Outcomes of Autism Care Management Program on Parent's Coping Patterns

Asmaa Hafez Afefe Barakat¹, Rasmia Abd El-Sattar Ali Mohammed², Fatma Ata Abd El-Salihen

¹Assistant Professor Psychiatric/Mental Health Nursing Department Faculty of Nursing/Ain Shams University, Egypt

Abstract: Parenting a child with autism increases stress in the areas of everyday's management of disruptive behaviors among those children in addition to the heavy caregiving responsibilities and concerns about the future of their child. This study is a quasi-experimental study aimed to assess the outcomes of autism care management program on improving knowledge, practice and coping patterns among parents who have children with autism. A sample of this study consisted of 60 parents from both settings (40 from special needs care center affiliated to the Institute of postgraduate childhood studies & 20 from the outpatient clinic for a child with autism at El Abbassia mental health hospital). The tools of data collection were: A) Interview questionnaire sheet, B) Parenting Stress Index C) Parent coping scale. Results of this study revealed that there was a lack in knowledge and skills as perceived by parents caring for children with autism before autism care management program. There was a significant difference in coping patterns among parents after program. Also a positive correlation between the four research variables: knowledge, skills, stress and coping patterns among parents caring for children with autism which can reflect the effectiveness of the program. Conclusion: parenting education intervention program has a significant effect on parents' knowledge, skills and coping patterns in caring for children with autism. Recommendation: Continuous health education and counseling programs are necessary to improve parents' coping patterns toward the care of their children with autism through reassuring the importance of follow up care.

Keywords: autism care management program, Parents, Children, Autism, knowledge, practice, Stress, Coping patterns.

Date of Submission: 14-08-2019

Date of Acceptance: 29-08-2019

- ... - ...

I. Introduction

Autism is a complex developmental disability; it is a neurologically based developmental disorder that characterized by varying degrees of impairment in communication skills, social interactions and the presence of repetitive and stereotyped behaviors (Wallace, 2010; Andra et al. 2016). Onset occurs before the child reaches the age of 36 months. It affects the normal functioning of the brain, and it affects boys four times more than girls (Makrygianni, & Reed 2010). Parents usually notice signs in the first two years of their Children's life. These signs usually develop gradually, but some children first develop more normally and then regress (Probst et al., 2010; Andra et al. 2016).

Caring for a child with autism is markedly difficult for parents. When the symptoms of autism get clear, the parents have confusion because of the uncertainty about their children. They may have a feeling of fear, rejection, or shock after the diagnosis is made by a professional following the assessment of the child (Johnston et al., 2012). Furthermore, The nature of parent's stress has been shown to several aspects of parents 'life such as daily care demands, emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social consequences (Singer &Powers, 2013). It means that, The parenting care activities of eating, toileting, grooming, hygiene, travelling, and communicating are difficult loads as well as the greater cost of care and follow up can lead to parents' physical, emotional and economic stress (Johnstonet al., 2012; Singer & Powers, 2013). Several Studies have found that there is a higher risk of marital discord and social isolation among parents with autistic children which in turn affects negatively on their coping patterns (McCubbin & Patterson, 2009; Hartley et. al., 2017). Also, families are concerned with communication, education and related services, relationships with professionals and the independence of the child and his/her future concerns (Wallace, 2010). All of those parenting worries and loads affect the individual cognitive process and contribute to the recognition of danger, threat or challenge. So that, parents tend to use

DOI: 10.9790/1959-0804100715 www.iosrjournals.org 7 | Page

²Assistant Professor of Community Health Nursing Department, Faculty of Nursing/Ain Shams University, Egypt

³Lecturer of Psychiatric/Mental Health Nursing Department Faculty of Nursing/Ain Shams University, Egypt

certain aspects of coping patterns against the environmental or internal stressors surrounding them either positive or negative (McCubbin& Patterson., (2009); Johnstonet et.al., 2012; Hartley et. al., 2017).

As a result of the stressful nature of the symptoms, the long-term therapy and the uncertainty about the child's prognosis as well as the effectiveness of the treatment, parents with autistic children have different characteristics of coping patterns (Bashir et. al., 2014). Some of the parents behave better than others, some of parents' coping patterns are designed to deal specifically with the stigma attached to the disorder, and others focus on dealing with problems and stress of daily living. To conclude, little of parents with autistic children are knowledgeable about the strategies and techniques that employ to have a semblance of normal family life. However, those parents need help to reestablish and manage daily life as the impact of the chronic illness (Gray,1994; Twoyet al., 2007: Dabrowska&Pisula, 2010). Furthermore, several types of research on autism recommended the need to develop strategies to manage the daily problems and improve coping among family members (Gray, 1994; Pottie&Ingram, 2008; Altiere, 2006; Dardas, 2014).

