

Effect of an Educational Program on Strains and Coping Patterns of Family Caregivers Having Autistic Children

Mona Abd Elsabour Hassan¹; Mai Elghareap Hassan²; Fatma Adel Kamal Shaishaa³

¹Professor of Family and Community Health Nursing, Faculty of Nursing, Port Said University; ²Assistant professor of Family and Community Health Nursing, Faculty of Nursing, Port Said University; ³Bachelor of Nursing, Faculty of Nursing, Mansoura University.

Received: 23/07/2024

Revised: 08/08/2024

Accepted: 06/11/2024

ABSTRACT

Background: Autistic children face stigma and discrimination worldwide, making them a vulnerable group. Aim: to assess effect of an educational program on the strains and coping patterns of the family caregivers having autistic children.. **Subjects and method:** A quasi-experimental method was used in this study. Subjects: A number of 67 family caregivers have autistic children. Setting: This study was performed in all integration schools (12 schools) that provide education for autistic children and in three specialized centers for autistic children in Port Said City. **Tools:** Three tools were used in this study, which include Tool I: a structured interview sheet; Tool II: a caregiver strain questionnaire); and Tool III: a brief cope scale. **Results:** results revealed that, in the pre-program of the studied caregivers, 14.9% of them had either an unsatisfactory or partially satisfactory knowledge level, after program implementation, 98.5% of them had a satisfactory level, 92.5% of the studied family caregivers had a high level of strain in the pretest; in the post-program, the percent decreased to 32.8%, more than 31.3% of the family caregivers had a low coping pattern in the pre-program; in the post-program, 98.5% of them had a high score of coping pattern. **Conclusion:** A highly statistically significant improvement was detected post program in the knowledge and coping strategies of caregivers of children with autism spectrum disorder, which means, the educational program was successfully attaining its aim of positively enhancing the knowledge, coping strategies of caregivers when caring for their autistic children. **Recommendation:** Continues health education for caregivers, that emphasizes improving their comprehension of ASD, practice, and better coping strategies.

Keywords: Autism ,strain, coping, family caregivers, children

INTRODUCTION

Autistic children face significant challenges due to widespread stigma and discrimination, making them a vulnerable group. They often lack access to essential health and educational services and struggle to participate in community life or receive adequate support. Additionally, their caregivers bear a heavy emotional, financial, and caregiving burden (WHO, 2021).

Autism is a relatively common condition in the United States, affecting one in every 68 children. It is significantly more prevalent among boys, with boys being five times more likely to be diagnosed than girls (*Centre for Diseases Control and Prevention, 2014*). *Sanchack & Thomas (2016)* reported that autism, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified are all variations of a single condition with differing developmental levels, collectively termed autism spectrum disorder (ASD).

Stress can lead to a variety of physical and psychological issues. Physically, people may experience frequent illnesses, extreme fatigue, pain, autoimmune conditions, heart problems, digestive disorders, sleep disturbances, weight changes, and skin problems like eczema. On a mental and emotional level, stress can cause social isolation, loss of interest in hobbies, and irritability (**Suthar et al., 2020**).

There are many emotional and financial burdens that autism imposes as a lifelong disability on families with a child with autism. Additionally, parenting this child will cost three times as much as normal child. However, caregivers of those children have insufficient access to assistance and services . Worldwide, health or social care systems do not provide any care for most children with autism and their family caregivers (**Pavlopoulou et al., 2020**).

When a family cares for someone with ASD, it becomes a part of their lives for the long term. This is why we often call them families living with ASD. Having a child on the spectrum significantly impacts the entire family unit, bringing both challenges and opportunities for parents. Since most individuals with ASD need help with daily tasks, family members often become their primary caregivers (**Estes et al., 2019**).

Family caregivers of autistic children who don't use healthy ways to manage stress are at high risk of experiencing negative consequences. They may become overwhelmed, depressed, and grieving, which can lead to physical health problems and exhaustion (**Mottron, 2017**). Caregivers who use effective and flexible coping methods to understand and deal with problems may experience less stress. Coping strategies are the mental and practical ways people handle challenges (**Kazemi, Azimian, Mafi, Allen, & Motalebi, 2021**).

The nurse's role in helping children with autism is a vital link in the performance of the nursing process. It is about the need for accurate assessment, free from preconceptions, and attentive to the needs and sufferings of others, often with difficult verbalization in dealing with autistic children. Therefore, nurses have a duty to provide comprehensive care and actively listen to the needs of their patients. When caring for autistic children, this means listening attentively to understand their unique challenges. Nurses act as a bridge between the healthcare team, the child, and the parents, providing crucial insights and advocating for the child's well-being (**Manning et al., 2021**).

