

■ Basic Research

Effectiveness of Nursing Intervention Based on Family Empowerment Model on Burden of Care and Self-Efficacy for Caregivers of Children with Autism Disorder

¹Saida El Sayed Hassan Ibrahim El-Azzab*, ²Shimaa Mohamed Hassan Ali, ³Faten Said Abdelhady Garf, and ⁴Doaa Mohamed Sobhy Elsayed

1. Assistant Professor of Psychiatric/Mental Health Nursing, Faculty of Nursing, Beni-Suef University, Egypt. 2. Lecturer of Psychiatric/Mental Health Nursing, Faculty of Nursing, Beni-Suef University, Egypt. 3. Lecturer of Community Health Nursing, Faculty of Nursing, Beni-Suef University, Egypt. 4. Assistant Professor of Community Health Nursing, Faculty of Nursing, Benha University, Egypt.

***The corresponding author:** E-mail address: saida.ibrahim@nursing.bsu.edu.eg, saida_hassan@yahoo.com. **Orcid** ID: <https://orcid.org/0000-0002-8615-8591>. Phone No: +201119942093.

Abstract:

Background: Autism disorders lead to significant disability and pressure on affected children and their families. Autism is an interrelated and complex developmental disability, a disorder of thinking and cognition, impaired of verbal and nonverbal communication, and limited self-care skills. Therefore, diagnosis of a child with autism is a shock to the family members, because of the needs, the problems suffered from, burden of care, health and psychiatric conditions, and impact of self-efficacy for caregivers. **Aim:** To evaluate the effectiveness of nursing intervention based on family empowerment model on burden of care and self-efficacy for caregivers of children with autism disorder. **Design:** A Quasi-experimental design (one group pre-post) was selected for conducting this study. **Setting:** This study was conducted in Psychiatric Outpatient Clinics at Benha University Hospital, Benha Teaching Hospital and Psychiatric and Addiction Hospital in Benha at Qalyubia Governorate, Egypt. The study **sample** involves fifty six family caregivers and their children with autism who were selected using a purposive sampling technique. **Tools:** Four tools for data collection were used, tool I: an interviewing questionnaire to assess; Socio demographic characteristics for the caregiver, personal characteristics of the autistic child, medical history of the disease, and caregiver's knowledge regarding autism; Tool II" Katz Index of Independence in Activities of Daily Living (ADL); Tool III: Zarit Burden interviewing questionnaire, Tool IV: General Self-Efficacy Scale (GSE). The intervention consisted of 8 sessions. **Results:** The study results showed that there were highly statistically significant positive correlations between caregivers' total knowledge, total burden of care, and total self-efficacy post program implementation, ($P < 0.001$). Also, there was a statistically significant positive correlation between caregivers' total knowledge and children' with autism total independency ($P < 0.05$). **Conclusion:** The results concluded that nursing intervention based on family empowerment model showed positive impact and effective improvement in burden of care and self-efficacy of parents of children with autism. As well as the caregivers' knowledge regarding autism improved after utilized of the nursing intervention program. **Recommendation:** The study recommended that application of nursing intervention based on family empowerment model in all governorates of Egypt in order to improve the awareness of parents and caregivers regarding autism, burden of care, and self-efficacy.

Keywords: Autism, Burden of Care, Caregiver, Empowerment, Self-Efficacy.

1. Introduction:

Autism Disorder (AD) is a kind of neurodevelopmental disorder. It is sorted by long-term problems with social communication and interaction in different societal environments, special interests and sensory processing of repetitive behaviors, symptoms beginning in early childhood in the first two years of life that make the child to need help in his or her daily life. AD is a significant cause of morbidity and significant health service use. Although AD begins in early development, it can persist during the course of a person's life ⁽¹⁾. The most common symptoms in children with AD are social communication disorders that incorporate inability to initiate a conversation, impairment in the use of facial expressions and eye interaction, impairment in using and understanding gestures, abnormal volume and tone, and repetition of words or phrases more and more, provide unrelated responses to questions, failure to share excitement, enjoyment, accomplishments, and feelings with others, abnormalities in using and understanding moods, difficulties in sharing creative play, poor performance skills, difficulties making friends ⁽²⁾.

Children with AD are extremely challenging for families to deal with for several reasons, recognized burden and care for the child with autism, accessible forms of social support and interactions between the child with autism and other family members are areas of important concern for families. It has been found that perceived stress by caregivers is negatively correlated with lower levels of various adaptive skills and positively correlated with the child's problem behaviors. Many parents reported getting little support from their expanded families in caring for their child ⁽³⁾. Parent of a child with AD is a stressful and challenging experience, especially in countries where several support services are restricted. The caregivers of children with AD often have impaired mental health, as well as anxiety and depression, a poorer life quality and wellbeing, and greater levels of stress. Mothers of children with AD have reported higher stress, caregiving burden, health difficulties, lower levels of resilience, and problems in various areas of caregiver and family life, including marital relationships, siblings, and family socialization ⁽⁴⁾.

Almost all caregivers of children with AD have the burden of caring, that were associated with caring for their children with a long-term chronic disorder. Caregiving burden has a multi-dimensional effect, including physical, psychological, emotional, and economic effects, as well as correlated stressful feelings such as shame, guilt, anger, embarrassment, and self-blame. (5).

Self-efficacy is an individual's belief and ability to succeed in specific situations or achieve a task and accomplish the behavior required to attain results. Most caregivers of children

with AD do not know how to reply to their children's difficult behavior. Caregivers are worried by the children's behavior but are unable to get any support. Subsequently, the caregivers can improve their self-efficacy in encouraging prevention of their children's exciting behavior, they can promote their encouragement in response to such behavior ⁽⁶⁾. Caregivers who can enrich their self-efficacy can react to their children's emotions, have the opportunity to assure peace of mind, and secure their children's physical safety. Accordingly, Caregivers will develop, maintain, and improve social interaction opportunities for their children and enhance their growth and development. Additionally, improving caregivers' self-efficacy to avoid challenging behavior will improve the mental health of both caregivers and children as well as prevent harm and maltreatment ⁽⁷⁾.

Caregivers have a great influence on the condition of their children with AD. Parent's contribution in caregiver support groups, as well as interaction between caregivers and nurses to encourage caregivers by improving their ability in caring of their children with AD. These activities create opportunities for caregivers to share their experience and feelings of the benefits of group decision-making. Empowerment is a process that will enable self-efficacy recognition. Caregivers will be able to analyze the real cause of the problem, be willing to solve problems with wisdom, and share knowledge and skills with health workers as a result of this process. Caregivers' self-efficacy will improve as a result of the process of communicating knowledge and skills ⁽⁸⁾. Additionally, **Severinsen et al.** ⁽⁹⁾ reported that caregivers play a key role in alleviating mental health problems in their children, while caregivers emotion awareness, emotion regulation, and response to their children's needs and their capacity to coach or guide their children's play a central role in the improvement of mental health. Caregivers' interventions are recognized as efficacious for the management of several mental health difficulties in children, as well reach children and alleviate mental health difficulties by guiding caregivers to help them to recognize and cope with needs of their children with autism.

Nursing intervention based on family empowerment have an advantage to improve health status and the life quality for caregivers of children with autism, and also enhance the life anticipation and improving life quality in children with chronic diseases and common genetic diseases like AD. Empowerment is a nursing intervention and educational model that supports caregivers to feel the desired change. It involves a fundamental redefinition of roles and relationships of health care professionals and autistic children' parents ⁽¹⁰⁾. Family Empowerment Model (FEM) confirms that family has an effective role on the motivation, psychological, knowledge, attitudes, and perceived threat of the members. The main

purpose of FEM is to empower the family members to enhance their health and their children with AD health level ⁽¹¹⁾.