Parents are engaged in the process of child development, so they need resources and support for caring of their children with appropriate assessment, education programs, and counseling to provide these children with the skills necessary for successful integration and become active and contributing members of their communities (Ghanizadehet al., 2009). Furthermore, parents require emotional support, advice, and training in working with their children. They also require access to up to date and accurate information about available treatment options and support services (Harris et al., 2007; Dardas, 2014). Parents' education and care management about their children with autism can help them modifying their children's behavior, which contains some activities for developing some social and self-care skills (Mohamed, 2012). Hence, parents' education about their children with autism can assist them adjusting their children's behaviors and social skills. Likewise, it improves their coping patterns and social interactions with their children, as well as decreasing parenting stress and aggression (Harris et al., 2007; Sinha, 2008; Ribeiro & Sousa, 2014).

Psychiatric mental and community health nurses play an important role to assess the parents and families level of understanding about autism, their coping abilities, and their access to support groups or services, as well as their willingness to avail themselves of these services (**Mohr, 2009**). Also, psychiatric mental and community health nurses can provide parents with anticipatory guidance to prepare the child adequately for increasing independence, and instruct families to keep channels of communication open with the child and the system (**Hassan, 2008; Dunlap, 2018**).

Significance of the study

The incidence of autism is on the rise. It is the third most prevalent developmental disorder. The World Health Organization states that 1 in every 500 children is autistic. Therefore, according to the latest demographic studies, it means that there are more than 140,000 children in Egypt who suffer from autism (Hassan, 2008 & Mohamed, 2012). This indicates that a considerable number of parents are directly involved in caringforthe children with autism. Furthermore, autism is a lifelong disorder that most of the families have to live and take care of their children on their own forever. The family will need to develop a series of coping patterns to allow them to deal with the parenting stress for the autistic child. The autism care management program is important to help parents to accept their parenting care for autism through providing knowledge and skills needed and to support them in the critical areas of managing daily lives. Such these programs help parents to find effective ways to cope and deal with stresses that are preventing them from achieving their goals and ambitions and to have a more positive outlook on life (Mohammed, 2012; Dunlap, 2018).

Aim of the study:

This study aimed to assess the outcomes of autism care management program on improving knowledge, practice and coping patterns among parents who have children with autism through the following:

- 1. Assess parents' level of knowledge and practice regarding autism care management before implementing the program.
- 2. Assess parents' stress and coping patterns before implementing the program.
- 3. Develop and implement autism care management program for parents based on their needs assessment.
- 4. Evaluate the outcomes of autism care management on parent's level of knowledge and practice after program implementation.
- 5. Evaluate the outcomes of autism care management on parents' coping patterns after program implementation.

The research hypothesis

The current study hypothesized that:

1. Parents with autistic children will have higher scores of knowledge and practice after autism care management program.

2. Parents with autistic children will have more positive ways of coping after autism care management program.

II. Subjects & Methods

RESEARCH DESIGN:

A quasi-experimental pretest-posttest study design was used

A- Sample and Setting:

The study was conducted at two settings: first; the special needs care center affiliated to the Institute of postgraduate childhood studies, second; an outpatient clinic for children psychiatric treatments at El Abbassia Mental Health Hospital. A minimum sample size of 50 was determined using the Fishers' formula z2pq/d2. A convenience sample was used counting 60 parents with autistic children during follow-up visits to the previously mentioned settings for children caring. The study subjects were selected according to the following inclusion criteria: had only one child diagnosed with autism (preschool age, both sexes and free from others neurological disorder or chronic physical disease or handicapped), is the first caregiver for the autistic child, both sexes, able to read and write, and willing to participate in the study by signing a written consent.

B-Tool of data collection:

Data were collected by using the following tools:

<u>1-Autism Interview Scheduled Sheet:</u> This tool was developed by Mohamed, 2012, to assess parents' knowledge and practice about the care of the autistic child. It consisted of 3 parts: Part I; Sociodemographic data, Part II; 25 Questions to assess parent's knowledge regarding the meaning, causes, signs and symptoms, autism treatment and care management which scored by yes=1 and no=0. Part III; 55 questions to assess parent's practice skills for a child suffering from autism, regarding the activity of daily living, hygiene, clothing, sleeping, social interaction skills, attention, concentration skills, communication skills, and physical activity. Questions were scored by 0 = no, 1 = sometimes, 2 = yes.

