism. **Conclusion:** Psychosocial program has positive effect on knowledge, stress and enhance coping strategies among studied parents after program implementation. **Recommendations:** Conducting further researches on large study sample size in different areas to generalize the results. Also regular assessment and monitoring of the studied family care givers' strains and coping.

Key words: Autism Spectrum Disorder, Coping Strategies, Parent, Stress.

Introduction:

Autism Spectrum Disorder (ASD) is a lifelong developmental disability that includes deficits in social interaction, communication and restricted, repetitive patterns of behavior, interests or activities. A child with ASD may show unusual interests and behaviors and may have problems with sleeping and eating. In recent years, the awareness regarding ASD has improved globally resulting in a rise in global prevalence of ASD. Caring for children with ASD is challenging as caregivers have to face difficulties in dealing with the unusual behaviors of their child, teaching them to interact, teaching them basic life skills, protecting them from danger and preparing for their transition into adulthood (Pandey & Sharma, 2018).

Autism is one of the most important developmental disorders, which severely affects both parents and children. This disorder imposes great physical, mental, and social pressures on families, particularly parents, and affects various dimensions of their lives. These parents, especially mothers, try to adapt with the painful events and the care burden and seek support from various resources. Hence, the healthcare providing is required to identify the needs and problems of these parents and help them to do their parenting roles well. (Mohammadi et al, 2019).

Based on the huge amount of autism case, scientists now have proposed several possible causes of the autism: risk factors during pregnancy, toxins, fetal growth restriction, and autoimmune; however the actual causes of autism remains controversial. Beyond the difficulties of communication and interaction, researchers have also identified other health

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issues accompanied with autism through field investigation, which includes: genetic disorder, intellectual disability, anxiety disorder, and epilepsy, minor physical diagnose, and sleep problem, all of which indicates the importance of special nursing service for the autistic children in their daily lives (Hu, 2020).

Parenting a child with ASD is a stressful and challenging experience, particularly in countries where numerous support services are limited. Caregivers of children with ASD often experience impaired mental health, including anxiety and depression, a poorer quality of life and wellbeing, and higher levels of stress as compared to caregivers of typically developing children. Previous studies revealed that mothers of children with ASD reported elevated psychological distress and caregiving burden, health-related problems, lower levels of resilience and problems in various areas of family life (Papadopoulos, 2021).

Psychosocial early interventions with parents in the treatment of autism have a main role with pharmacological treatment. Parents are mostly found with high level of stress with lots of marital and other family and psychosocial issue and a psychosocial group intervention make improvement on parents mental health, reduce stress, increase positive coping in parents but there is limited of psychosocial support for parents with the children of autism (Lodder, Papadopoulos & Randhawa, 2020).

The basic goal of the nurse is to determine problems and develop a plan of intervention to decrease the prevalence and severity of symptoms. Nurses can also guide parents to determine which services and treatment are better for the children and those that are not beneficial. Being available to guide the parents as they face the demands that may become devastating will help them become resilient and attain a more valuable conclusion for the family. Instructing the public is one more important form of advocating for families confronting autism (Mostafa, 2019).

Significance of the study:

The demands and responsibilities of raising a child with autism spectrum disorder (ASD) impose a severe stress on parents with a higher incidence among boys than girls at a ratio of 4:1. Centers for Disease Control and Prevention (CDC), 2020 reported that approximately 1 in 54 children in the United States "U.S" are diagnosed with an autism spectrum disorder (ASD).

The number of people with autism in Egypt is estimated at 800,000, according to the Social Solidarity Ministry. One in every 160 children shows signs of having this mental condition and the rate among men is times that recorded in women (Ahmed & Abou El-Seoud, 2019). In the last ten years, the worldwide prevalence of autistic disorders has increased, its prevalence was 18.5 per 1,000 (one in 54) among children aged eight years and below, this may be due to a more effective diagnosis of autism across the spectrum (Mai, & Chaimongkol, 2022).

Aim of the Study:

This study aims to evaluate the effect of psychosocial program on stress and coping strategies among parents having children with autism spectrum disorder.