1.1. Significance of the Study

The diagnosis of AD has become more common in recent years as a trend in escalating prevalence rates observed over the past decade. More boys have been diagnosed with AD than girls, with a sex ratio of 3 (boys): 1 (girls). The Centers for Disease Control and Prevention's Autism and Developmental Disabilities Network (**CDCAD**) ⁽¹²⁾ estimates that the present prevalence in the United States is one in every fifty-four children, whereas the incidence in Europe has increased quickly in recent years, owing to improved awareness of autism and thus an increased likelihood of being diagnosed with the disorder. According to data, the expected incidence of autism in Greece is 1.15% of school-age children. As well, **Casagrande and Ingersoll** ⁽¹³⁾ stated that caregivers of children with autism describe challenges such as lower life quality, negative mental and physical health signs, and lower satisfaction of life.

The Egyptian assistant minister of education for special needs children said that the number of autistic children in Egypt is between 1-1.5 million child ⁽¹⁴⁾. Egyptian mothers of children with AD had a destructive impact of their mental health, well-being, social life and caring for a child with AD aggravated the stigmatization of children with autism and their caregivers. Furthermore, these financial concerns, for example cost-effective burden and the requirement for additional income to cover the high lifelong cost of management and special education associated to AD, are significant contributors to increased caregivers fatigue, particularly in low-income families. Mothers of children with autism who perceived lack of social support confront more challenges to their parenting skills related with the child's characteristics, which exacerbates parental stress and depressive symptoms ⁽¹⁵⁾.

Special attention should be given to children with autism and their family from the community and psychiatric/mental health team members, as they have a right to live and play an active role and be productive members of society. The current study will add to the body of knowledge for caregivers of children with AD, and will add to practice of evidence for dealing with those caregivers of children with AD to serve as an important evidence to direct the promotion of mental health and wellbeing, decreased level of burden and increased level of self-efficacy post implement of nursing intervention program among caregivers of children with AD, so this study was conducted to evaluate the effect of nursing intervention based on family empowerment model on burden of care and self-efficacy for caregivers of children with autism disorder.

2. Aim of the Study:

The aim of this study was to evaluate the effectiveness of nursing intervention based on family empowerment model on burden of care and self-efficacy for caregivers of children with autism disorder. This was done by achieving the following goals:

- Assessing the level of knowledge regarding autism among caregivers of children with autism disorder.
- Assessing the level of independence among children with autism disorder.
- Assessing the level of burden among caregivers of children with autism disorder.
- Assessing level of self-efficacy among caregivers of children with autism disorder.
- Designing and implementing nursing intervention based on family empowerment model for caregivers of children with autism disorder.
- Evaluating the effectiveness of nursing intervention based on family empowerment model for caregivers of children with autism disorder.

2.1. Research Hypotheses:

H.1: Caregivers' knowledge regarding autism will be improved after conducted of nursing intervention.

H.2: The level of burden among caregivers of children with autism disorder will be decreased post implement of nursing intervention.

H.3: Caregivers of children with autism disorder will experience high level of self-efficacy post implement of nursing intervention program.

3. Subjects and Methods

3. 1. Research Design

A Quasi-experimental design (one group pre-post) was selected for conducting this study.

3. 2. Setting:

This study was conducted in Psychiatric Outpatient Clinics at Benha University Hospital, Benha Teaching Hospital and Psychiatric and Addiction Hospital in Benha at Qalyubia Governorate, Egypt.

3. 3. Sample:

The sample involves fifty six family caregivers and their children with autism (all children with autism) from the previously mentioned settings who were chosen using a purposive sampling technique. The study subjects were selected corresponding to the following

inclusion criteria: Both genders of family caregivers for children aged 3 to 12 years who have been medically diagnosed with autism, as well as the caregiver agree to contribute to the study. **Exclusion criteria:** Children with any other chronic problem and caregivers with substance abuse or unable to read or write.

3. 4. Tools: Four tools were using for Data collection:

Tool I: A questionnaire for structured interviews. It was designed by the researchers and contained four components:

a- Data of socio demographic characteristics for the caregiver of the autistic child that included 6 questions covered the following: The primary caregiver of the child with autism, age, occupation, educational level, residence, and income.

b- Personal characteristics of the autistic child which included age, gender, number of siblings, and order of the child.

c- Medical history of the disease that included level of autism, onset of the disease, family history of autism, and the family member who had autism.

d- Caregiver's knowledge regarding autism, contained 6 closed ended questions that covered, meaning, causes, signs & symptoms, levels of autism, prevention of autism, and types of treatment. **Scoring system:** The knowledge questions were weighted based on the items in each question, and the scores were determined based on the numbers of correct answers. The mean and standard deviations were calculated. Total knowledge score was evaluated in three categories as follows: Good: >75%, average: 50% - 75% and poor: < 50%.

Tool II: Katz Index of Independence in Activities of Daily Living (ADL): It was originally developed by **Katz, Down, Cash and Grotz** ⁽¹⁶⁾. It was adapted from **Wallace and Mary** ⁽¹⁷⁾. A full comprehensive assessment of daily living activities, the most applicable instrument to measure functional status as a measurement of the client's capability to achieve activities of daily living individually. The index ranks adequacy of performance in the six functions of toileting, continence, dressing, feeding, bathing, and transferring. **Scoring system:** Responses to questions were in the form of yes or no. Each answer with yes in the independence activity equals 1 score and each answer with no mean dependency and equal zero score. **Scoring system of independence in daily living activities was categorized as the following:** Score from 0: < 2 indicate very dependent. Score from 2: < 4 indicate dependent. Score from 4: < 6 indicate slightly independent. Score equals 6 indicate high independent.

Tool III: Zarit Burden interviewing questionnaire for family caregiver: It was designed by **Zarit, Reever and Bach-Peterson** ⁽¹⁸⁾. It was adapted from **Seng, Luo, Ng and Lim** ⁽¹⁹⁾. It provides a comprehensive assessment of both objective and subjective burden, is one of the most commonly used burden measures. It is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. It is assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. **Interpretation of Score: The result was categorized as the following** 0 - 21 little or no burden, 21 - 40 mild to moderate burden, 41 - 60 moderate to severe burden, 61 - 88 severe burden

Tool IV: General Self-Efficacy Scale (GSE): It was adapted from **Schwarzer and Jerusalem** ⁽²⁰⁾. It evaluates how one copes with daily activities and stressful life events through their self-perceived efficacy. It can be applied to both the general adult population and adolescents above the age of 12. This is a self-report measure consisting of 10 items, each rated on a 4-point scale: Not at all true (1); Hardly true (2); Moderately true (3); Exactly true (4). GSE scores range from 10 to 40, where the higher the score, the greater the individual's generalized self-efficacy. Scoring: The total score is calculated by finding the sum of all items and categorized as follow: Score from 10: < 20 indicate low self-efficacy. Score from 20: < 30 indicate moderate self-efficacy. Score from 30: 40 indicate high self-efficacy.

3. 4. 1. Validity and Reliability

Five experts from the fields of psychiatry/mental health nursing and community health nursing considered the content validity. The developed tool was reviewed for item relevance and concept measurement. Modifications were performed as needed. Cronbach's Alpha coefficient test was used to assess reliability, and it revealed that the tool contained relatively homogeneous items. The internal consistency of caregiver's knowledge regarding autism, Katz Index of Independence in Activities of Daily Living (ADL), Zarit Burden interviewing questionnaire for family caregiver, and General Self-Efficacy Scale (GSE) was 0.79, 0.81 , 0.80 and 0.82 respectively which these values are highly acceptable as well as acceptable levels of concurrent/ criterion validity.

3.5. Pilot Study

The pilot study was conducted on six caregivers of children with AD which illustrated 10% of the sample size from the same study setting, utilizing the interviewing questionnaire as a pre-test sheet, to examine the content, clarity, applicability, and consistency of the tools. No modifications were made, so the pilot study sample was included in the total sample.

3.6. Field Work

Data were gathered over the course of four months, commencing at the beginning of October 2021, and ending at the end of January 2022. The researchers conducted it at the predetermined settings. Each setting was visited one time per week from 9 a.m. to 12 mid-day. The researchers introduced themselves to each caregiver of a child with autism and offered a simple explanation of the purpose and nature of the work and consent to participate in the study. Each caregiver was then interviewed on an outpatient basis applying a structured interview questionnaire to collect sociodemographic characteristics of the caregivers and their children and to assess the medical history of illnesses related to the children and caregivers' knowledge about autism. At that time, estimation of independence in daily living activities of children with autism utilizing tool II. Then, consideration of caregivers' burden related to care providing applying tool III and caregivers' self-efficacy was assessed by tool IV. Prior to sessions and following the last session of the intervention, the questionnaires were completed twice. The average amount of time to complete the questionnaire was between 40 and 50 minutes. The collected information served as a baseline evaluation (pretest). After that, the participants were divided into eight groups for empowerment nursing intervention, each group composed of seven participants. The researchers interviewed 3-5 groups/week.