The community health nurse becomes a link between the multiprofessional team and the caregivers of the autistic children. Therefore, Community health nurse should understand the contributing factors of challenges for parents of children with ASD & their needs. She can help families in coping strategies, inform them about available formal and informal supports, provide support for proper family functioning & care giving. Significance of the study (**Magalhães¹ et al., 2020**).

Significance of the results

Autism is a lifelong condition that often requires parents to provide constant care for their children without much support. This constant responsibility can be incredibly stressful. Understanding autism and learning how to manage it can help reduce this stress. Globally, a significant number of children have autism, and most of them and their families lack essential support from healthcare and social services (**WHO, 2021**).

According to the Egyptian Social Solidarity Ministry, approximately 800,000 people in Egypt are believed to have autism (*Shehata, 2020*). *Yousef, (2021)*. Caring for an autistic child in Egypt can be extremely difficult for caregivers because there are very few available support services (*Leontine et al., 2020*).

Caregivers of autistic children often experience significant physical health issues due to the stress of their role. These problems can include frequent illnesses, extreme fatigue, chronic pain, autoimmune diseases, heart problems, digestive issues, sleep disturbances, weight changes, and skin conditions like eczema. While psychological issues aggravated by stress\strain include: loss of interest in activities, estrangement from friends and family, and feelings of irritability, frustration, and sadness (*Abdullah, 2014*).

There is an urgent need to implement some initiatives to raise awareness of autism among medical professionals and parents of autistic children (*Ozdemir, 2020*). Also, support family caregivers of these children, and provide them with necessary information about coping strategies to deal with their autistic children, So this study was performed to evaluate how an educational program affects the stress levels and coping methods of parents caring for autistic children.

AIM OF THE STUDY

The aim of the current study is to evaluate how an educational program affects the stress levels and coping methods of parents caring for autistic children.

Research Objectives:

1. Identify difficulties faced by the family caregivers of autistic children.
2. Determine the challenges faced by the family caregivers of autistic children.
3. Design an educational program about the difficulties and challenges for the family caregivers of autistic children.
4. Implement an educational program about the difficulties and challenges for the family caregivers of autistic children.

5. Evaluate the effect of the educational program on the dealing with difficulties and challenges of family caregivers of autistic children.

SUBJECTS AND METHODS

A. Technical design

Study Design

A quasi-experimental design of one group (pre-test and post-test) was used to conduct this study.

Study Setting

This study was conducted in all integration schools (12 schools) which provide education for autistic children & three specialized centers for autistic children in Port Said city.

Study Sample

A number of 67 family caregivers have autistic children. Setting: This study was performed in all integration schools (12 schools) that provide education for autistic children and in three specialized centers for autistic children in Port Said City.

The sample size was determined using a statistical formula developed by Steven Thimpson to ensure the study had a 95% chance of detecting significant results (**Daniel, 1999**):

$$n = \frac{N \times P(1 - P)}{(N1 \times (d2 / Z2) + P(1 - P))}$$

Where:

n= Sample size

N= total size (1074 total population).

d = the error rate is equal to 0.05.

P = Percentage of availability of the character and objectivity= (0.1

Z = the corresponding standard class of significance equal to 0.95 = (1.96).

$$n = \frac{1074 \times 0.5(1-0.5)}{1074 - 1 \times (0.052 \div 1.962) + 0.5(1-0.5)} = 63$$

Assuming a 5% attrition rate:

$$363 \times 5\% = 18.15$$

$$63 + 4 = 67$$

Tools of data collection

Tool I: Structured Interview Sheet: It was developed by **Abu El-Soud, Ouda, Abdou & Mohamed (2018)**. It consisted of two parts:

Part I: Sociodemographic data of studied family caregivers it was used to assess sociodemographic characteristic it was composed of 13 items it include the following: (age, marital status, working condition, educational level, family income, relative ken between the father and the mother, presence of family history of autism, current place for follow up of the child condition, frequency of follow up child's condition, attended training courses about caring of autistic child, titel of these courses, place of courses held, number of these courses).

Part II : knowledge of caregivers about autism: it was used to assess knowledge of caregivers it composed 2 categories as a follow:

First category : knowledge about autism it composed of 10 items as (meaning of autism , risk factors of autism , risk factors causes autism during childbirth ,social symptoms of autism, attitudinal symptoms of autism , factors cause autism during pregnancy , factors that occur after the birth of a child and lead to autism , needs of an autistic child, methods of treating an autistic child, symptoms of autism in terms of verbal and non- verbal communication) .

Second category: knowledge about strain and coping methods, it composed of 9 items as (definition of strain, signs, symptoms of strain and, causes of strain, coping methods of strain , sources of stress for family caregiver, adaptive patterns, factor affecting the extent of coping to strain for family caregivers with autistic children).