2-Parenting Stress Index-Short Form (PSI-SF): Abidin developed it, 1995 in Hasket et. al., 2006 to assess stress associated with parenting. It is a 36 itemswhich have three subscales, each consisting of 12 items; 1-Parenting Distress (The extent to which parents feel competent, restricted, conflicted, supported, and/or depressed in their role as a parent.), 2- Parenting-Child Dysfunctional Interaction (The extent to which parents feel satisfied with their child and their interactions with them.), and 3- Difficult Child (How a parent perceives their child to be, whether the child is easy or difficult to take care of.). The items of the scale range from 1 (strongly disagree) to 5 (strongly agree) with a fifth-grade reading level. The total scores range from 36 to 180. The high score of stress starts at or above a score of 90 and the score of 27 for each subscale.

<u>3-Parent coping scale:</u> It was developed by **Mohamed, 2012**, [15] to assess the coping patterns of parents with autistic children. It consisted of 18 items divided into five subscales; 1-Social support, 2- Problem focusing coping, 3- Emotional focusing coping, 4- Seeking spiritual support, 5- Appraisal. Each item was rated on 3 points Likert scale. Scoring for each statement following: (0 = no, 1 = sometimes, 2 = yes), Higher score indicates more positive parents coping.

Content validity and reliability:

1) Validity:

The Content validity was ascertained by a group of 3 experts from the community health nursing department, 2 experts from psychiatric/mental health nursing department, Faculty of Nursing, Ain Shams University. The aim was to determine relevance, clarity, completeness, simplicity, and applicability of the study tools. Expert's responses were either agreed or disagreed or agreed with modifications for the face and content validity. About 90% of the experts were in agreement with the proposed tool and accordingly, the required modifications were done.

2) The Reliability:

Testing reliability of the proposed tools was done statistically by Cronbach Alpha test which was 0.91 for the interviewing questionnaire, 0.83 for parenting stress index, 0.95 for parent coping scale

Ethical considerations

The ethical considerations in this study included the following: The researchers clarified the objectives and the aim of the study to subjects included in the study. The researchers maintain an anonymity and confidentiality of subjects' data. Subjects were allowed to choose to participate or not and they were informed that they have the right to withdraw from the study at any time without giving any reason.

Pilot study

A pilot study was conducted on 10 % of subjects (6 parents) to test the applicability and feasibility of the study tools as well as time needed to fill these tools. Obtained results used as a guide to reconstruct the changes needed in the data collection tools and those subjects were excluded from the study sample.

Field Work:

The actual field work of this study started at the beginning of June 2018 and had been completed of December 2018. The process of data collection and designing of autism care management program sessions was accomplished throughout four sequential phases, as follows:

- 1-Assessment Phase: Each parent was interviewed and assessed at times before program to obtain baseline data and after program implementation to assess the effectiveness. Tools of data collection were filled by the researcher for each parent. Time consumed for completion of each form for each parent was around 20 30 minutes according to parent's physical, mental readiness and time of waiting in Out-Patient Clinic for follow up their children conditions in the previously mentioned study settings.
- **2-Preparation phase:** Based on a comprehensive analysis of related literature and the assessment phase, autism care mangement program sessions were designed including objectives, outlines, content, teaching methods, number of sessions, timing, photos, instructions, explanations, and examples. The booklet, program sessions, and plan were revised by a jury of 3 experts in psychiatric/mental and community health nursing field to confirm its validity for covering, representative and accuracy of knowledge, care practices and coping strategies used by parents with autistic children. Likewise, the handout revised for the degree to which studies and theories supported the details of it. As well, the hand out was utilized by six parents with autistic children, who were excluded from the study group to revise its applicability.
- 3- Conduction phase: Developed autism care management program content was applied by the researchers. Each parent was taught knowledge and care practices plus coping strategies for four consecutive health education sessions. All knowledge given to the parents were repeated, and all care practices were demonstrated and discussed by the parents during researchers' interview. This is to ensure that each parent learned essential awareness about his/her child care management. Handouts were given to the parents as a self-learning reference if needed at home. Examples, clarifications, questions, and explanations were provided during researcher-patient instruction. The four health education sessions are including one for building rapport and explaining the objectives, introduction and program outlines, one for knowledge, one for the child care practice and the third for coping strategies. Each session period was varying between 1.30 to 2 hours. Follow up was firmly enforced every two days at mentioned settings and telephone communications were kept. The four sessions were conducted over one week.
- **4-Evaluation phase:** the study groups were re-assessed by study tools, in the week that followed the program sessions. The scores of the study tools before and after the educational program sessions were compared. The difference between the scores was estimated to determine the effect of using the developed autism care management program.

