EAS Journal of Nursing and Midwifery

Abbreviated Key Title: EAS J Nurs Midwifery ISSN: 2663-0966 (Print) & ISSN: 2663-6735 (Online) Published By East African Scholars Publisher, Kenya

Volume-5 | Issue-5 | Sep-Oct -2023 |

Original Research Article

OPEN ACCESS

DOI: 10.36349/easjnm.2023.v05i05.005

Effect of Nursing Intervention Program for Parents Caring of Children with Autism Regarding to their Daily Activities

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> **Article History** Received: 20.09.2023 Accepted: 26.09.2023 Published: 18.10.2023

Journal homepage: https://www.easpublisher.com



Abstract: Background: Caring for children with Autism spectrum disorder regarding their daily activities is challenging for parents. Aim: This study aimed to assess the effect of nursing intervention program for parents caring of children with autism regarding to their daily activities. Design: A quasi-experimental design used in the present study one group (pre\ posttest). Setting: The study was carried out in Children and Adolescent Psychiatric Outpatient Clinics in Suez Canal University Hospital (SCUH) & Outpatient Clinic for children psychiatric treatment at Abbasia Mental Health Hospital affiliated to General Secretariat of Mental Health and Addiction in Cairo governorate. Subjects: Study subjects included all available (50) parents have autistic children from the mentioned settings. Tool: A Structured Interview questionnaire included three parts; Part 1: Socio-demographic characteristics of parents, Part 2: Characteristics of the studied children with autism, Part 3: Assessment of parents' knowledge & Part 4: Assessing the parents' reported practice regarding to self-reliance during their children daily activities. Results: revealed that more than two thirds, (68%) of parents were mothers. More than two thirds (78%) of father's age was ranged from 30-50 years. More than two thirds (88%) of studied parents' identification of autism, causes, predictors and symptoms of autism and management of autism post program implementation compared to preprogram *Conclusion*: there was a statistically significant improvement in total knowledge about autism of the parents caring of children with autism pre and post program implementation. *Recommendations:* Replication of the same study on larger probability sample at different geographical locations for data generalizability.

Keywords: Autism, Children, Daily Activities, Nursing intervention Program, Knowledge, Reported practice and Dependence.

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INTRODUCTION

Autism Spectrum Disorder (ASD); Neurodevelopmental Disorders (NDD) is an umbrella term for conditions arising from disruptions or extreme variations of the maturation, architecture, and functioning of the developing brain. NDD affect cognition and behavior, persistently reduce functional adaptive skills and quality of life, and are associated with increased mortality (Rice *et al.*, 2022).

The Daily Living Skills (DLS) of children with ASD are similarly deficient and often considerably below their chronological age. These children exhibit basic deficits in social-communication, restricting and repetitive behaviors, and interests. The DLS that are necessary for everyday independence at home, school, and in the community are commonly learned by particular ages during a person's development. For example, most 2-3-year-olds learn to dress and feed themselves, and most 8–10–year-olds can wash themselves alone (Ghanouni & Jarus, 2021).

The psychological adjustment of the parents has been a major focus of the vast research on the effects of the birth of a handicapped child on the family. Support from friends, relatives, and social support groups, other parents of children with ASD, service providers, activism, and religion are a few coping strategies that parents frequently use when taking care of their kid who has ASD. Furthermore, a parent's capacity to handle high levels of stress depends on the potency and quantity of coping mechanisms they use to handle the demands of stressors connected to an ASD kid (Al-Oran & Khuan, 2021).

According to studies, parents who employ problem-focused coping mechanisms to manage their stress are less stressed than those who resort to avoidance tactics. Family intervention programs have helped anxious families see challenging circumstances as less overwhelming and have taught them to manage their emotions and enhance social interactions. Family interventions help mothers and dads to control their bad behavior and negative beliefs, such as obsessive notions about spending practically all of their time with the kid and focusing on other aspects of their lives, such as being a couple, having hobbies, having friends, or working. When a child's handicap is identified, the family must be able to choose this course of action of intervention (Side & Kumar, 2022).