Scoring system:

The knowledge of the caregivers was scored as follow: the answer don't know was scored (0), incomplete correct answer was scored (1) and complete correct answer was scored (2). For each area of knowledge, the scores for each subject were added together and then divided by the total number of items in that subject. The scores were replaced into a percentage. If a mother scored 65% or higher, her knowledge was considered satisfactory. A score between 50% and 65% meant her knowledge was partially satisfactory, and below 50% was considered unsatisfactory."

Abu El-Soud, Ouda, Abdou& Mohamed (2018).

Tool II: Caregiver strain questionnaire-short form (CGSQ-SF):

It was developed by **Platt (1985)**, and the Arabic version was adopted from **Abu El-Soud, Ouda, Abdou& Mohamed (2018)**.It was used to assess strains family caregivers faced during caring of their autistic children. The CGSQ-SF consists of 10 items as a following :

In a questionnaire (10 items) classified to objective strain (6 items) and subjective internalized strain (4 items), Objective strain refers to the observable negative actions that result from the caregiver problems (e.g., financial strain (income enough or not enough), difficulty with neighbors or police, and disrupted family relations). The subjective internalized strain subscale measures the caregiver's own negative emotions, such as worry, exhaustion, and guilt.

Scoring system:

The total score CGSQ-SF was calculated as, not at all (1), a little (2), sometimes (3) to quite bit (4) very much (5) to assess the degree to which caregivers experience difficulties, challenges, and other negative consequences of caring a child with behavioral or emotional problems. The score was categorized as low or high. The CGSQ-SF total score was considered low if the scores were < 50% and high if the scores were ≥ 50%.

Tool III: Brief cope scale:

A brief cope scale was developed by **Carver (1997)**, and the Arabic version was adopted from **Abou El-Soud et al (2018)**, to evaluate the family caregivers pattern of coping with challenges associated with caring of their autistic children. A brief cope scale consisted of 28 items; as, I've been getting emotional support from others, I've been refusing to believe that it has happened, I've been giving up trying to deal with it, I've been looking for something good in what is happening, I've been giving up the attempt to cope, I've been making jokes about it , I've been getting comfort and understanding from someone. , I've been praying or meditating,

I've been trying to get advice or help from other people about what , I've been getting help and advice from other people) .

Scoring system:

Abou El-Soud et al (2018), It has 4-point scale as: I have not been doing this at all (1), A little bit (2), A medium amount (3) /I have been doing this a lot (4). The total score was determined by combining the scores from all the different patterns. Caregivers who scored higher on the coping pattern scale used more coping strategies. If a caregiver's score was below 50%, their coping pattern was considered low. However, if their score was 50% or above, their coping pattern was considered high.

B- Operational design**Tools' validity**

Validity testing was done to the tools by submitting the tools to a jury of 7 professional judges, community health nursing, who decided that the Arabic version of tools showed good validity “, (This is from the original article by Abou El-Soud, Ouda, Abdou and Mohamed (2018).

Tools' reliability

The reliability for first tool(knowledge) as measured by using the Cronbach's alpha test was 0.7, The reliability for second tool (caregiver strain) was 0.9 and for the third tool (family caregivers' pattern of coping with challenges)was 0.8.

Field Work

The study was implemented on 67 family caregiver through the following four phases: Assessment, design program, implementation, and evaluation. Collection of the data (pre, post), and implementation of sessions, covered a period of six months in October, November December 2022, February, Mars and April 2023.

Assessment phase (Pre-test phase):

Before implementing the educational program, the study tools were applied to assess family caregiver's knowledge, Strains & coping pattern regarding of autism spectrum disorder ASD. The researcher spent six months conducting fieldwork, interviewing each caregiver individually for approximately 30-35 minutes using the previously described research methods. The data was obtained during this phase sessions (pretest), confidentiality of all gathered information was strictly protected.

Implementation phase

- The educational sessions were carried out Hamzat Wasl Center. The subjects were divided into small groups (7 groups), each group consists of nine to ten family caregivers, the researcher visited center three days each week.
- The implementation of educational program was conducted as, each group obtained three sessions a week, each session was taken in average about an hour.

A variety of teaching and learning approaches were employed during the sessions, including data shows that include pictures, videos were introduced to caregivers.

Each session began by reviewing what happened last time and outlining the goals for the current session. This was done in simple, easy-to-understand language that the caregivers could follow. At the same time, the sessions included techniques to keep

caregivers motivated and engaged. Any questions or inquiry for caregivers was answered.

Evaluation phase (Post-test)

After implementation of educational program, post-tests were done immediately to evaluate the effect of educational program on difficulties and challenges of family caregiver using the same tools in pretest.