Data analysis and results

Data was computerized, coded, analyzed and tabulated. Statistical Packages for the Social Sciences (SPSS) version 21.0 for Windows and Microsoft Excel Spread Sheet Package (Office 2010) were used for the results of the study. Tests for significance were used; mean and standard deviation as well as percentage, frequency, chi-square, T-test and P

III. Results

Table (1): Socio-demographic Characteristics among Parents of Children with Autism (Total n =60).

Socio-demographic characteristics	n	%0				
Age:						
23<30	33	55				
30<40	19	31.7				
40≤ 50	8	13.3				
Mean ± SD= 30.9± 4.9						
Sex:						
Male	20	66.7				
Female	40	33.3				
Residence:						
Urban	40	66.7				
Rural	20	33.3				

Level of education:						
Read& write	32	53.3				
Middle education	19	31.7				
High education	9	15.00				
Occupation:						
Employed	24	40				
Unemployed	36	60				
Income						
Adequate	11	18.3				
Inadequate	49	81.7				
No of children:						
2	26	43.3				
3	23	38.4				
< 3	11	18.3				

Table (1) shows that more than half of the subjects (55%) their age ranged between 23–30 years and about two-thirds of them (66.7%) were female and came from rural areas (the same percentage). Also, approximately more than half of the subjects had only read and write education and unemployed (53.3%, 60% respectively). Regarding income, most of the subjects were unsatisfied with their income (81, 7%) as well as, the same percentage had from 2-3 children, including the autistic child.

Table (2): Comparison of Parents' Knowledge about Autism as before and after the Autism Care Management Program (n=60).

Vladas abaset autism	Before		After		4.44	
Knowledge about autism	Mean1	SD1	Mean2	SD2	t-test	P value
Definition	1.7167	0.45442	1.7833	0.41545	2.053	0.045*
Signs & symptoms	1.767	0.39020	1.8500	0.36008	3.426	0.01**
Predisposing factors	1.1667	0.37582	1.5000	0.50422	5.431	0.00***
Features of Diagnosis	1.1667	0.3758	1.4333	0.49972	4.632	0.00***
Treatment	1.1500	0.36008	1.4000	0.49403	4.435	0.00***
Components of care	1.0333	0.18102	1.4333	0.49972	6.272	0.00***
* = p < 0.05					ctory: <50	

Table (2): illustrates the knowledge about autism as perceived by the subjects before and after autism care management program. It was clear that there was a lacking in knowledge about autism among subjects in the first assessment. But, after program sessions, there was apparent progress in the knowledge about autism among subjects. This improvement was observed in all items of the knowledge about autism. For example, the mean score markedly changed among subjects from 1.03 to 1.433 (p-value 0.000***) regarding knowledge about autism components of care. When comparing all of these items before and after program. Significant statistical differences were found among subjects.

Table (3): Comparison of Parents' Caring Skills for Children with Autism before and after the Autism Care Management Program (n=60).

Parents' caring skills	Before		After		T-test	P value
Parents caring skins	Mean1	SD1	Mean2	SD2	1-test	r value
Self-feeding	1.2833	0.45442	1.4833	0.53652	3.494	0.01**
Elimination training	1.4333	0.49972	1.6333	0.51967	3.494	0.01**
Wearing clothes	1.2833	0.45442	1.5000	0.50422	4.040	0.00***
Personal hygiene	1.2500	0.43667	1.4833	0.50394	4.238	0.01**
Sleep hygiene	1.6000	0.49403	1.7667	0.42652	3.435	.0.00***
communication	1.4500	0.50169	1.6161	0.49030	3.435	0.01**
Social interaction	1.4500	0.50169	1.6000	0.48402	3.227	0.02*
Attention and concentration	1.1500	0.36008	1.4667	0.50310	5.229	0.00***
* = p <0.05						

Table (3) clarifies that there was obvious decreasing in parents' caring practice for a child with autism, before the program sessions. However, after the program, there were observable positive changes in favor of subjects regarding all perceived items of caring skills for a child with autism. For instance, before the program sessions, there were low mean scores values in self-feeding skills (1.2833), Elimination skills (1.433) and personal hygiene skills (1.25) among subjects. Which were considerably increased compared to the first assessment, after the program to (1.4833, 1.633, and 1.4833 respectively). Parents care practice for their autistic children regarding communication and social interaction skills as well as skills needed to increase child's

attention, and concentration was apparently improved among subjects after program sessions. So that, there was a statistically significant difference in all items scores and total mean scores comparisons, after the health education, T value = 3.435, 3.227, 5.229 respectively.