This will be accomplished through the following objectives:

- 1) Assess knowledge of parents about autism pre and post program.
- 2) Assess stress among parents of children with autism pre and post program.
- 3) Assess coping strategies of parents having children with autism pre and post program.
- 4) Design and implement psychosocial program to enhance coping strategies among parents of children with autism.
- 5) Evaluate the effect of psychosocial program on stress and coping strategies among parents of children with autism

Research hypothesis:

Psychosocial program will have positive effect on improving stress and coping strategies among parents having children with autism.

Subjects and Methods:

1) The technical design:

A) Research design:

Quasi experimental research design has been utilized to conduct the current study.

B) Setting:

The study was conducted at psychiatric out-patient clinic in El- Fayoum General Hospital

C) Subject:

Sample types and size:

Convenient sample was selected from parents having children with autism. The sample size was 60 from the studied parent according to these criteria:

Child :

- Age group from 3years -12 years old
- Confirmed diagnosis with autism spectrum disorder.
- Regular visit to the outpatient child psychiatry clinic.
- Free from other mental or physical disorder.

•Parent:

- All ages
- Both genders
- Agree to participate in the study.

D) Tools for data Collection:

Tool I: A Structured Questionnaire sheet.:

It was developed by the researcher in Arabic language after reviewing the relevant literature and guidance of supervisor and consists of the following parts:

Part (1): Socio-demographic characteristics of parents as age, sex, educational level, occupation, family income, housing and family history.

Part (2): Socio-demographic characteristics of child such as age, sex, birth order, educational level of the child, and degree of autism, presence of any mental illness besides autism, does the child participate in any of the behavior modification programs and when the autism disorder discovered?

Part (3): Knowledge assessment questionnaire:

Knowledge assessment questionnaire developed by the researcher 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):

The parent stress scale was developed by (Hosny, 2006). The scale was designed to measure level of stress directly associated with parenting role. The PSS consists of 72 items divided into six subscales: somatic symptoms (15 items), psychological symptoms associated with child disability (12 items), psychological stress resulting from child communication problems(10 items), psychological stress resulting from child behavioral disturbance(17 items), psychological stress resulting from child social skills deficit(13 items) and psychological stress resulting from financial aspects(5 items). All items were answered by using 5-point likert scale.

Scoring system:

The scoring 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). When the parent has a score from Zero to 69 it means that the parent has a mild stress level, from 70 to 192 it means the parent has a moderate level of stress and score from 193 to 288 it means that the parent has a severe stress level.

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 consist of 64 questions (Arabic version), divided into 7 subscales (Seeking information (11 item), Problem Solving (8 item), Social support (12 item), Avoidance, Escape, and Denial strategy (13 item), Exercise strategy (7 item), Relaxation strategy (6 items) and Religiosity strategy (7 items).

Scoring system:

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All items were answered by using a 5 point likert scale. 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.

Psychosocial Program:

The psychological program consists of 12 sessions to be covered in (4) theoretical sessions and (8) practical sessions.

Ethical consideration

Ethical approval was obtained from the scientific ethical committee of the faculty of nursing Helwan University; in addition, consents from patients were obtained orally to ensure willingness to engage in the study after explaining its purpose and nature, the researcher also provided strict concern to keep their privacy. It hasn't any harmful effect on them, the information was confidential and they can withdraw from the study at any time.

II. Administrative design:

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:

This design included description of preparatory phase, pilot study and field work, methods and procedures of the study, design and implementation of the training program and evaluation phase.

Pilot study:

It was conducted on 6 parents of children with autism representing 10% of the total study sample, the aim of the pilot study was to evaluate clarity, visibility, applicability and content validity as well as the time required to fulfill the developed tools. Subjects who shared in pilot study were excluded from the main study sample.

Field work:

The researcher collected data starting at the mid of (November 2021 till the end of May 2022) through interviewing parents of children with autism comes to outpatient clinic at El- Fayoum General Hospital using the pre constructed tools, data were collected on Sunday, Tuesday and Wednesday each weak from 9:00am to 12pm, 2:3 parent interviewed/day. The time needed by each participant to complete the questionnaire ranged between 45-50 min, the total number 60 from parent having children with autism.

-The intervention program was developed and implemented by the investigator in the form of health education & booklet included information about autism, how to deal with the child problems and how to cope with stressors facing them related to child problems and distributed to the parents. Each session take approximately one hour. The studied parent classified into 6 subgroups each subgroup composed of (10) parent, each subgroup attended 12 sessions as one session per week, implementation of all sessions for all subgroups were in parallel sessions, Sunday(group 1&2), Tuesday (group 3&4) and Wednesday (group5&6). The time for each session was about one hour.