Pilot Study

A pilot study was carried out on 10% of the sample (7 family caregivers). It was done to check if the developed tool was appropriate, easy to understand, and practical to use, and to estimate the questionnaire completion time. The pilot subjects were not included in the main study sample

Ethical Consideration

The Scientific Research Ethics Committee in Faculty of Nursing in Port Said University approved the study protocol with code NUR (8/5/2022) (13). All ethical issued was taken into consideration during all phases of the research and included the following:

1. Explained the aim of the research to the deans of faculties and students (participants) to take their permission to do the study.
2. The aim of the research was explained to all participants to highlight the importance of their involvement.
3. Participants were informed about the research and confirmed that their information would be kept private and used solely for research purposes.
4. The researcher informed the study participants that they could withdraw from the study whenever they wanted.

A. Administrative Design

An official letter included the title and purpose of the study was sent from the Dean of the Faculty of Nursing- Port Said University to the Undersecretary of

Ministry of Education in Port Said city, to gain his approval for conducting the study to the prementioned schools, then official letters were sent to each directors of schools ,also official letters were sent to prementioned centers to gain their cooperation.

B. Statistical Design

Analysis of data was done using SPSS software package. To compare different groups based on categorical data, we used the chi-square test. When more than 20% of the expected cell counts were less than 5, we applied either Fisher's Exact test or the Monte Carlo correction to the chi-square test. To analyze differences between various stages, we employed the McNemar and Marginal Homogeneity tests. A paired t-test was used to compare two related groups of numerical data. The relationship between the two numerical variables was also examined using Pearson's correlation coefficient. The p-value was less than 5% is considered significant.

RESULTS

Table (1) presents sociodemographic characteristics of the studied family caregivers of ASD children, 32.8% of the studied caregivers aged 35 to less than 40 years old, and 49.3% of them had middle education, while 64.2% didn't work. Regarding family income, 73.1% of the studied caregiver mentioned that, their income not enough. Furthermore, 77.6% of them were married. Whereas, 73.1% of them said that there is no ken relation between the parents, and 77.6% reported there is no family history of autism.

Figure (1) shows that, in pre-program 74.1% of the studied caregivers had unsatisfactory level or partially satisfactory level of overall knowledge which improved to 97% had satisfactory level post implementation of the program.

As illustrates in **Table 2;** presents highly statistically significant differences between pre and post program total level of strains in the three tested domains ($p < 0.001$). According to nonverbal strain 85.1% of the studied caregivers had high level nonverbal in strain pre-program which decreased to 32.8% post-program. Regarding verbal strain 97% of the studied caregivers had high level verbal strain which decreased to 71.6% post-program. Concerning overall caregiver level of

strain(stressors),92.5% of the studied family caregivers had high level in pretest meanwhile in post program percent decreased to 32.8%.

Table (3) presents that there were statistically differences between pre and post program coping pattern ($P < 0.001$) in all tested domains except domains regarding the joke, denial, and behavioral disengagement. It noticed that the highest improvement was regard to religion (96.35), acceptance (78.4%), and active adaption (74.6%) compared with pre-program scores (79.9%, 47%, 44%) respectively. Data also shows that 68.7% of the family caregivers had high coping level pattern at preprogram phase, meanwhile in posttest percentage increased to 98.5%.

Table (4) shows that there was a positive correlation between the studied caregiver's total knowledge score and coping pattern pre& post program, while there was negative correlation between their total strain scores and coping pattern scores pre and post program ($P > 0.05$).

Table (1): Distribution of the studied sample according to their sociodemographic characteristics (n = 67).

Items	No.	%
Age		
20-	1	1.5
25-	14	20.9
30-	14	20.9
35-	22	32.8
40-	12	17.9
45+	4	6.0
Educational level		
Can't read and write	1	1.5
Read and write	7	10.4
Elementary / Basic	10	14.9
Middle education	33	49.3
Other	16	23.9
Working condition		
Working	24	35.8
Not working	43	64.2
Family income		
Enough	18	26.9
Not enough	49	73.1
Marital status		
Married	52	77.6
Widower	7	10.4
Divorced	8	11.9
Ken relation between the father and the mother?		
Yes	18	26.9
No	49	73.1
Presence of family history of autism		
Yes	15	22.4
No	52	77.6