Table (4): Comparison of Parenting Stress Index before and after the Autism Care Management Program (n=60)

		(H=00).				
Parenting stress index (PSI)	Before		After		T-test	P value
Parenting stress fildex (PSI)	Mean1	SD1	Mean2	SD2	1-test	P value
Parental Distress	1.4667	0.50310	1.6500	0.48099	3.639	0.01**
Parent-Child Dysfunctional Interaction	1.5231	0.50310	1.6000	0.49403	3.013	0.04*
Difficult Child	1.5000	0.50422	1.5500	0.50169	1.762	0.83
* = p < 0.05	** =	p <0.01	:	$*** = p \ 0.00$	01	

Table (4): this table shows that many of stress symptoms that reported by parents as a result of parental distress and parent-child dysfunctional interaction were significantly improved after the program (the mean changed from 1.4667, 1.5231 to 1.6500 & 1.6000 respectively).

Table (5): Comparison of Parenting coping Scale before and after the Autism Care Management Program (n=60).

Domenting coming coals	Before		After		T-test	P value
Parenting coping scale	Mean1	SD1	Mean2 ±	SD2	1-test	
Social support	1.7500	0.43667	1.8167	0.39020	-2.053	0.045*
Problem focusing coping	1.3167	0.46910	1.3761	0.50394	-1.981	0.17
Emotional focusing coping	1.3579	0.46212	1.4500	0.50169	-3.435	0.034*
Seeking spiritual support	1.4000	0.49403	1.5333	0.50310	-3.013	0.04*
Appraisal	1.3833	0.49030	1.4500	0.50169	-3.435	0.05*
* = p < 0.05	** = $p < 0.01$					

Table (5) illustrates that many of parents were not aware how to use different coping patterns to face the stress resulting in care for children with autism before the educational program. While, after intervention statistical significant differences found among studied subjects, it can be meant that, parents became more aware to use different types of coping patterns in caring for their children. The studies subjects improved their responses regarding social support (mean changed from1.7500 to 1.8167), emotional focusing coping (mean changed from 1.3579 to1.4500), seeking spiritual support (the mean changed from1.4000 to1.5333) and appraisal (the mean changed from 1.3833 to 1.4500).

Table (6): The relationship between Parent's Coping Patterns, Knowledge, practice, and Stress after the Autism Care Management Program.

	Parenting coping	•
Variables	Pearson correlation coefficient	P value
Total knowledge	477	0.000***
Total practice	378	0.01**
Total PSI	-382	0.01**
* = p < 0.05	** = p < 0.01 **	** = p 0.001

Table (6): studying the relationship between total parents' scores in knowledge, practice, and stress and their coping patterns regarding care of autistic after program. There is appositive relationship between the three variables; parent's knowledge, practice and their coping patterns and their coping. Pearson's correlation test = r (after) = 477, 378. A negative correlation can be observed between the two variables; parents' stress and their coping patterns; r (after) = 382. This means that parents who have, higher scores of knowledge and skills as well as have lower scores in stress, will have highest scores of copping patterns regarding care of children with autism.

IV. Discussion

Autism is a complex neurobiological disability that affects communication, social interaction, and behavior. Research indicates that parent's education regarding care of children with autism is crucial for improving outcomes for children and parents (Smith& Dillenbeck, 2006; Mohamed 2012). Necessary knowledge and skills regarding care of the disorder help parents to adapt to stressors and become more confident in dealing with the everyday living situations. So that, nurses can provide parents guidance, support and emotional assurance to help their children increasing independence, improving children's communication and social skills which are an important part to reduce parents' stress and enhance coping (Mohamed,2012;Elbahnasawy&Girgis, 2011; Dunlap, 2018).