The Nursing Intervention:

The researchers created and applied nursing intervention to empower family caregivers. The overarching goal of the intervention was to raise participants' self-efficacy and lessen caregivers' burden by increasing participants' knowledge and understanding of the disease, empowering them against stressful situations, and providing them with suitable problem-solving techniques. The four steps of a nursing intervention are as follows:

***First Step:** To increase caregivers' understanding of autism. This step consisted of three sessions, each lasting 35-45 minutes. Every session allowed for open discussion among participants to share their experiences and ask questions. **First and Second Sessions:** Caregivers introduced themselves, and the researchers explained the overall goals, method of evaluation, and responsibilities of the subjects in program sessions. Also, they obtained information regarding the meaning of autism, causes of autism, signs & symptoms of autism, levels of autism, prevention of autism, and types of treatment. There were included skills and activities that researchers organized for alleviating the social and mental health effects of disease on caregivers. Apply strategies to decrease distracting child behaviors, discuss goals for dealing with their children, concepts of listening and empathy and acceptance of the necessity for support. Enhancing the caregivers' abilities in dealing with

their children and understanding the need to decrease unnecessary stimulus. These were discussed with the caregivers by applying supplementary educational tools such as lectures, posters, and group discussions. A guide booklet about autism was given to the attendees at the conclusion of this session. The researchers reviewed related literature before creating this booklet. **Third Session:** The contributors participated in questions and answers, counseling, and group discussions regarding the nature and diversity of needs and problems facing the caregiver of a child with autism. This session also focused on dealing with burdens, community support, motivation, and dealing with problem-solving strategies. Group discussion/reflection corresponding to the life abilities of the members, question-and-answer methods were used to learn about problem-solving techniques.

***Second Step:** To improve self-efficacy and reduce the burden of care, it comprised four sessions and was conducted through demonstration and re-demonstration training techniques and useful performance procedures. The period of each session was approximately 35-45 minutes. The researchers explained to caregiver the following skills and their implication, such as creating a schedule for a child with autism care and sticking to it, learning communication skills to match their children with autism, joining a support group with other parents having children with autism to exchange experience and feelings, practice self-management to be powerful and make meal planning, creation and diverse in food for caregiver and child with autism to ensure enough nutrients and power. The researchers trained caregivers to use relaxation strategies such as deep breathing and progressive muscle relaxation to alleviate stress and tension symptoms gained from burden of care for their children with autism. In front of the contributors, the researchers demonstrated the procedure of the skills. The participants were given the opportunity to learn skills through training and repetition until they were capable of performing them. Finally, participants' skills became completely efficient.

*** Third step:** Promote self-esteem and confidence by encouraging participation in learning activities. At this stage, caregivers were encouraged to participate in all teaching sessions aimed at identifying autism-related concerns. The caregivers were asked to re-demonstrate all learned skills in every group session in order to play an active and effective role in the care of their children with autism. This step was hold in one session.

*** Fourth step:** It contained of the evaluation strategy. At the beginning of each session, two verbal questions were asked to the caregivers from the previous session to gauge feedback. Additionally, caregivers were questioned about their ability to accurately indicate the relevant skills in order to assess their self-efficacy. Evaluation of self-esteem and self-confidence were evaluated by the level of collaboration in teaching. One month after the

last meeting, the researchers made phone calls to each caregivers to verify the recommended skills and to confirm that the materials provided were being applied. In the final evaluation, caregivers were administered the post-test by using the same pre-test tools to assess caregivers' level of knowledge, burden, and self-efficacy after the application of the intervention sessions.

3.7. Administrative Design

3.7. 1. Administrative Approval

The authoritative letters were obtained from the Faculty of Nursing Benha University to Managers of Psychiatric Outpatient Clinics at Benha Teaching Hospital, Benha University Hospital, and Psychiatric and Addiction Hospital in Benha to get permission for data collection.

3.7. 2. Ethical Consideration

All ethical issues are emphasized; Formal consent was obtained from each caregiver prior to conducting the interview and providing them with a brief orientation to the purpose of the study. They were also assured that all information gathered would be kept private and used solely for the purposes of the study. Caregivers had the option to withdraw from the study at any time and for any reason.

4. Statistical Analysis:

The Statistical Package for Social Sciences (SPSS) version 21 was utilized for data entry and statistical analysis. Descriptive statistics were used to present data in the form of frequencies and percentages for qualitative variables and mean and standard deviation for quantitative variables. Qualitative variables were compared using Chi-square test (χ^2) and matrix association to detect relation between the variables. A significant level value was considered when p- value <0.05 and a highly significant level value was considered when p- value <0.001 , while p- value >0.05 indicated non-significant result.

5. Results:

Table (1) reveals personal characteristics of the studied children with autism. It was cleared that 53.6% of children were aged 3 to <5 years with a mean age of 4.3 ± 1.8 years. As regards gender, 71.4% of children were male. Concerning the number of siblings, 44.6% of children had two siblings. Regarding the order of the child, 33.3% of them were ordered as the second child.

Table (2) shows socio-demographic characteristics of the studied caregivers. It was observed that 60.7% of the primary caregivers were mothers. 48.2% of caregivers were aged 30 to <40 years with a mean age of 31.45 ± 7.65 years. Concerning the occupational status, 51.8% of caregivers were working. Also, 39.3% of them had secondary education.

Regarding residence, 60.7% of caregivers lived in rural areas and 46.4% had enough monthly income.

Table (3) denotes that 58.9% of the studied children had severe autism. Regarding the age of disease onset, 57.1% of children diagnosed with autism from 1 to less than 3 years. Concerning the family history of autism, 41.1% of children had a family history of autism and 52.2% of them had an autistic uncle or aunt.

Table (4) reveals that improving the mean scores of studied Caregivers' knowledge after the program compared to before the program involving (the meaning of autism, causes of autism, signs and symptoms of autism, levels of autism, prevention of autism, and types of treatment for autism). There were highly statistically significant changes concerning the study sample's knowledge about autism between before and after implementation of the program at $P < 0.001$.

Figure (1) illustrates that 58.9 % of the studied caregivers had poor total knowledge regarding autism preprogram which decreased to 4% post program implementation. Also, pre-program 7.1% of caregivers had good knowledge that increase to 76.8% after implementation of program.

Table (5) reveals that improving mean score of studied children's independence in activities of daily living post program compared to preprogram including (bathing, dressing, toileting, transferring, continence and feeding). As well highly statistically significant changes regarding independence of daily activities were found between pre and post implementation of the program at $P < 0.001$.

Figure (2) displays that 28.6 % of the studied children with autism were very dependent on activities of daily living preprogram which decreased to 5.4% post program implementation. Also, preprogram 57.1% of the studied children were dependent that decreased to 26.8% post program implementation. While 14.3% of children were slightly independent pre/program that increased to 57.1% post program. Moreover, 0.0% of children were highly independent preprogram that increased post program to 10.7%.

Table (6) presents that improving mean change of studied caregivers' burden of care post program compared by preprogram. Also, highly statistically significant variations concerning burden of care were found between pre and post application of the intervention at $P < 0.001$.

Figure (3) shows that 0.0 % of the studied caregivers had the little total levels of burden during the care of children with autism preprogram which increased to 33.9% post program implementation. Also, preprogram 14.3% of the studied caregivers had a mild total levels of burden that increased to 57.1% post program implementation. While the percentage of

moderate total burden among the studied caregivers was 50% preprogram that decreased to 9% post program. Moreover, 35.7% of caregivers had severe total burden preprogram that decreased post program to 0.0%.