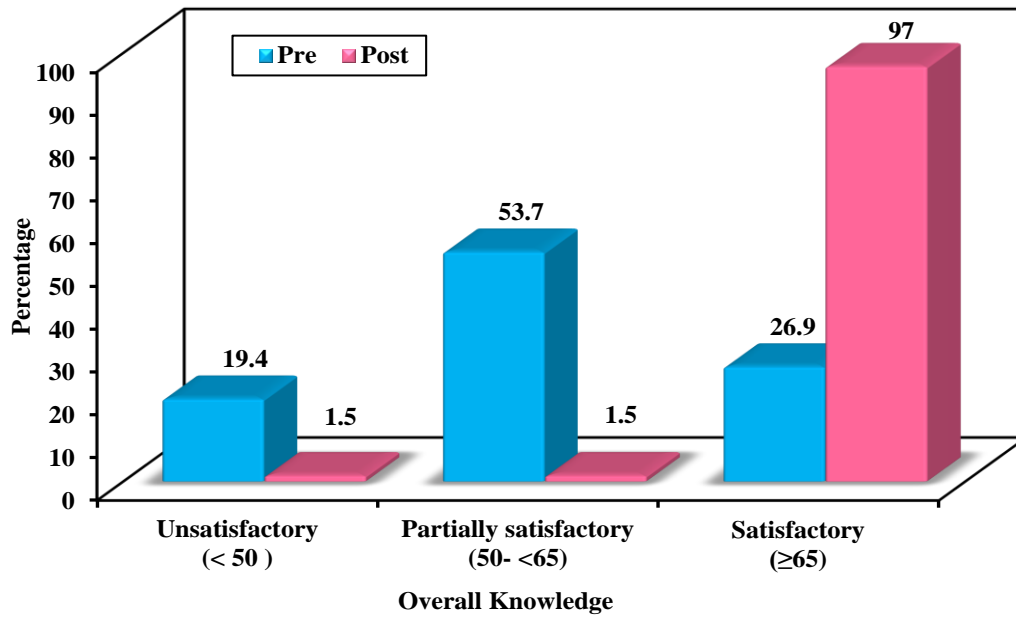


Figure (1): Distribution of the studied sample according to overall knowledge throughout program phases (n=67).

Table (2): Distribution of the studied sample according to their total levels of strains throughout the program phases (n=67).

	Pre		Post		McN p
	No.	%	No.	%	
Nonverbal strain (objective)					
Low (< 50)	10	14.9	45	67.2	<0.001*
High (≥50)	57	85.1	22	32.8	
Verbal strain (subjective)					
Low (< 50)	2	3.0	19	28.4	<0.001*
High (≥50)	65	97.0	48	71.6	
Overall Caregiver strain					
Low (< 50)	5	7.5	45	67.2	<0.001*
High (≥50)	62	92.5	22	32.8	

McN: McNemar test

p: p value for comparing between **pre** and **post**

*: Statistically significant at $p \leq 0.05$

Table (3): Distribution of the studied sample according to their total score of coping patterns throughout the program (n = 67).

Pattern of coping	Pre				Post				P
	A	B	C	D	A	B	C	D	
	%	%	%	%	%	%	%	%	
Active adaptation	4.5	11.9	39.6	44.0	0.0	0.7	24.6	74.6	<0.001*
Planning	5.2	23.9	39.6	31.3	0.0	1.5	38.8	59.7	<0.001*
Reframe positive shape	7.5	9.0	53.7	29.9	0.0	2.2	30.6	67.2	<0.001*
Acceptance	1.5	7.5	44.0	47.0	0.0	0.0	21.6	78.4	<0.001*
The joke	38.8	55.2	5.2	0.7	44.0	36.6	17.9	1.5	0.196
Religion	0.0	3.0	17.2	79.9	0.0	0.0	3.7	96.3	<0.001*
Use emotional support	5.2	47.8	37.3	9.7	0.0	0.7	74.6	24.6	<0.001*
Benefit from the support of other	7.5	35.1	45.5	11.9	0.0	0.7	68.7	30.6	<0.001*
Self-distraction	16.4	16.4	59.0	8.2	0.0	3.7	46.3	50.0	<0.001*
Denial	36.6	50.7	11.2	1.5	48.5	19.4	28.4	3.7	0.187
Emotional release	7.5	33.6	51.5	7.5	0.0	5.2	67.2	27.6	<0.001*
Take sedatives	84.3	10.4	5.2	0.0	94.8	5.2	0.0	0.0	<0.001*
Behavioral disengagement	42.5	12.7	35.8	9.0	46.3	3.0	33.6	17.2	0.140
Self-blame	16.4	30.6	46.3	6.7	25.4	73.1	1.5	0.0	<0.001*
Total percentage coping score									
Low (< 50)	%				%				
High (≥ 50)	31.3				1.5				<0.001*
	68.7				98.5				

A = I haven't been doing this at all, B = little bit, C = medium amount, and D = I've been doing this a lot.