As regards to the socio-demographic characteristics among studied subjects, the current study shows that about two-thirds of the studied subjects were female. This can be due to that culturally the caregivers of the children are a part of a female role. These results are supported by Mansur, 2010 and Mohamed, 2012, who confirmed that the highest percentage of the parents' caregivers under this study, were mothers and they also mention in their studies that the effects of caregiving roles are highly gendered with a female who provide most of the care for the disabled child. As well, more than half of the subjects had a low level of education and unemployed which can explain the present results of being financially unsatisfied. In addition to the studied subjects reported that part of their money expended to the care of their disabled children. The analysis of the present study is agreed by Ahmad et al. 2009 and Elbahnasawy& Girgis, 2011 who mentioned that parents are caring autistic children always suffer from financial burdens as results of medical care cost.

Comparison of parent's knowledge and skills scores regarding autism and the care management as perceived by studied subjects before and after autism care management program, significant differences can be observed. This result can reflect the effectiveness of the program. On the other hand, most of the studied subjects have limited educational level which in turn finds some difficulties to looking for and understand the autism disorder, and its management protocol so that they are willing to enhance their knowledge and skills to maintain a healthy life for their children. This result is consistent with Mahmoud et al., 2009 and Mansour, 2010 who mentioned in their studies that, parents suffered from limited knowledge and skills about autism and its management. Harmonious to these illustrations, Khushabi et al., in 2011 clarified those parents caring for autistic children are frequently improved by instruction and education to increase their competences and be more active to learn new caring skills. Parents are only ones, who understand children limitations about social skills, communication, and unusual, repetitive behaviors. Another study is also matching with this view, Elbahnasawy& Girgis in 2011, who illustrated that improving knowledge and skills needed among parents regarding autism is an important step for parenting coping patterns. Furthermore, Elder & D'Alessandro in 2009 mentioned that families of children on the autism spectrum always have many questions and much to learn as they manage the disorder and create meaningful lives for their children and themselves. These results are inconsistent with Mahmoud et al., 2009 who reported that most of the parents with autistic children under study are not motivated to attend the education program because they spend all of the time in caring of children. They also analyzed their results that, many parents prefer to manage symptoms without proper awareness. Dissimilar also to this discussion, Mohammed in 2012, In Egypt, reported that parents took a lot of training and teaching without any real or essential effect on their skills of child care. Hence, this study can highlight the importance of the autism care management program.

Concerning the stress and coping patterns among studied subjects in the current study, there is positive and significant changes in the stress and coping patterns scores after autism care management program. It means that parents become more understanding in dealing with their stress raised from the care of autistic children. After implementing the program, there are significant differences regarding parental distress such as guilty feeling toward the disabled child, feeling trapped by parenting responsibilities, unable to enjoy and relax. Parent-child dysfunctional interaction scores are significantly improved after program such as improving child's sleep and eating schedule, getting the child to do something independently, teaching child new vocabulary, child rewards for positive behavior. Meanwhile, non-significant changes among studied subjects regarding feeling stress from a difficult child but the scores are slightly improved after program. One possible explanation is that parents are aware that autism is a lifelong disability needs positive challenges and patience so that parents should find positive outlets by using different coping patterns to obtain rest, relaxation and enjoyment. This analysis is by the study of Elbhnasawy& Girgisin 2011, who interpreted their results that children with autism have resistant to change and difficult to express their feelings and ideas. In addition to, the current study revealed that parents are willing to seek social support from family and significant others without feeling shame and stigma as well as seek spiritual support such as acceptance and seeking support from God. A more active problem and emotional -focusing coping patterns are realized among studies subjects. These results are in the same line of Altiere in 2006, who confirmed that information exchanged at the interpersonal level provides emotional support, maintains self-esteem and feelings of belonging to obtain an active communication with mutual understanding for valuable coping behaviors. These results are also supported by Berglund in 2009, who illustrated that education, is an important resource to the parents caring for disabled children and is viewed as one of the key stress buffering factors and a method for using active coping patterns.

The result of the present study reveals that there is astatically significant relationship between parents' coping patterns and the three variables; knowledge, skills and parent's stress index. It means that coping patterns and stress reduction among studies subjects can be improved by literacy, education and required skills related to autism care management. So that, the four study' variables are interrelated and each other lead to both. This result is supported by **Gray**, **2006** who confirmed that there were significant changes in the types of coping strategies reported by the parents caring for autism in the follow-up study as a result of parent's education and counseling. Furthermore, **Wand et al., in 2010** supported the current study and mentioned that the integration between information and skills, positive attitudes and positive coping patterns among parents could promote parents' well-being and the development of positive changes on their children with autism. So that parenting Education program is an essential not only for increasing positive coping patterns, but also, it improves quality of life of parents and their autistic children. Moreover, research suggests that autism care mangement program that is grounded in a family-centered framework is best practice for meeting the needs of children with autism and their families (**Smith&Dillenbeck**, **2006**; **Alkhalafet al.**, **2014**).