The researcher collect data twice, once pre implementation the program (pretest) and the second post completion 12 sessions (posttest).

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. Statistical Presentation and analysis of the present study was conducted using the mean, standard deviation, chi-square test was used to compare between groups in qualitative and linear correlation coefficient was used for detection of correlation between two quantitative variables in one group. By (IBM SPSS Statistics for Windows, Version 20.0 Armonk, NY: IBM Corp).

Results:-

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

Items	N	%
Age (years)		
<30	12	20.0

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

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

Items	N	%
Age (years)		
<5	18	30.0
5- <10	37	61.7
10 or more	5	8.3
Mean±SD	5.87±2.22	
Gender		
Male	50	83.3
Female	10	16.7
The degree of autism		
Mild	24	40.0
Moderate	32	53.3
Severe	4	6.7
Child's birth order		
First	18	30.0
Second	22	36.7
Third	2	3.3
last only	18	30.0
Does the child participate in any of the behavior modification programs		
Yes	30	50.0

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

Table (2): this table shows 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

Figure (1): Distribution of total levels of knowledge among parents having children with autism. (pre&post program). (N-60)

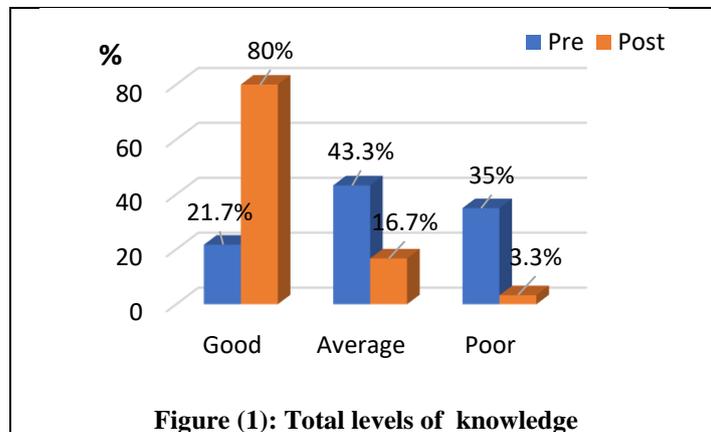


Figure (1): This figure reveals that slightly more than two fifth of studied parent have average levels of knowledge "pre-program" while post program after implementation (80%) of them have good knowledge.

Table (3): Distribution of total levels of different types of stress among parents having children with autism. pre&post . (N-60)

Levels of stress	Pre						Post						Chi-square	
	Severe		Moderate		Mild		Severe		Moderate		Mild		X ²	P-value
	N	%	N	%	N	%	N	%	N	%	N	%		
Physical symptoms	42	70.0	12	20.0	6	10.0	8	13.3	32	53.4	20	33.3	39.749	<0.001*
Psychological symptoms associated with a child's disability	37	61.7	14	23.3	9	15.0	11	18.3	34	56.7	15	25.0	23.917	<0.001*
Psychological stress resulting from the child's communication problems	42	70.0	11	18.3	7	11.7	7	11.7	39	65.0	14	23.3	43.013	<0.001*
Psychological stress resulting from behavioral problems	40	66.7	12	20.0	8	13.3	10	16.7	35	58.3	15	25.0	31.386	<0.001*

Psychological stress resulting from the lack of social skills of the child	41	68.3	10	16.7	9	15.0	12	20.0	30	50.0	18	30.0	28.868	<0.001*
Psychological pressures resulting from financial aspects	38	63.3	15	25.0	7	11.7	9	15.0	28	46.7	23	38.3	30.357	<0.001*

Table (3): this table shows that there is highly statistically significant difference between pre and post program implementation in all different types of stress among parents having children with autism with p-value <0.001*.