The role of the nurse as a key worker once diagnosis is completed, for example the specialist nurse has a pivotal role to play in meeting unmet needs and reducing stress experienced by families after diagnosis and help them to plan the journey ahead for long term involvement with the child and family and pediatric nurses may have acted as care coordinator with parents of autistic children (Elgar, 2020).

Little was known about the prevalence of ASD among the population with disability in Egypt. But now, Prevalence of ASD children with developmental disorders in Egypt was documented to be ranged around 5.4/1000 which means 33.6% (Metwally *et al.*, 2023).

AIM OF THE STUDY

This study aimed to assess the effect of nursing intervention program (pre/post) for parents caring of children with autism regarding to their daily activities through the following:

- 1. Assessing parents' knowledge and practice regarding to their autistic children's daily activities.
- 2. Implementing and evaluating the effect of nursing intervention program on parents caring for their autistic children regarding to daily activities.

Research hypothesis: Nursing intervention program has a positive effect on parents' knowledge and care provided to their autistic children's regarding daily activities.

SUBJECT AND METHODS

Four primary designs were pontraited in the current study as follows:

- I. Technical design.
- II. Operational design.
- III. Administrative design.
- IV. Statistical design.

I- Technical design: The technical design covered research design, setting, subjects and tools of data collection employed in the present study.

Research design: A quasi-experimental design used in the present study one group (pre\ posttest).

Setting: The study was carried out in Children and Adolescent Psychiatric Outpatient Clinics in Suez Canal University Hospital (SCUH) & Outpatient Clinic for Children Psychiatric Treatment at Abbasia Mental Health Hospital affiliated to General Secretariat of Mental Health and Addiction in Cairo Governorate.

Subject: A convenience sample included all available (50) parents of autistic children from the previously mentioned settings.

Tools of data collection: One tool was used to collect necessary data to fulfill the study aim.

A Structured Interview questionnaire: It was adapted from (Elsaid *et al.*, 2012) *Data* was collected from parents of children with ASD which composed of four parts:

Part 1: Socio-demographic characteristics of the studied parents composed of 2 sections:

Section 1: General data of parents included: Age, relation, number of children, marital status, occupation, level of education and monthly income. Section 2: Family history for children with ASD included: History of mental illness, genetic history and attending educational courses about dealing with children with autism.

Part 2: Characteristics of the studied children with autism composed of 2 sections:

Section 1: General data of the children which included Gender, age, growth and order. Section 2: Medical history of the children included Autism score, presence of any history of mental illness in family, genetic history and early discovery first diagnosis of autism and suspected of illness that encountered by parents while caring for their autistic child.

Part 3: Assessment of parents' knowledge, included; (25) questions MCQ regarding to meaning, causes, signs & symptoms and treatment methods of autism. This tool adapted from (Rosi *et al.*, 2019) & (Elsaid *et al.*, 2012).

Scoring system: Items total score of 25 for 25 items was rated on two ranks as (incorrect=0 & correct=1).

Total Scoring system :The total score of this scale classified into two results based on the following:

- Satisfactory level of knowledge $\geq 60\%$ (mean \geq 15-25 score)
- Unsatisfactory level of knowledge <60% (mean <15 score)

Part 4: Assessment of parents' practice for child suffering from autism regarding to their daily activities. This tool adapted from Cooke *et al.*, (2020). It includes 9 main parts:

- Feeding (8 statements),
- Toilet (7statements)
- Personal hygiene (4 statements)
- Clothing (3 statements)
- Sleeping (3statements)
- Social interaction skills (9statements),
- Attention and concentration skills (6 statements)
- Communication skills (9 statements)
- Physical activity (6statements).

Scoring system:

Items total score of 110 for 55 items was rated on three ranks as (0=no, 1=sometimes and 2=yes).

Total Scoring system

The total score of this scale classified into two results based on the following: Satisfactory level of knowledge $\geq 60\%$ and unsatisfactory level of knowledge < 60%.