V. Conclusion

Based on the results of this study and research hypothesis, autism care management program has positive outcomes on parents' coping patterns that are caring for children with autism. Knowledge and practice among parents are significantly improved after implementing the program. Also, there is a positive relationship between parents' knowledge, practice and coping patterns and a negative relationship between those three variables with parenting stress index. Finally, this research is stressing on improving parents' positive coping methods to re-arrange their way of life to accommodate the children with autism.

VI. Recommendations

Based on the results of the current study, it was recommended that:

- 1. Continuous health education and counseling programs are essential to improve parents' knowledge, skills and coping patterns toward the care of their children with autism.
- 2. Community and health care services given to the children with autism and families should be based on real assessment and appropriate intervention.
- 3. Since autism spectrum disorder is a lifelong condition, further research to assess and implement the health care needs of those children in school age and adult.
- 4. Further researches are needed to identify most common family problems in the community with appropriate interventions
- 5. Future research could replicate and expand on study methods to include more participants and details about results of education programs on autism children and their families.

References

- [1] Abidin, R. R. Parenting Stress Index, 3rd Edition: Professional Manual. Odessa, FL: Psychological Assessment Resources 1995 In Haskett E.M., Ahern S.L., Ward S.C., &Allaire A. Stress, Factor Structure Validity of the Parenting Stress, Journal of clinical child and adolescent psychology 2006, 35(2): 302-312.
- [2] Ahmad G., Mohammad J., Hamid A., Helping Families for Caring Children with Autistic Spectrum Disorders Arch.Iranian Med 2009; 12 (5): 478 482.
- [3] Al-Khalaf A., Dempsey I. & Dally K. The Effect of an Education Program for Mothers of Children with Autism Spectrum Disorder in Jordan, International Journal for the Advancement of Counseling 2014; 36 issue 2: 175-187.
- [4] Altieri, J. M. Family Functioning and Coping Behaviors in Parents of Children with Autism, Master thesis of Science in Clinical psychology, Eastern Michigan University, Ypsilanti, Michigan. 2006, 1-55.
- [5] Andra S.S., Austin C. & Arora M. The tooth exposome in children's health research. CurrOpinPediatr. 2016 Apr; 28(2):221-7.
- [6] Bashir A., Bashir U., Lone A. & Ahmad Z. Challenges Faced by families of Autistic Children, International Journal of Interdisciplinary Research and Innovations 2014; 2 issue: 64-68.
- [7] Berglund I.G., Doctoral Thesis in Nursing: Health and Care Sciences, School of Health and Welfare, Jönköping University 2017.
- [8] Dabrowska, A. &Pisula, P. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome, Journal of Intellectual Disability Research 2010; 54 part 3, 266–280.
- [9] Dardas L.A. Stress, Coping Strategies, and Quality of Life among Jordanian Parents of Children with Autistic Disorder 2014, Autism; 4(1): 1-6.
- [10] Dunlap, J.J., Interacting With Individuals on the Autism Spectrum, ANA Journal, 2018; 13(4) https://www.americannursetoday.com/interact-autism-spectrum/
- [11] Elbhnasawy T.H. & Girgis M.N. counseling for mothers to cope with their autistic children, Journal of American science 2011; 7(7): 183-192.
- [12] Elder, J.H. &D'Alessandro, T. supporting families of children with autism spectrum disorders: questions parents ask and what nurses need to know, PediatrNurs. 2009; 35(4):240-5, 253.
- [13] Ghanizadeh A., Alishahi M. &Ashkani H. Helping Families for Caring Children with Autistic Spectrumdisorders, Archives of Iranian Medicine, 2009; 12:478-482.
- [14] Gray E.D. Coping with autism: stresses and strategies, Sociology of Health & Illness 1994; 16 (3): 275-300.