Table (7) denotes improving the mean changes of studied caregivers' self-efficacy post program compared by preprogram. Also, highly statistically significant variations concerning self-efficacy were found between pre and post implementation of the nursing intervention at $P < 0.001$.

Figure (4) displays that 60.7 % of caregivers had low self-efficacy levels during care of children with autism preprogram which decreased to 12.5% post program implementation. Also, preprogram 33.9% of the studied caregivers had a moderate level of self-efficacy that increased to 73.2% post program implementation. 5.4% of caregivers had a high self-efficacy preprogram that increased post program to 14.3%.

Table (8) clears that there was a negative correlation between the studied caregivers' knowledge, burden of care, self-efficacy, and the studied children's independency pre-program implementation with no statistically significant difference ($P > 0.05$). While post program, there were highly statistically significant positive correlations between caregivers' knowledge, burden of care, self-efficacy post program implementation at $P < 0.001$. Also, there was a statistically significant positive correlation between caregivers' knowledge and children with autism independency of daily activities ($P < 0.05$).

Table (1): Distribution of Personnel Characteristics for the Studied children (n=56)

Personnel characteristics	Frequency	%
Age in years		
3-<5	30	53.6
5-7	26	46.4
Mean \pm SD	4.3 \pm 1.8	
Gender		
Male	40	71.4
Female	16	28.6
Number of siblings		
No	15	26.8
1	11	19.6
2	25	44.6
≥ 3	5	8.9
Order of the child		
1st	15	26.3
2nd	19	33.3
3rd	16	28.1
≥ 4 th	7	12.3

Table (2): Distribution of the Socio-Demographic Characteristics of the Caregivers of Children with Autism (n=56)

Socio-demographic characteristics	Frequency	%
The primary caregiver of the child with autism		
Father	12	21.4
Mother	34	60.7
Grandma	10	17.9
Age		
<20 years	8	14.3
20-<30	14	25.0
30-<40	27	48.2
≥40	7	12.5
Mean±SD	31.45±7.65	
Occupation		
Working	29	51.8
Not working	27	48.2
Educational level		
Cannot read or write	6	10.7
Basic education	20	35.7
Secondary education	22	39.3
University education	8	14.3
Residence		
Rural	34	60.7
Urban	22	39.3
Income		
Not enough	25	44.6
Enough	26	46.4
Enough and save	5	8.9

Table (3): Distribution of Studied Children According to Medical History of Disease (n=56)

Variables	Frequency	%
Level of autism		
Level1 (mild) need little support	10	17.9
Level 2 (moderate) need moderate support	13	23.2
Level 3(severe) need a great deal of support	33	58.9
Onset of the disease		
Less than one year	8	14.3
1-<3 years	32	57.1
≥3 years	16	28.6
Family history of autism		
Yes	23	41.1
No	33	58.9
The family member who had autism (n=23)		
Father/mother	2	8.7
Brother/sister	9	39.1
Uncle/aunt	12	52.2

Table (4): Mean Change in Knowledge of Studied Caregivers Regarding Autism at Pre/Post Program (n=56)

Items	No.	Pre-program	Post-program	Paired t test	P value
		Mean \pm SD	Mean \pm SD		
Meaning of autism	7	2.1429 \pm .77292	5.5179 \pm 1.22089	- 51.701	0.000
Causes of autism	6	2.7679 \pm .97218	4.3214 \pm .95550	-7.686	0.000
Signs and Symptoms of autism	9	3.4107 \pm 1.10826	7.6607 \pm 1.19509	- 21.487	0.000
Levels of autism	3	1.2857 \pm .45584	2.4821 \pm .50420	- 22.333	0.000
Prevention of autism	4	1.5000 \pm .50452	3.4821 \pm .53906	- 14.324	0.000
Types of Treatments	6	2.1429 \pm .74903	4.8571 \pm .74903	- 13.559	0.000
Total knowledge score	35	13.2500\pm1.88052	28.3214\pm2.25717	- 55.187	0.000

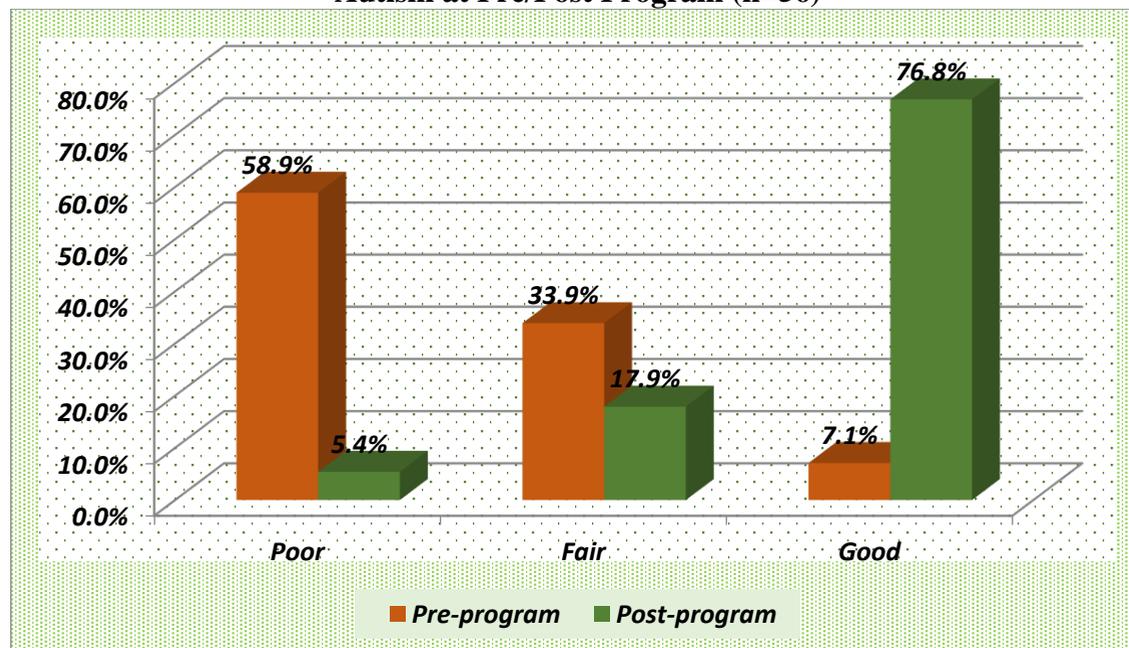
Figure (1): Percentage Distribution of Studied Caregivers' Knowledge Regarding Autism at Pre/Post Program (n=56)

Table (5): Mean Change of Studied Children' Independence in Activities of Daily Living at Pre/Post Program (n=56)

Items	Pre-program	Post-program	Paired t test	P value
	Mean \pm SD	Mean \pm SD		
Bathing	2.5179 \pm .50420	4.8036 \pm 1.13490	-14.233	0.000
Dressing	2.9107 \pm .79262	5.1071 \pm .80178	-12.261	0.000
Toileting	3.4643 \pm 1.00841	4.6964 \pm .73657	-6.191	0.000
Transferring	2.6786 \pm .50837	5.6250 \pm .77606	-55.000	0.000
Continece	2.6429 \pm .72434	5.2143 \pm .67995	-18.166	0.000
Feeding	2.3571 \pm .48349	4.6786 \pm 1.14586	-15.599	0.000
Total independence score	16.5714 \pm 1.88638	31.5179 \pm 2.10619	-51.360	0.000