Nursing Intervention Program for Parents Caring of Children with Autism Regarding to their Daily Activities (pre/post)

It aimed to improve knowledge and reported practice of parents regarding to their autistic children's daily activities post nursing intervention program and improve the autistic children's self-reliance. It was developed and designed by the researcher through a review of recent and related literature as: meaning of autism, causes, clinical manifest-tation, diagnosis, management, problems of autism children and ways to treat it, communication skills for the child, methods of feeding skill for a child with autism, general hygiene for a child with autism, problems of clothing for a child with autism, sleep instructions so that the child sleeps alone, hyperactivity and distraction and how to improve focus and attention, communication problems and knowledge of parents' activities, addressing communication problems, social relations and how to improve social relations, ways to improve coping skills and how to overcome tantrums and nervousness for a child with autism. It was developed by the researcher based on reviewing literature reviews (Herlina & Susilana, 2017).

1: Assessment phase:

The researcher after constructed the tools. The data was collected by the researcher throughout assessing parents Sociodemographic data and family history, children general data and medical history, parents' knowledge, parents reported practice and child's self-reliance *tool I (part 1, 2, 3 & 4)* as a baseline data assessment pre intervention program.

2: Planning phase:

Once the initial assessment finished, the researcher planned the sessions of individualized parents for start explanation of session consequence and providing the intervention program.

3: Implementing phase:

The practical part for parents was implemented in the form of sessions, each session differ in content than another. Each session based on principles and skills of communication. 3 theoretical, 6 practical and one evaluative sessions were provided for the study parents with the total hours were 8 hours and half for each group include breaks; distributed on two days (Monday & Wednesday) a week for each group for all sessions during the first 3 months except for session No. 10 (evaluation session), and 7 and a half hours were divided into the two days and a 5-minute break time was given between each session and the other. Each session had its own title, objectives and content guided by the parent's hand out.

Theoretical sessions

The1st session:

Interviewing: As part of the pre-assessment data collection, parents were divided into 10 groups, each of which had 5 parents, and each group was questioned individually. The previously specified instruments for gathering data. To acquire the baseline data, this information was gathered during the first session.

- This session concerned with building rapport relationship.
- It was designed to identify and comprehend the program and its purpose and collect demographic data of parents and children in 15 minutes.

The 2nd session

It was aimed to discuss identification of autism and illustrate causes of autism in 30 minutes.

The 3rd session

It was aimed to determine predictors and symptoms of autism and management of autism in 45 minutes.

Practical sessions

The 4th session

It was aimed to assess and explain the importance of teaching skills for child to become independent, Assess the child eating pattern (feeding), Implement procedure of eating skills to train the child to eat independently. Also, to assess and describe elimination problems in the child with autism, acting out activity for caring for elimination problems with the child in 45 minutes.

The 5th session

It was aimed to assess and describe personal hygiene in the child with autism, describe the child

behavior regarding personal hygiene and train parents to use general hygienic skills. Also, assess and describe the clothing of the autism children, acting out guidelines for dressing child independently in 45 minutes.

The 6th session

It was aimed to assess the child sleeping pattern and design guidelines for sleeping the child alone in his/ her bed in 15 minutes.

The 7th session

It was aimed to explain the importance of improving social interaction skills for the child, conduct social relation with others and apply social clues as say hallo by hand & head movement when accept of refuse something, assess the child stereotyping behavior and practice guide line for training the child to modify unwanted behavior in 45 minutes.

The 8th session

It was aimed to describe the child attention and concentration skills pattern and explain the important of improving concentration skills for the child, with autism such as eye contact and talking her parents. Also, to classify the parent activities for managing child communication problems and maintain verbal, nonverbal communication with the child, assess child pronunciation pattern Maintain verbal and non-verbal communication with the child, practice guideline for training the child for imitating voice and use non - verbal communication beside vocabulary to integrate principles of effective communication and communicate effectively in 45 minutes.

The 9th session:

It was aimed to explain the importance of improving social interaction skills for the child, conduct social relation with others and apply social clues as say hallo by hand & head movement when accept of refuse something, assess the child stereotyping behavior and practice guide line for training the child to modify unwanted behavior in 45 minutes.