MH: Marginal Homogeneity Test - p: p value for comparing between **pre** and **post**-*: Statistically significant at $p \leq 0.05$

Table (4): Correlation between total Knowledge, Overall Caregiver strain with Overall coping pattern (n = 67)

		Pre	Post
Overall, Knowledge vs. Overall Caregiver strain	R	-0.197	-0.026
	P	0.109	0.835
Overall, Knowledge vs. Overall coping pattern	R	0.575*	0.037
	P	<0.001*	0.766
Overall Caregiver strain vs. Overall coping pattern	R	-0.432*	-0.273*
	P	<0.001*	0.025*

r: Pearson coefficient

*: Statistically significant at $p \leq 0.05$

DISCUSSION

Parents who have children with autism face higher levels of stress and challenges compared to Parents who have children with other disabilities. Caregiver strain refers to the negative impact experienced by those caring for a child with special needs. Caregivers of individuals with autism often experience significant challenges, including financial difficulties, disrupted daily life, work and career interruptions, physical exhaustion, and feelings of loneliness, worry, anger, and sadness. There is a need to better understand the stress and strain that autism caregivers face (**Bradshaw et al., 2020**).

Family caregivers of autistic children who don't use healthy ways to manage stress are at a high risk of experiencing negative consequences. These can include destructive behaviors, feelings of hopelessness, depression, and grief. This can lead to physical health problems and caregiver burnout (**CDC, 2014**).

The pre- educational program caregivers have less knowledge regarding autism and coping strategies to stressors could be explained by the fact that nearly half of the studied caregivers have middle education and the majority of caregivers have not enough family income and are unemployed. Furthermore, the majority of caregivers have no family history of cases with autism; therefore, they lack the experience dealing with such cases.

Such findings are in agreement with that of **Abd El Hameed et al. (2012)** on 100 caregivers of autistic children and indicated that caregivers reported a significant improvement in their knowledge and practices which reflect on their children's skills in emotional, motor, and language skills, prior and after program implementation.

The present study indicated a significant improvement in family caregivers dealing with both nonverbal and verbal strains post- educational program compared with pre- educational program. Hence, the overall caregiver strains were significantly lower post- educational program compared with the pre- educational program.

Such findings are in accordance with that of **Ji et al. (2014)** who included 42 caregivers of children with ASD and demonstrated significant improvements in the mental health related quality of life (HRQOL), family functioning, self-efficacy, and positive coping style at the end of the multidisciplinary parent education program.

Moreover, **Bradshaw et al. (2021)** study on 374 parents of children with ASD demonstrated that parents of children with ASD reported higher stress levels on the child predictors across Caregiver Strain Questionnaire (CGSQ) when their children exhibited disruptive behavior, more severe autism symptoms, and oppositional or hyperactive tendencies.

Furthermore, **Abu El-Soud et al. (2020)** study on 36 caregivers of ASD children found that the caregivers in the study lacked sufficient knowledge about autism, stress, and coping mechanisms. Despite this, they experienced high levels of stress and reported using coping strategies frequently.

The present study indicated a statistically significant increase in all positive patterns of coping post- educational program compared with the pre- educational program as the majority of the studied caregivers showed increased adoption of items related to religion, active adaption, and acceptance patterns. Moreover, all negative patterns of coping items were significantly decreased in post- educational program compared with pre- educational program scores. Hence, the total percentage coping score was significantly higher post- educational program compared with the pre- educational program.

Similarly, a randomized treatment-control study done by **Smith et al. (2018)** on 15 caregivers of children with ASD demonstrated that there was a significantly increased coping self-efficacy from pre-intervention to post-intervention.

Iida et al. (2018) found that a parent training program helped mothers of children with ASD. The mothers reported feeling less stressed and depressed after the program. They also coped with stress better, using positive thinking more and avoidance less. Both depression levels, as measured by the Beck Depression Inventory Second Edition, and trait anxiety scores decreased significantly.

The present study indicated that there was statistically significant relation between the studied family caregivers' total knowledge level score and their educational level, occupation and family income at the level of pre- educational program implementation.

Similarly, **Abd Alkazam and Al-Dujaili, (2022)** study on 52 caregivers of ASD children demonstrated that the caregiver, level of education, age, job, training on autism spectrum disorder, and residency were statistically significant in terms of knowledge skills.

In accordance, **Surmen et al. (2015)** studied 160 caregivers of autistic children and demonstrated that there was significant increase in autism awareness with increased level of education in the community. And this can be explained as education leads to the increasing trends in awareness about autism. Furthermore, **Al-Farsi et al. (2022)** study on two-hundred and twenty caregivers who seek consultation for their children with ASD reported that socio-economic factors like advanced education correlated with higher quality of life, frequently associated with secure employment and greater income.

The present study revealed that there was a statistically significant relation between the studied caregivers' total strains score and their family income and being not attending training courses on how to deal with autistic child in pre- educational program, and marital status, family history of autism and the frequency of follow-up of the autistic child in post- educational program.

Furthermore, **Abu El-Soud et al. (2018)** found that housewives reported feeling more stressed compared to working mothers. They explained this to housewives who were overwhelmed by household chores and caring for autistic children, leaving them with no time for breaks or personal well-being.

The present study indicated that there was a positive correlation between the studied caregiver's total knowledge score and coping pattern pre- educational program, while there was negative correlation between their total strain scores and coping pattern scores pre- and post- educational program.