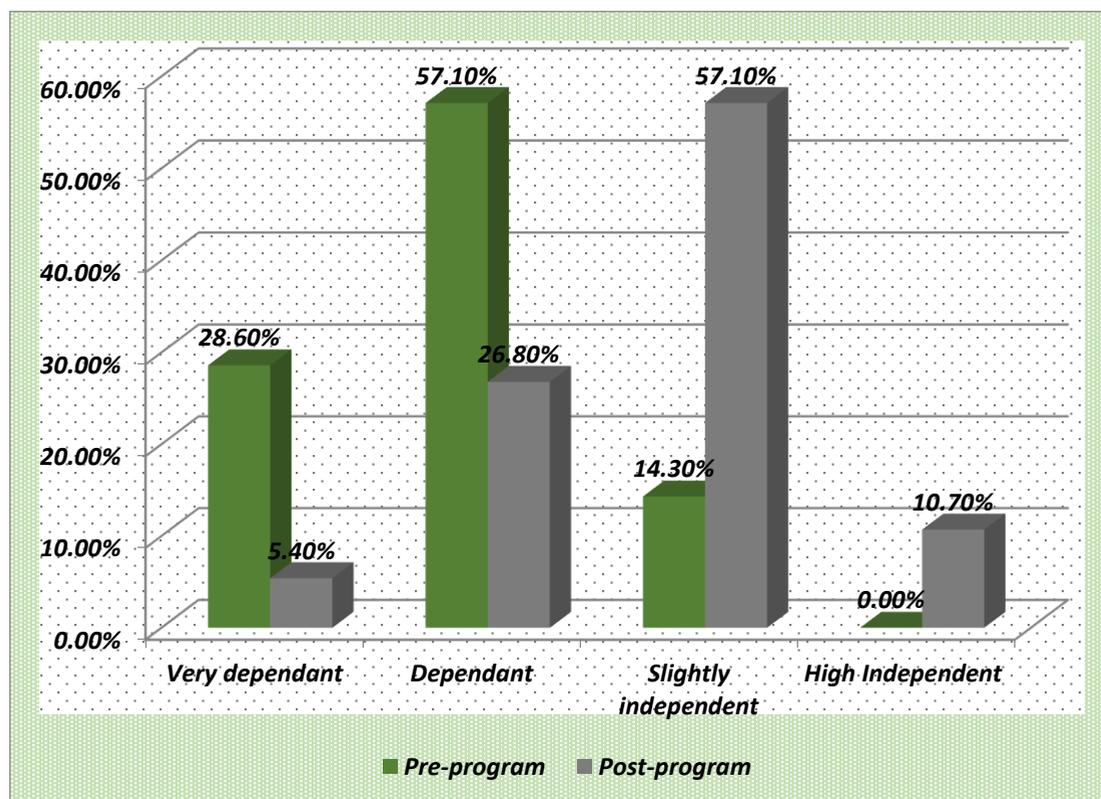
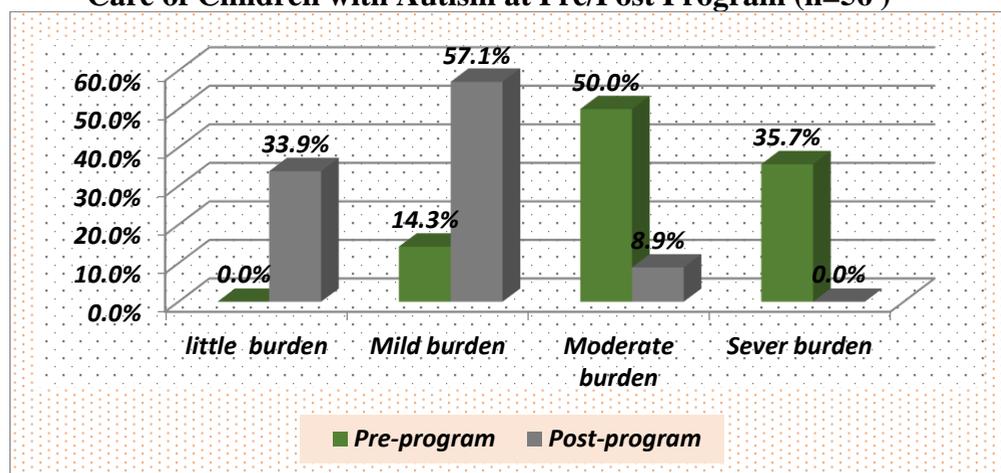
Figure (2): Percentage Distribution of Studied Children's Level of Independence in Daily Living Activities at Pre/Post Program (n=56)

Table (6): Mean Burden of Studied Caregivers Regarding Care of Children with Autism at Pre/Post Program (n=56)

Items	Pre-program	Post-program	Paired t test	P value
	Mean \pm SD	Mean \pm SD		
1- Do you feel that your relative asks for more help than he/she needs?	3.1250 \pm .33371	1.0357 \pm .76192	-19.178	.000
2- Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	3.1429 \pm .35309	1.2857 \pm .67995	-17.981	.000
3- Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	3.1607 \pm .37059	1.2679 \pm .75054	-15.954	.000
4- Do you feel embarrassed over your relative's behavior?	3.5893 \pm .53178	.7857 \pm .77961	-20.284	.000
5- Do you feel angry when you are around your relative?	3.7500 \pm .43693	1.2500 \pm .61051	-25.331	.000
6- Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	3.6429 \pm .51974	1.1250 \pm .76426	-21.070	.000
7- Are you afraid what the future holds for your relative?	3.6250 \pm .52440	1.3214 \pm .60624	-20.254	.000
8- Do you feel your relative is dependent on you?	2.9821 \pm .40412	1.0893 \pm .74533	-16.335	.000
9- Do you feel strained when you are around your relative?	3.6607 \pm .47775	1.3214 \pm .71623	-20.909	.000
10- Do you feel your health has suffered because of your involvement with your relative?	3.7143 \pm .45584	1.5357 \pm .68661	-20.091	.000
11- Do you feel that you don't have as much privacy as you would like because of your relative?	3.7500 \pm .43693	1.1786 \pm .74118	-21.107	.000
12- Do you feel that your social life has suffered because you are caring for your relative?	3.7321 \pm .44685	1.1071 \pm .70527	-23.290	.000
13- Do you feel uncomfortable about having friends over because of your relative?	3.1250 \pm .33371	1.3750 \pm .58968	-19.621	.000
14- Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	3.7857 \pm .41404	1.0893 \pm .58081	-32.022	.000
15- Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	3.1071 \pm .31209	1.0000 \pm .73855	-18.184	.000
16- Do you feel that you will be unable to take care of your relative much longer?	3.1071 \pm .31209	1.1071 \pm .67900	-19.621	.000
17- Do you feel you have lost control of your life since your relative's illness?	3.6429 \pm .48349	1.4107 \pm .70780	-18.679	.000
18- Do you wish you could leave the care of your relative to someone else?	3.8036 \pm .40089	1.1607 \pm .73303	-23.530	.000
19- Do you feel uncertain about what to do about your relative?	3.8036 \pm .40089	1.2500 \pm .69413	-23.672	.000
20- Do you feel you should be doing more for your relative?	3.7321 \pm .44685	1.3036 \pm .60059	-24.725	.000
21- Do you feel you could do a better job in caring for your relative?	3.7857 \pm .41404	1.2143 \pm .67995	-24.578	.000
22- Overall, how burdened do you feel in caring for your relative?	3.7500 \pm .43693	1.4643 \pm .50324	-24.221	.000
Total	77.5179\pm4.54469	26.6786\pm7.50299	-40.726	.000

Figure (3): Percentage Distribution of Studied Caregivers' Level of Burden During Care of Children with Autism at Pre/Post Program (n=56)**Table (7): Mean Change of Studied Caregivers' Self-Efficacy During Care of Children with Autism at Pre/Post Program (n=56)**

Items	Pre-program		Post-program	Paired t test	P value
	Mean \pm SD		Mean \pm SD		
1. I can always manage to solve difficult problems if I try hard enough	2.0893 \pm .28774		3.1429 \pm .94250	-8.367	.000
2. If someone opposes me, I can find the means and ways to get what I want.	2.0714 \pm .25987		3.4821 \pm .73833	-14.402	.000
3. It is easy for me to stick to my aims and accomplish my goals.	2.0536 \pm .22721		3.4107 \pm .78107	-12.757	.000
4. I am confident that I could deal efficiently with unexpected events.	2.1429 \pm .35309		3.3036 \pm .82945	-10.512	.000
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.	2.0357 \pm .18726		3.5357 \pm .76192	-14.277	.000
6. I can solve most problems if I invest the necessary effort.	2.1429 \pm .35309		3.3214 \pm .87609	-9.230	.000
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	2.0179 \pm .13363		3.5357 \pm .78542	-14.043	.000
8. When I am confronted with a problem, I can usually find several solutions.	2.0893 \pm .28774		3.3036 \pm .87219	-9.998	.000
9. If I am in trouble, I can usually think of a solution	2.0536 \pm .22721		3.2857 \pm .86790	-10.814	.000
10. I can usually handle whatever comes my way.	2.0179 \pm .13363		3.6964 \pm .46396	-24.709	.000
Total	20.7143\pm1.34454		34.0179\pm5.11145	-19.090	.000