- [15] Gray. D.E. Coping over time: the parents of children with autism, Journal of Intellectual Disability Research 2006; 50, part12: 970-976.
- [16] Harris, Weiss, Jane M. Right from The Start: Behavioral Intervention for Young Children with Autism Bethesda, Woodbine House, 2007, 156-170. Available at: HTTP://www.pediatrics.org/egi/full/105/e65.
- [17] Harris, Weiss, J. M. Right from the Start: Behavioral Intervention for Young Children with Autism, 2nd ed. Behavior Analysis in Practice 2009; 2(1): 68-72.
- [18] Hartley, L.S., Papp, m.l. Mihaila, I., Bussanich, M.P. Goetz, G., and Hickey, J.E., Couple Conflict in Parents of Children with versus without Autism: Self-Reported and Observed Findings, J Child Fam Stud. 2017; 26(8): 2152–2165.
- [19] Hassan, L. Caregiver's Awareness Regarding Autism Children, Master Thesis. Faculty of Nursing, Community department, Ain Shams University, Cairo, 2008.
- [20] Johnston, E., Goldberg, S., Morris, S., Levenson, J. Stress in UK families conducting an intensive home-based behavioral intervention for their young children with autism and Down syndrome. Journal of Autism and Developmental Disorder, 2012; 31, 327-36.
- [21] Khushabi K.,FarzadFard S. Z., Kakasoltani H. R. &Pouretemad H. R. Coping Strategies and Stress in Mothers with Autistic Children in Comparison with Mothers with Normal Children. Journal of Family Research 2011; 6(1): 87-97.
- [22] Mahmoud S., Ragab O. &Girrgais N. Functioning, and Coping Patterns Among Caregiver Having a child with autism. The Egyptian Journal of Medical Sciences 2009; 30 (1).
- [23] Makrygianni M.K. & Reed P.H. A Meta-analytic Review of the Effectiveness of Behavioural Early Intervention Programs for Children with Autistic Spectrum Disorders. Research in Autism Spectrum Disorders 2010; 4, 577-593.
- [24] Mansour K. Parent awareness regarding care of their children suffering from autism. Unpublished master's thesis, University of Ain Shams, Cairo, Egypt 2010.
- [25] Mohamed E. Counseling Intervention for Parents caring for Children with Autism. Unpublished Doctoral Thesis. Faculty of Nursing, psychiatric and mental health nursing department, Ain Shams University. Cairo, 2012, 10-164.
- [26] McCubbin HI. & Patterson JM.: The Family Stress Process: The Double ABCX Model of Family Adjustment and Adaptation. Marriage and Family Review 2009; 6, 7-37.
- [27] Mohr W.K. Psychiatric Mental Health Nursing, Evidence-Based Concept, Skills, and Practices 7th ed. Lippincott, Williams & Wilkins, 2009, 807:808.
- [28] Pottie G. C. & Ingram M.K. Daily Stress, Coping, and Well-Being in Parents of Children With Autism: A Multilevel Modeling Approach Journal of Family Psychology 2008; 22; (6): 855–864.
- [29] Probst P., Jung F., Micheel J., Glen I. Tertiary Preventive Interventions for Autism Spectrum Disorders (ASD) in Children and Adults: An Evaluative Synthesis of two TEACCH Based Outcome Studies Life Span and Disability 2010;12,129-167.
- [30] Ribeiro M., Sousa A., Vandenberghe L. & Porto C. Parental stress in mothers of children and adolescents with cerebral palsy. Revista Latino-Americana de Enfermagem 2014; 22(3):440-7.
- [31] Singer G.H.& Powers L.E. Contributing to Resilience in Families: An Overview. InSinger GH, Powers LE eds. Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions. Baltimore, Brookes 2013, 1-26.
- [32] Sinha, D. The family scenario in a developing country and its implications for mental health: The case of India. In P. R. Dasen, J. W. Berry, & N. Sartorius (Eds.), Health and cross-cultural psychology: Toward applications; 2008, 48–70
- [33] Smith V.K. & Dillenbeck A. Developing and Implementing Early Intervention Plans for Children with Autism Spectrum Disorders, Seminars in Speech and Language 2006; 27(1): 10-20.
- [34] Twoy R. Connolly M.P. & Novak M.J. Coping strategies used by parents of children with autism, Journal of the American Academy of Nurse Practitioners 19 2007, 251–260.
- [35] Wallace R.B.Tertiary prevention. In Encyclopedia of Public Health, 2010, retrieved fron http://www.enotes.com/publichealtencyclopedia/tertiary-prevention.

Asmaa Hafez Afefe Barakat. "Outcomes of Autism Care Management Program on Parent's Coping Patterns." IOSR Journal of Nursing and Health Science (IOSR-JNHS), vol. 8, no.04, 2019, pp. 07-15.