CONCLUSION

Caregivers of children with ASD faced high levels of stress, significant psychological distress, insufficient coping skills, and frequent physical and mental burnout. The present study supports the implementation of educational programs regarding knowledge, coping strategies and reducing distress among caregivers of children with ASD.

RECOMMENDATIONS

1. Nurses are encouraged to take a more active role to improve the health of children with autism and families should contribute to mitigating the burden care of parents by informing families about social support systems.
2. Larger scale studies with longer follow-up regarding the implementation of educational programs to caregivers of children with ASD are recommended.
3. Further studies that include gathering detailed information about the++ child's condition, particularly any aspects (like IQ, behavior, or communication) that could create challenges for the parent's ability to cope.

Reference

- Abdullah, A. M. (2014).* Autism disorder: Strategies of education, rehabilitation and intervention programs, Cairo, EgyptianLebanon Center, PP.45-59.
- Abu El-Soud et al. (2018) Abu El-Soud, S.G., Ouda, W.E.S., Abdou, A., El Sayed, S. and Mohamed, M.F., 2020. Assessment of Knowledge, Strains and Coping of the Family Care Givers Having Autistic Children. Port Said Scientific Journal of Nursing, 7(2), pp.202-219.
- Al-Farsi, O.A., Al-Farsi, Y.M., Al-Sharbati, M.M., Al-Adawi, S., Cucchi, A., Essa, M.M. and Qoronfleh, M.W., 2020. Quality of life among caregivers of children with autism spectrum disorders, intellectual disability, and typical development. Applied Research in Quality of Life, pp.1-17.
- Bradshaw, J., Gillespie, S., McCracken, C., King, B.H., McCracken, J.T., Johnson, C.R., Lecavalier, L., Smith, T., Swiezy, N., Bearss, K. and Sikich, L., 2021. Predictors of caregiver strain for parents of children with autism spectrum disorder. Journal of Autism and Developmental Disorders, 51, pp.3039-3049.
- Carver, C. S. (1997).* You want to measure coping but your protocol's too long: Consider the brief cope. International journal of behavioral medicine, 4(1), 92-100.
- Center for Disease Control and Prevention (2016). Prevalence of autism spectrum disorder among children aged 8 years. Autism and Developmental Disabilities Monitoring Network, 11 sites United States, 2014/63 (SS02). pp. 1-21.

- Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Pediatric Medicine (Hong Kong, China)*, 2.
- Ji, B., Sun, M., Yi, R. and Tang, S., 2014. Multidisciplinary parent education for caregivers of children with autism spectrum disorders. *Archives of Psychiatric Nursing*, 28(5), pp.319-326.
- Kazemi, A., Azimian, J., Mafi, M., Allen, K. A., & Motalebi, S. A. (2021). Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC psychology*, 9(1), 1-9.
- Leontine, W., de Nijs, P. F., Duvekot, J., Greaves-Lord, K., Hillegers, M. H., Brouwer, W. B., & Hakkaart-van Roijen, L. (2020). Children with an autism spectrum disorder and their caregivers: Capturing health-related and care-related quality of life. *Journal of autism and developmental disorders*, 50(1), 263-277.
- Magalhães¹, J. M., Lima, F. S. V., de Oliveira Silva, F. R., Rodrigues, A. B. M., & Gomes, A. V. (2020). Nursing care to the autistic child: an integrative review. *Enfermería Global*(58), 551.
- Manning, J., Billian, J., Matson, J., Allen, C., & Soares, N. (2021). Perceptions of families of individuals with autism spectrum disorder during the COVID-19 crisis. *Journal of Autism and Developmental Disorders*, 51(8), 2920-2928.

Mottron, L. (2017). Should we change targets and methods of early intervention in autism, in favor of a strengths-based education?. *European child & adolescent psychiatry*, 26(7), 815-825.

Ozdemir, M., Ilgin, C., Karavus, M., Hidiroglu, S., Luleci, N. E., Ay, N. P., ... & Save, D. (2020). Adaptation of the Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire: Turkish version. *Northern clinics of Istanbul*, 7(1), 40.

Pavlopoulou, G., Wood, R., & Papadopoulos, C. (2020). Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK.

Shehata, M. H., Kandeel, W. A., Raouf, E. R. A., Hashish, A. F., El-Din, E. M. S., Shabaka, D. A., & Tarkan, R. S. (2020). Assessment Of Obesity And Its Correlation With Some Gut Microbiota In A Sample Of Egyptian Autistic Children. *European Journal of Molecular & Clinical Medicine*, 7(11).

Smith, C.H., Turbitt, E., Muschelli, J., Leonard, L., Lewis, K.L., Freedman, B., Muratori, M. and Biesecker, B.B., 2018. Feasibility of Coping Effectiveness Training for Caregivers of Children with Autism Spectrum Disorder: a Genetic Counseling Intervention. *Journal of genetic counseling*, 27(1), p.252.