Figure2: Distribution of total levels of stress among parents having children with autism. pre&post . (N-60)

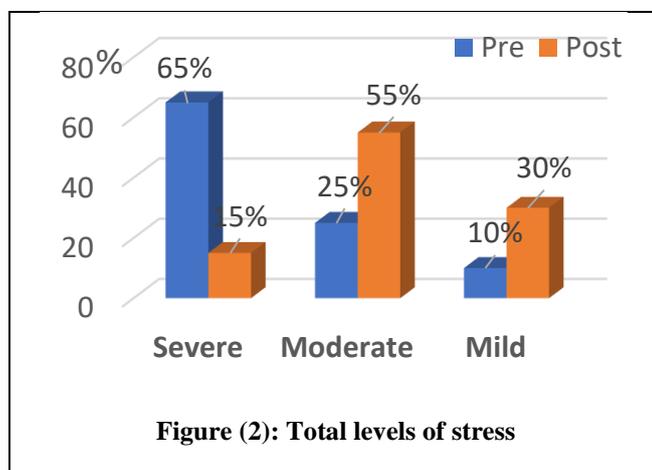


Figure2: This figure reveals that there is highly statistically significant difference between pre and post program implementation regarding parent level of stress , while (65%) of them had severe stress but post program (55%) had moderate stress.

Table (4): Distribution of total levels of different types of coping strategies among parents having children with autism. Pre & post. (N-60)

Levels of Coping strategies	Pre				Post				Chi-square	
	High		Low		High		Low		X ²	P-value
	N	%	N	%	N	%	N	%		
Cognitive building strategy	21	35.0	39	65.0	51	85.0	9	15.0	31.250	<0.001*
Problem Solving Strategy	26	43.3	34	56.7	47	78.3	13	21.7	15.424	<0.001*
Social support strategy	23	38.3	37	61.7	46	76.7	14	23.3	18.039	<0.001*
Strategy of avoidance, escape and denial	36	60.0	24	40.0	16	26.7	44	73.3	13.575	<0.001*
Aerobic strategy	19	31.7	41	68.3	43	71.7	17	28.3	19.221	<0.001*
Relaxation Strategy	23	38.3	37	61.7	50	83.3	10	16.7	25.497	<0.001*
Religiosity Strategy	18	30.0	42	70.0	53	88.3	7	11.7	42.254	<0.001*

Table (4): reveals that there is highly statically significant difference between pre and post program implementation in all different types of coping strategies among parents having children with autism with p-value <0.001*.

Figure3: Distribution of total levels of coping strategies among parents having children with autism. Pre &post. (N-60)

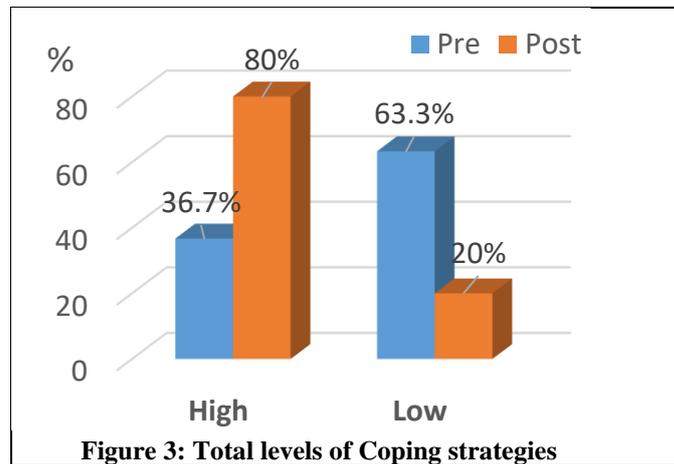


Figure3: Reveals that there is highly significant difference between total level of coping strategies among parents having children with autism pre and post program.

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

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, et al., 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

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ASD in males in the general population. Also the study of (Pandey & Sharma, 2018) reported that the majority of autistic children are males.

Concerning total knowledge level of parents regarding autism, the findings of the present study indicated that the highest percentage of parents had an average level of knowledge about autism before implementation of the program. Meanwhile, after implementation of the program the majority of parents had a good level of knowledge about autism. This came in line with the study of (Bassam, Tork, 2019) who clarified that before implementation of the program the highest percentage of parents had unsatisfactory knowledge regarding autism but after the implementation of the program, the majority of them had a satisfactory level of knowledge. Moreover, the study of (Prece and Trajkovski, 2017) that assess the impact of education program for parent with autistic children and found that the program improved parent knowledge regarding autism compared to pre- program implementation. Also 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.