Figure (4): Percentage Distribution of Studied Caregivers' Level of Self-Efficacy During Care of Children with Autism at Pre/Post Program (n=56)

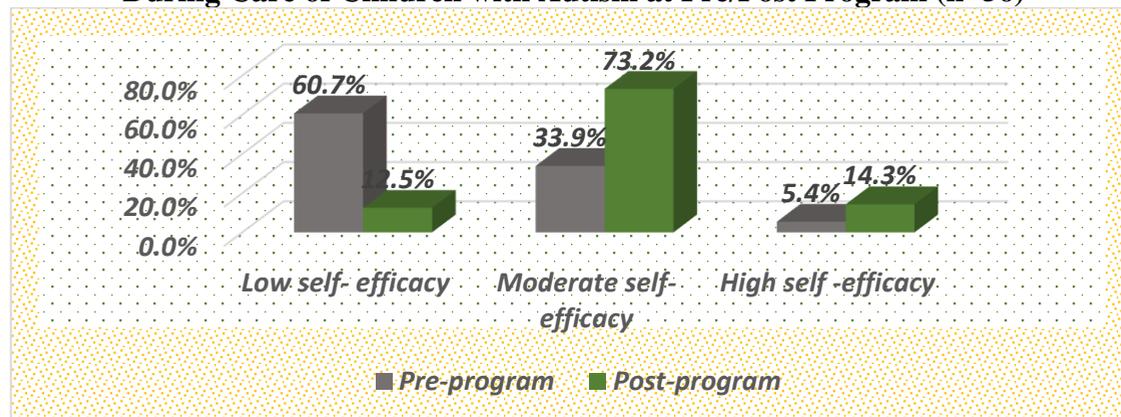


Table (8): Correlation Between Studied Caregivers' Knowledge, Self-Efficacy, Burden of Care, and Independence of Children with Autism at Pre/Post-Program.

Knowledge	Independency		Burden		Self-efficacy	
	r	P value	r	P value	r	P value
Pre-program	0.187	>0.05	0.062	>0.05	0.083	>0.05
Post-program	0.342	<0.05*	-0.452	<0.001**	0.472	<0.001**

6. Discussion:

Autism is a severe psychiatric disorder characterized by impairments in three domains social interaction, communication, and repetitive stereotyped behavior. Symptoms often begin before the age of three years and persist throughout the lifespan. Autism is usually a severely disabling condition that requires lifelong adult supervision. Early recognition of behavior associated with autism is critical to implement appropriate intervention and family involvement⁽²¹⁾. Also, children with AD have a high rate of comorbid diagnoses, as well as additional emotional and behavioral challenges, and generally poor long-term consequences. Moreover, caregivers of children with AD also report challenges such as mental disorders and physical illness symptoms, low satisfaction of life, and diminished life quality⁽¹³⁾.

Caregivers burden regarding individuals with chronic disorders is explained as a condition resulting from dealing with physical dependence and mental incapacity of the person in require of attention and care⁽²²⁾. There are several consequences of a caregiver's burden, such as mental health issues such as anxiety, depression, stress, and burnout disorder, poor physical health such as diabetes and high blood pressure), and other negative things such as

social isolation and family dysfunction, excessive use of health facilities, and economic difficulties^(23, 24). Self-efficacy for parenting is important for positive management outcomes. Parents of children with AD might be at risk for depressed parenting self-efficacy; These parents may have a greater risk for poor management of their children. It is essential for the health care provider to be aware of this as a potential barrier to success in therapy. Because of these factors, there is a requirement to help these families with a family empowerment model to support them and their children⁽⁸⁾. Hence, the present study was recognized to evaluate the effectiveness of nursing intervention based on family empowerment model on burden of care and self-efficacy for caregiver of children with autism disorder.

The present study outcomes indicated that more than half of the studied children were aged 3 to <5 years and more than two-thirds are males. The outcome of the study was inconsistent with that of another study by **Yousef et al.**⁽²³⁾ revealed that more than half of the sample was from 2 - 3 years. While these results are consistent with those of **Yousef et al.**⁽²⁵⁾ indicated that three-quarters of the children with autism were males. This result also was similar to **Zemantic et al.**⁽²⁶⁾ who revealed that the majority of the studied sample were males. According to **Papadopoulos**⁽⁴⁾ found that more boys than girls were diagnosed with autism disorder.

The present study findings illustrated that three-fifths of the primary caregivers were mothers and nearly one-half of them were aged 30 to <40 years with a mean age of 31.45 ± 7.65 years. This study also indicated that greater than half of primary caregivers living in rural areas, and this explains the result that more than half of the caregivers were mothers because it's the nature of the situation and living in the countryside, the mothers stay the only ones who caregiving for their children and all family members. These results agreed with **Smart**⁽⁶⁾ who found that almost all of the participants were female. On the same line, **Rahgoi et al.**⁽¹¹⁾ illustrated that the mean age of mothers in the studied group (35.7 ± 5.6 years) and the control group (36.1 ± 6.4 years).

The current study results showed that more than one-half of caregivers were working and 46.4% of them had enough monthly income. This result may be due to the need for money to cover the cost of treatment so that the caregivers were working. The result was in the same line with **Zemantic et al.**⁽²⁶⁾ who found that more than one-half of primary caregivers were employed and had a high monthly income. While the previous findings are incongruent with those of **Teymouri et al.**⁽²⁷⁾ who revealed that the majority of primary caregivers (mothers) were house wives.

The present study results revealed that nearly three-fifths of the studied children had severe autism, and also nearly three-fifths of those children diagnosed with autism from one to less than three years. This result may be due to the child growth and development not observed closely for early signs of AD, and lack of the care giver's knowledge about the disease. According to the **CDCAD** ⁽¹²⁾ which revealed that knowing a family health history of AD can help the child's doctor take better care of the child. The doctor may check the child more carefully for early signs of AD and might refer him to a specialist for additional evaluation. When a child is carefully examined, signs of AD can sometimes be observed at eighteen months or younger. This finding is in contrast with **Yousef et al.** ⁽¹⁹⁾ indicated that nearly two-thirds of children with autism had mild to moderate AD, and more than one-third had severe AD. This result also in contrast with **Smart** ⁽⁶⁾ who illustrated that the AD children were diagnosed on average at around age of five years.

The results of the current study indicated that over than two-fifths of the children had a history of family autism and more than one-half of them had uncle or aunt with autism. This results mean that, if you have a child or other family member with AD, you are more likely to have another child with AD, specifically if you have a daughter with AD or more than one child with AD. Other members of your family are also more likely to have a child with AD. The outcomes of the present study were corresponded with **Hansen et al.** ⁽²⁸⁾ who found that a family having health history of AD becomes further possible to have another child with AD. Which clarified by the outcome of the present study.

The present study showed that improving mean scores of the studied caregivers' knowledge post-program compared to pre-program and highly statistically significant differences concerning knowledge were found between before and after implementation of the program with $P < 0.001$. This result might be connected with the importance, effectiveness, and success of the program. This result agreed with **Casagrande and Ingersoll** ⁽¹³⁾ who found that the enrichments in knowledge and attitudes of parent's concerning diagnosis of their child's and suitable treatments, special education of law or human rights to care, and support approaches or particular abilities.

The findings of the present study indicated that improving the mean and standard deviation of the studied children with autism independence in activities of daily living post-program compared by pre-program. This result might be related to the importance of the caregivers' needs to help and discuss every issue about their children's need in an effective way as done by researchers during application of the present program. The results of the present study were congruent with **Toelken** ⁽²⁹⁾ who illustrated that the children with autism showed increased independence across all tasks. While the outcome is reversed with **Kilincaslan et**

al. ⁽³⁰⁾ found that scores of the children with AD were low in DLA especially in personal hygiene, dressing, safety, and interpersonal skills.