Surmen, A., Hidiroglu, S., Usta, H.H., Awiwi, M., Oguz, A.S., Karavus, M. and Karavus, A., 2015. A study exploring knowledge, attitudes and behaviours towards autism among adults applying to a Family Health Center in Istanbul. Northern clinics of Istanbul, 2(1), p.13.

Suthar, N., Jain, S., Nebhinani, N., & Singhai, K. (2020). Autism spectrum disorder and its differential diagnosis: A nosological update. Journal of the Indian Association for Child and Adolescent Mental Health-ISSN 0973-1342), 16(1), 86–101.

Sanchack, K. E., & Thomas, C. A. (2016). Autism spectrum disorder: Primary care principles. American family physician, 94(12), 972-979.

World Health Organization (WHO), (2021). Autism spectrum disorders and other developmental disorders from raising awareness to building capacity, WHO, Geneva, Switzerland, PP.6-50, ISBN: 978 92 4 150661.

Yousef, A. M., Roshdy, E. H., Fattah, N. R. A., Said, R. M., Atia, M. M., Hafez, E. M., & Mohamed, A. E. (2021). Prevalence and risk factors of autism spectrum disorders in preschool children in Sharkia, Egypt: a community-based study. Middle East Current Psychiatry, 28(1), 1-14.

العلاقة بين الكفاءة الذاتية والالتزام للعلاج بالأدوية عن طريق الحقن لمرض السكري من النوع الثاني

منى عبد الصبور حسن¹؛ مى الغريب حسن²؛ فاطمة عادل كمال شعيشع³

¹أستاذ تمريض صحة الأسرة والمجتمع بكلية التمريض جامعة بورسعيد؛ ²أستاذ مساعد بقسم تمريض صحة الأسرة والمجتمع بكلية التمريض جامعة بورسعيد؛ ³معيدة بقسم التمريض الباطني والجراحي جامعة بورسعيد؛
بكالوريوس التمريض- كلية التمريض- جامعة المنصورة.

الخلفية: يواجه الأطفال المصابون بالتوحد وصمة عار في جميع انحاء العالم مما يجعلهم مجموعة ضعيفة .
الهدف: تقييم اثر البرنامج التعليمي علي أنماط الاجهاد والتكيف لمقدمي الرعاية الاسرية الذين لديهم أطفال توحد .
طرق البحث: تصميم شبه تجريبي لهذه الدراسة . **مكان الدراسة:** أجريت هذه الدراسة في (12) مدرسة دمج وثلاثة مراكز متخصصة للأطفال المصابون بالتوحد في مدينة بورسعيد **عينة البحث:** عدد من 67 من مقدمي الرعاية الاسرية الذين لديهم أطفال توحد. **الأدوات:** تم استخدام ثلاث أدوات ,الأداة الاولى : ورقة المقابلة المنظمة ,الأداة الثانية : استبيان ضغوط مقدمي الرعاية الاسرية _النموذج القصير ,الأداة الثالثة :مقياس التعامل المختصر. **النتائج:** كشفت النتائج في مرحلة ما قبل البرنامج 14.9% من مقدمي الرعاية الاسرية المدروسين مستوي غير مرضي او مرضي جزئيا من المعرفة, وبعد تنفيذ البرنامج كان لدي 98.5%منهم مستوي مرضي , وكان لدي 92.5% من مقدمي الرعاية الاسرية المدروسة مستوي عالي من الضغوط في الاختبار القبلي , وفي مرحلة ما بعد البرنامج انخفضت النسبة الي 32.8% وكان لدي أكثر من 31.3% من مقدمي الرعاية الاسرية نمط مواجهة منخفض في مرحلة ما قبل البرنامج ,وفي مرحلة ما بعد البرنامج كان لدي 98.5%منهم درجة عالية من نمط المواجهة . **الاستنتاج:** تم الكشف عن تحسن كبير احصائيا بعد البرنامج في المعرفة واستراتيجيات التكيف لمقدمي الرعاية الاسرية الذين لديهم أطفال توحد مما يعني ان البرنامج حقق بنجاح هدفه المتمثل في تعزيز المعرفة واستراتيجيات التكيف بشكل إيجابي لمواجهة ضغوط مقدمي الرعاية الاسرية الذين لديهم أطفال توحد .
التوصية: مواصلة التثقيف الصحي لمقدمي الرعاية الاسرية مع التركيز علي تحسين فهمهم لاضطراب طيف التوحد وممارسته علي استراتيجيات تكيف افضل.

الكلمات المرشدة: توحد, ضغوط, تكيف, مقدمي الرعاية الاسرية لاطفال التوحد.