Concerning total level of stress, the finding of study revealed that were highly statistically significant difference between pre and post program implementation regarding parent total levels of stress, that more than two third of parent had severe stress level preprogram implementation, while post program slightly more than half of them had moderate levels of stress, this may be due to post program implementation the parent level of knowledge improved and become more knowledgeable regarding how to deal with child's problem and met their needs that lead to decrease levels of parent stress. This agree with the study of (Khatua, 2021) who entitled "Effects of Father-Based Intervention on Parental Style, Stress, Sense of Coherence, and Coping in Parents of Children with Autism" shows that the stress scores reduced after one month intervention in both parents after intervention and stress come down significantly in them. Also the study of (Karaman, 2018) who study "Effect of Stress-Response Psycho-Training on the Stress Levels of Mothers with Autistic Children" found a significantly reduce parent stress levels after program implementation.

Regarding total level of coping strategies, the study finding revealed that there was highly significant difference between total level of coping strategies among parents having children with autism pre and post program. That slightly more than two third of studied parent had low level of coping strategies preprogram implementation, while post program implementation, the majority of parents had high 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 These supported by (Manohar et al, 2019) who studied Brief parent-mediated intervention for children with autism spectrum disorder found a significant difference was observed in the reduction of parental stress and enhancement of coping strategies after intervention. And the study of (Hidayah & Lestari, 2019) who entitled "Effects of self-help group's intervention on coping strategies of parents of children with Autism Spectrum Disorder" their finding showed a significant increase in parents' coping strategies before and after interventions.

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 may be due to that high educational level of parents lead to increase their knowledge and awareness about autism, when the educational level of the mothers decreased, the incidence of autism awareness significantly decreased. This came in line with the study of (Kavita Garg., 2019) who report that age of parents had a statistical significant association with the level of knowledge.

The finding of study revealed that there was statistically significant relation between total stress levels of studied parent and age of parent, educational level, with job and residence and with the monthly income of the family, this disagree with (Khatua, 2021) showed there is no statistically significant relation found between parental stress and age of parents but agree with regarding monthly income of parents.

The result of study indicated that there was highly significant relation between total coping strategies levels and age of parents and with educational level. May be due to that parent with higher levels of education and older parent than younger were able to access more reliable information about the different aspects of special need of their child and possible support that parents with a higher level of education more frequently accepted responsibility and their ability for coping. This supported by the study of (Demšar & Bakracevic., 2021) who entitled Depression, Anxiety, Stress, and Coping Mechanisms among Parents of Children with Autism Spectrum Disorder, reported statistically significant

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differences in the use of different coping strategies by parents' education level which individuals with higher levels of education used acceptance strategies more and understand that the child's diagnosis was not their fault and could therefore concentrate on daily problem solving and less on negative emotions.

The finding of study revealed there was highly significant negative correlation between coping strategies and level of stress of the studied parent's pre and post program implementation that high levels of parenting stress resulted in low levels of positive coping; this due to they overwhelming by coordinate caring child with while assume other family activities. 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.

Moreover, agree with the study of (Miranda et al., 2019) who entitled " Parenting stress in mothers of children with autism without intellectual disability" found that mothers who utilized more active coping strategies and relied less on disengaged coping strategies, either at the time of diagnosis or over time, experienced lower levels of parenting stress.

The findings of study revealed that was highly significant negative correlation between levels of stress and knowledge of the studied parent's pre and post program implementation. This may be due to when parents have low level of knowledge about child condition and about the disease this increase their level of stress and become more distressed. This supported by the study of (Yusuf et al., 2019) who entitled "Association between distress and knowledge among parents of autistic children" reported that parental stress significantly associated with parent knowledge.

Conclusion:

In the light of the present study findings, it can be concluded that:

The study confirmed that the psychosocial program has a positive effect on the stress and coping strategies among parents having children with autism.

Recommendations:

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

- 1) The study recommends emphasize the importance of carrying out educational programs to improve knowledge and care of autism in the parents.
- 2) The study also recommends conducting further researches on large study sample size in different areas to generalize the results. Also regular assessment and monitoring of family care givers' strains and coping is recommended.
- 3) Simple illustrated booklets, posters and guidelines for parents about the care of their autistic children should be available in each setting providing care for those children.

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