The current study finding indicated improving mean score of studied caregivers' burden of care post-program compared by pre intervention. This finding may be due to this type of intervention that can led to the collaboration between family caregivers and health team to create improvement of the knowledge, ability and skills in the family which decrease the burden of care. This result is in the same line with **Rahgoi et al.** ⁽¹¹⁾ who indicated that intervention based on empowerment led to diminishing the care burden in mothers of children with AD.

The present study result clarified improving mean score of studied caregivers' self-efficacy post program compared by preprogram. Also, there were highly statistically significant differences regarding all self-efficacy items between pre and post program implementation. This result might be because of the importance and the effectiveness of nursing intervention which improve the health status, self-efficacy, and quality of life for parents and leads to enhance in general health of their children with autism. This result is in the same line with **Smart** ⁽⁶⁾ who found that there is a higher parenting self-efficacy among parents of the children with autism who supported and empowered by their family, friends, and the health team.

The current study results indicated that a highly statistically significant positive correlation were detected between caregivers' knowledge, burden of care, and self-efficacy post program implementation. From our opinion this result might be because of increasing mother's experience which help them in reducing burden of care and enhance their self-efficacy to prevent challenging behavior. This result is congruent with that of **Rahgoi et al.** ⁽¹¹⁾ showed that positive effect in training program for increasing the mother's knowledge which reduce the burden of care and strengthening their self-efficacy.

The present study result clarified that a statistically significant positive correlation was noticeable between caregivers' knowledge and children' independence. This result may be a cause of the importance of increasing mother's awareness and knowledge regarding autism which help them to prevent the children's challenging behavior and helping them to be more independent. This finding was matched with **Toelken** ⁽²⁹⁾ who indicated that there was encouraging independence among children and adults in all daily living activities after the training program.

Based on the findings, implementing the program assists parents of children with AD to identify their weaknesses, and feel strong enough to change their situation. This feeling of ability is accomplished by gaining information, obtaining support, and life skills

enhancement. Also, caregivers may respond to their children's reactions, and gain an opportunity to ensure their children's mental health and physical safety. Therefore, caregivers develop, maintain, and enhance opportunities for their children's social participation and promote their development and growth. Additionally, enhancing caregivers' self-efficacy to avoid challenging behavior, and enhance both caregivers and children's mental health as well as avoid harm and neglect. Moreover, their attendance in the program discussions focused on their requirements and transferring their knowledge to one of their family members improves their caring performance and declines their caregiving burden and improves their self-efficacy.

7. Conclusion:

Based on the findings of the current study concluded that nursing intervention based on family empowerment model showed positive impact and effective improvement in self-efficacy of parents of children with autism. Also, the caregivers decreased the level of burden from care of their children with autism disorder after implementing nursing intervention. As well as the caregivers' knowledge regarding autism improved after utilized of the nursing intervention program. Which verifies the hypothesis of the research.

8. Recommendation:

Corresponding to the results and conclusion of the present study, these following recommendations are suggested:

- Application of nursing intervention based on family empowerment model in all governorates of Egypt in order to improve the awareness of parents and caregivers regarding autism, burden of care, and self-efficacy.
- There is a requirement of the development of community mental health as primary health care services that will focus not only on the management of children with autism but also on meeting the mental health needs of caregivers.
- Locally based family support groups should be established to assist and advocate for caregivers of children with autism to promote their mental health and physical well-being in the community.
- Further research: Replication of the present study on larger representative probability sample size in various Egypt governorates is recommended to achieve more generalization of the results.

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References

1. Naji W, Waheeb M, & Hamza D. Autism spectrum disorder: Review article. *Medico Legal Update* 2020; 20(2): 320 - 325. Available at: <https://doi.org/10.37506/mlu.v20i2.1123>.
2. Hyman S, Levy S, Scott M, & Myers S. Identification, evaluation, and management of children with autism spectrum disorder clinical report. *Pediatric Collections: Autism Spectrum Disorder* 2020; 145 (1): 6 -74. Available at: <https://doi.org/10.1542/9781610024716-part01-ch002>.
3. Jain A, Ahmed N, Mahour P, Agarwal V, Chandra K, & Shrivatav N. Burden of care perceived by the principal caregivers of autistic children and adolescents visiting health facilities in Lucknow City. *Indian J Public Health* 2021; 63(4): 282 - 287. Available at: <http://www.ijph.in> on Thursday, July 1, 2021, IP: 254.253.25.69.
4. Papadopoulos D. Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences* 2021; 11(3): 309. Available at: <https://doi.org/10.3390/brainsci11030309>.
5. Amer H, Salama A, El Feshawy R, and EL-nagar S. Effect of family empowerment nursing intervention on caregivers' strains and health-related quality of life of children with hepatitis C, *Egyptian Journal of Health Care, EJH* 2021; 12(1): 487.
6. Smart L. Parenting self-efficacy in parents of children with autism spectrum disorders. Theses and Dissertations. Brigham Young University. 2016: 5842. Available at: <https://scholarsarchive.byu.edu/etd/5842>.
7. Kabashima Y, Tadaka E, & Arimoto A. Development of the parental self-efficacy scale for preventing challenging behaviors in children with autism spectrum disorder. *PLoS ONE* 2020; 15(9): 1-14. Available at: <https://doi.org/10.1371/journal.pone.0238652>.
8. Shoghi M, Shahbazi B, & Seyedfatemi N. The effect of the family-centered empowerment model (FCEM) on the care burden of the parents of children diagnosed with cancer. *Asian Pac J Cancer Prev.* 2019; 20(6):1757-1764.
9. Severinsen L, Stiegler J, Nissen-Lie H, Shahar B, & Zahl-Olsen R. Effectiveness of emotion-focused skills training for parents: study protocol for a randomized controlled trial in specialist mental health care. *BMC Psychiatry.* 2022; 22(1): 453.
10. Hakim A, Palizban E, & Angali K. The effect of family-centered empowerment model on the Level of parents' knowledge of children with ostomy. *JPEN* 2015; 1 (4): 22 - 31.
11. Rahgoi A, Sojoodi T, Fallahi Khoshknab M, Rahgozar M, & Shahshahani S. Effects of empowerment program on the burden of care in mothers of children with Phenylketonuria. *Iran J Child Neurol.* 2019; 13(2): 53 - 60.
12. Centers for Disease Control and Prevention. Autism spectrum disorder, family health history, and genetics. CDC 2022. Available at : <https://www.cdc.gov>.
13. Casagrande K, & Ingersoll B. Improving service access in ASD: A systematic review of family empowerment interventions for children with special healthcare needs. *Rev J Autism Dev Disorder* 2021; 8 (2): 170 - 185. Available at: <https://doi.org/10.1007/s40489-020-00208-9>.
14. Egypt's Ministry of Social Solidarity. Egyptians estimated to have autism. 2022 Available at: <https://english.ahram.org.eg/News/463963.aspx>. Accessed on: 25/8/2022.
15. Gobrial E. The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Soc. Sci.* 2018; 7(8): 133. Available at: <https://doi.org/10.3390/socsci7080133>.