Evaluative sessions

The 10th session:

It is aimed to summarize program and its objectives and do post evaluation in 120 minutes.

Methods & media of teaching included:

The methods for teaching used included; group discussion, role play, open discussion, small group activity, demonstrations and practical work. Wile, media included; hand out, posters, pictures, real situation, video films, real objects, flipchart, and computer- assisted education.

4: Evaluation phase:

Upon the completion of effect of nursing intervention program sessions, the post-test done for

parents to evaluate the outcomes of the effect of nursing interventions program using the same pre - test format.

- Data collection of this study carried out in the period 3 months.
- Data collected in two days of the week for each sitting 'mentioned before' at morning.
- Each parent interviewed and assessed after implementing nursing interventions to: assess the effectiveness of imple-menting nursing interventions program on parents.
- The researcher invited other parent s having children with autism to be a role model and help them through giving them their experiences of caring.
- The researcher collected the data from each parent in more than one session because the parents have short time well as presence of many variables.
- The program sessions were frequently repeated by the researcher. Each session began with an overview of what had been covered in the previous session and the new session's objectives. The researcher also provided homework reminders to make sure that the parents were remembering the concepts and abilities they had learned during the session.

Content validity and reliability

To achieve the criteria of trustworthiness of the tools of data collection in this study, the tools tested and evaluated for their face and content validity, and reliability by group of experts Professors to ascertain relevance, clarity, and completeness of the tools experts elicited responses either agree or disagree for the face validity and for content reliability, important and not important, and comments.

The required corrections and modifications done "the researcher revised each tool and delete repeated statements and modified some statement" under supervisor of the researcher supervisors according to the group comments.

The items on which the experts agree were included in the tools. The reliability of the tools that assessed through Cronbach Alp.

Scale reliability of parent's practice was 0.82, face validity was 0.92 and statistical validity was 0.83.

Pilot study:-

The pilot study was carried out in April 2020. It was conducted on 10 % (5)of the sample size (they are excluded from the study sample) from the total sample in order ensure the clarity of questions, applicability of the tools and the time needed to complete them and perform the required modification according to the available resources. Pilot study based on "revised each tool and deleted repeated statements and modify some statement" under supervisor of the researcher supervisors. The researcher modified items as: seeking advice from minister, ask relatives about how they feel about problems faced and seek for problem solving.

Field work:

The researcher was contacted with the directors of the mentioned settings as well as administrative staff to explain the purpose of the study. The researcher met 50 Parents, 25 parents from each previously mentioned setting. They were informed that they have pre and post nursing intervention sessions in addition to home activities. Data was collected through interviewing the parents. Data collection took a period of 6 months started from end of April 2021 at the end of September of 2021.

III-Administrative design:

To all individuals in charge of the study settings, a formal letter from the Dean of the Faculty of Nursing, Suez Canal University, for permission to perform the study were sent. In order to obtain permission and assistance for data collection, this letter also contained a photocopy of the data collecting instruments and the study's purpose.

IV-Statistical design:

The Statistical Package for the Social Science (SPSS V 0.26) was used to code and input the acquired data. For qualitative factors, data were shown using descriptive statistics as frequencies and percentages. Chi-square test was used to compare qualitative

variables. The inter-relationship between quantitative variables was evaluated using the Pearson correlation coefficient (r). The study's selected confidence level was 95%. A p value of 0.05 was used to define statistical significance.

RESULTS

Table (1) shows that, more than two thirds (68%) of parents were mothers. More than two thirds (78.6%) of father's age were ranged from 30-50 years, more than half (52.9%) of mother's age were less than 30 years. Half (50%) of fathers had Technical institute. While (41.2%) of mothers had technical institute education.

Table (2) illustrates that, there was a statistically significant improvement in total knowledge level about autism of the parents caring of children with autism pre and post program implementation with (p<0.001).

Table (3) Shows that, there was a statistically significant improvement in total reported practice of parents caring of children with autism pre and post program implementation with (p<0.001).