16. Katz S, Down T, Cash H, & Grotz R. Progress in the development of the index of ADL. *The Gerontologist* 1970; 10(1): 20-30.
17. Wallace M. & Mary S. Katanz index independence in activities of daily living. *Urologic Nursing* 2007; 27(1): 93 – 94.
18. Zarit S, Reeve K, & Bach-Peterson J. Zarit Caregiver burden interview. *PsycTESTS Dataset* [Preprint] 1980. Available at: <https://doi.org/10.1037/t41877-000>.
19. Seng B, Luo N, Ng W, and Lim J. Validity and reliability of the zarit burden interview in assessing caregiver burden, *Annals of the academy of medicine* 2010; 39(10): 758 - 763.
20. Schwarzer R, & Jerusalem M. Generalized self-efficacy scale. In J. Weinman, S. Wright, & M. Johnston, *Measures in health psychology: A user's portfolio. Causal and control beliefs*, Windsor, UK: NFER-NELSON 1995: 35-37.
21. Shrestha R, Barbaro J, & Dissanayake C. Changes in knowledge on the signs of autism in young children (11–30 Months) among female community health volunteers in Nepal, *journal of autism and developmental disorders* 2021; 34(7): 1 - 21.
22. Misquiatti A, Brito M, Ferreira F, & Junior F. Family burden and children with autism spectrum disorders: Perspective caregivers. *Rev. CEFAC*. 2015;17(1):192 – 200.
23. Ampalam P, Gunturu S, & Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry* 2012; 54(3): 239 -243.
24. Desouki H, El-Azzab S, & Abu-Salem E. An educational intervention to reduce the burden on family caregivers of patients with schizophrenia. *SSRG International Journal of Nursing and Health Science* 2019; 5(1):18 - 26. Available at: <http://www.internationaljournalsrsg.org>.
25. Yousef A, Roshdy E, & Abdel Fattah N. Prevalence, and risk factors of autism spectrum disorders in preschool children in Sharkia, Egypt: A community-based study. *Middle East Curr Psychiatry* 2021; 28: 36. Available at: <https://doi.org/10.1186/s43045-021-00114-8>.
26. Zemantic P, Kurtz-Nelson E, & Barton H. Family empowerment: Predicting service utilization for children with autism spectrum disorder. *J Autism Dev Disord* 2021. Available at: <https://doi.org/10.1007/s10803-021-05329-6>.
27. Teymouri F, Alhani F, & Kazemnejad A. The effect of family-centered empowerment model on self-efficacy and self-esteem of children with asthma. *Preventive Care in Nursing & Midwifery Journal* 2017; 7: 18 - 26.
28. Hansen S, Schendel D, Francis R, Windham G, Bresnahan M, Levine S, Reichenberg A, Gissler M, Kodesh A, Bai D, Yip BHK, Leonard H, Sandin S, Buxbaum JD, Hultman C, Sourander A, Glasson E, Wong K, Öberg R, & Parner E. Recurrence risk of autism in siblings and cousins: A multinational, population-based study. *J Am Acad Child Adolesc Psychiatry* 2019; 58(9): 866 - 875. Available at: <https://doi.org/10.1016/j.jaac.2018.11.017>.
29. Toelken S, & Miltenberger R. Increasing independence among children diagnosed with autism using a brief embedded teaching strategy. *Behavioral Interventions* 2012; 27(2): 93 - 104. Available at: <https://doi.org/10.1002/bin.337>.
30. Kilincaslan A, Kocas S, Bozkurt S, Kaya I, Derin S, & Aydin R . Daily living skills in children with autism spectrum disorder and intellectual disability: A Comparative Study from Turkey. *Research in Developmental Disabilities* 2019; 85: 187 - 196. Available at: <https://doi.org/10.1016/j.ridd.2018.12.005>.

الملخص العربي

فعالية التدخل التمريضي بناءً على نموذج تمكين الأسرة على عبء الرعاية والكفاءة الذاتية لمقدمي الرعاية للأطفال المصابين باضطراب التوحد"

المقدمة: يعتبر التوحد أحد أكثر الاضطرابات انتشاراً، الذي يتسم بقصور في مهارات التفاعل الاجتماعي، اللعب، بالإضافة إلى سلوكيات نمطية متكررة، كما يمثل التوحد إعاقة نمائية متداخلة ومعقدة، اضطراباً في التفكير والإدراك، والتواصل اللفظي وغير اللفظي، ومهارات رعاية الذات لذا يعد تشخيص الطفل بالتوحد بمثابة صدمة للوالدين بل لجميع أفراد الأسرة، لما تحتاجه من خدمات، وما تعانيه من مشكلات و عبء الرعاية الصحية والنفسية والكفاءة الذاتية.

الهدف من الدراسة: تهدف هذه الدراسة إلى تقييم فعالية التدخل التمريضي بناءً على نموذج تمكين الأسرة على عبء الرعاية والكفاءة الذاتية لمقدمي الرعاية للأطفال المصابين باضطراب التوحد. تحقق ذلك من خلال الأهداف التالية :-

- تقييم مستوى المعرفة فيما يتعلق بالتوحد بين مقدمي الرعاية للأطفال المصابين باضطراب التوحد.
- تقييم مستوى الاستقلالية لدى الأطفال المصابين باضطراب التوحد.
- تقييم مستوى العبء لدى مقدمي الرعاية للأطفال المصابين باضطراب التوحد.
- تقييم مستوى الكفاءة الذاتية لدى مقدمي الرعاية للأطفال المصابين باضطراب التوحد.
- تصميم وتنفيذ برنامج فعالية التدخل التمريضي بناءً على نموذج تمكين الأسرة على عبء الرعاية والكفاءة الذاتية لمقدمي الرعاية لطفل مصاب باضطراب التوحد.
- تقييم فعالية التدخل التمريضي بناءً على نموذج تمكين الأسرة على عبء الرعاية والكفاءة الذاتية لمقدمي الرعاية للأطفال مصاب باضطراب التوحد.

فرضية البحث:

- سيتم تحسين معرفة مقدمي الرعاية فيما يتعلق بالتوحد بعد إجراء التدخل التمريضي.
- سيتم تقليل مستوى العبء بين مقدمي الرعاية للأطفال المصابين باضطراب التوحد بعد تنفيذ التدخل التمريضي.
- سوف يحصل مقدمو الرعاية للأطفال المصابين باضطراب التوحد مستوى عالٍ من الكفاءة الذاتية بعد تنفيذ البرنامج.

نوع البحث: استخدمت هذه الدراسة تصميمًا شبه تجريبي (قبل/ بعد اختبار مجموعة واحدة).

منهجية البحث: أجريت هذه الدراسة في العيادات الخارجية للطب النفسي بكلية من مستشفى بنها الجامعي، ومستشفى بنها التعليمي، ومستشفى الطب النفسي والإدمان في بنها بمحافظة القليوبية. علي عينة هادفة مكونة من 56 من مقدمي الرعاية الأسرة وأطفالهم المصابين بالتوحد. تم تطبيق البرنامج من خلال 8 جلسات. في الفترة من بداية أكتوبر 2021 حتى نهاية يناير 2022. **ادوات البحث:** كما تم استخدام 4 ادوات: **الاداة الأولى: استمارة استبيان لتقييم:** الخصائص الاجتماعية والديموغرافية لمقدمي الرعاية، والخصائص الشخصية للطفل المصاب بالتوحد، والتاريخ الطبي للمرض، ومعرفة مقدمي الرعاية فيما يتعلق بالتوحد، **الاداة الثانية** مؤشر كاتز للاستقلال في أنشطة الحياة اليومية، **الاداة الثالثة** استبيان مقابلات زاريت بوردن لتقييم عبء الرعاية، **والاداة الرابعة:** مقياس الكفاءة الذاتية العام.

النتائج: أظهرت نتائج الدراسة أن هناك ارتباطات إيجابية ذات دلالة إحصائية عالية بين المعرفة لمقدمي الرعاية، و عبء الرعاية، والكفاءة الذاتية بعد تنفيذ البرنامج ($P < 0.001$). أيضاً، كانت هناك علاقة إيجابية ذات دلالة إحصائية بين معرفة مقدمي الرعاية واعتماد الأطفال ذوي التوحد على انفسهم ($P < 0.05$).

الخلاصة: خلصت النتائج إلى أن التدخل التمريضي بناءً على نموذج التمكين الأسري أظهر تأثيراً إيجابياً وتحسناً فعالاً في عبء الرعاية والكفاءة الذاتية لأباء الأطفال المصابين بالتوحد. بالإضافة إلى تحسن معرفة مقدمي الرعاية فيما يتعلق بالتوحد بعد الاستفادة من برنامج التدخل التمريضي.

التوصيات: وصت الدراسة بتطبيق التدخل التمريضي على أساس نموذج تمكين الأسرة في جميع محافظات مصر من أجل تحسين وعي الأباء ومقدمي الرعاية فيما يتعلق بالتوحد وعبء الرعاية والكفاءة الذاتية..

الكلمات المفتاحية: التوحد، عبء الرعاية، مقدمي الرعاية، تمكين، الكفاءة الذاتية.