Table (4) illustrates that, there was a statistically significant between total parents' knowledge score and total parents reported practice score of autistic children score in posttest when p-value was <0.001*

General data of the parents	No.	%
Parents for the child		
Mother	34	68
Father	16	32
Mother age		
<30 years	18	52.9
30-50 years	16	47.1
X±SD	31.4±4.57	
Father age		
<30 years	1	7.1
30-50 years	11	78.6
>50 years	2	14.3
X ±SD	36.61±4.28	
Mother education		
Illiterate	6	17.6
Primary school	5	14.7
Secondary school	5	14.7
Technical institute	14	41.2
University education	4	11.8
Father education		
Illiterate	1	7.14
Primary school	1	7.14
Secondary school	2	14.29
Technical institute	7	50
University education	3	21.43

Table 1: Characteristics of the studied parents, (n=50)

		(n=50)			
Total knowledge level	Pre		Post	;	Chi-squ	lare
	No	%	No	%	\mathbf{X}^2	P-value
Satisfactory	13	26	42	84	33.980	< 0.001*
Unsatisfactory	37	74	8	16		
Total	50	100	50	100		
<0.001* Significant difference						

Table 2: Total knowledge of the parents caring of children with autism pre and post program implementation

<0.001* Significant difference

Table (3): Total reported practice of the Parents Caring of Children with Autism pre and post program implementation (n=50)

1111	Jieme	mano	n (n–	50)		
Total reported practice	Pre		Post	ţ	Chi-squ	are
	No	%	No	%	X ²	P-value
Satisfactory	15	30	44	88	34.776	< 0.001*
Unsatisfactory	35	70	6	12		
Total	50	100	50	100		
<0.001* Significant difference						

Table 4: Correlation between total knowledge score and Total skills score in posttest

	Total knowledge			
	score post			
	r	P-value		
Total skills score post	0.845	< 0.001*		
<0 001* Significant difference				

DISCUSSION

The term "autism spectrum disorders" (ASDs) refers to a class of neurodevelopmental abnormalities that have severe delays in motor and physical activity (PA) behavior development. Children with ASD may not have access to programs that promote physical activity and enjoyment because of social and behavioral problems, which leads to their inactivity. Children with ASD are more likely to develop a number of comorbid disorders, including obesity and overweight, due to their lack of physical exercise. Prior research regularly examined social variables as important contributors to ASD children's physical activity to determine major correlates of physical activity (Russell et al., 2021).

S0, the aim of the current study was to assess the effect of nursing intervention program for parents caring of children with autism regarding to their daily activities. To fulfill this aim two research hypothesis was stated:

- 1. Assessing parents 'practice regarding to their autistic children's daily activities pre \post nursing intervention program.
- 2. Implement and Evaluate the effect of nursing intervention program on parents' care providing to their autistic children's daily activities.

In relation to characteristics of studied children and their parents, the current study mentioned that, more than two thirds of parents were mothers; this might be due to that most mothers are the ones who take care of their children. This finding was agreed with Zorcec & Pop-Jordanova (2020) who reported that majority of the studied parents were mothers. Also, this result was

disagreed with Mohamed et al., (2020), who founded that more than two thirds of study group 2 was males.

The constant study mentioned that, more than half of studied mothers' age was less than 30 years, this might be related to children' age. This study was agreed with Fraatz & Durand, (2021), who revealed that more than half of studied mothers their age were ranged from 28-58 years. Also, this result in disagreement with Naheed et al., (2019), who reported that mean age of mothers was 45.7 years.

The present study revealed that, more than two thirds of fathers' ages were ranged from 30-50 years. This result supported by Hosseinpour et al., (2022), who reported that mean age of fathers was 36.79 years. Also, this finding in agreement with Di Renzo et al., (2020), who mentioned that fathers' age ranged from 39-45 years.

The constant study mentioned that, half of mothers had technical institute education. This study was disagreed with Rfat et al., (2023), who mentioned that less than one quarter of studied mothers had middle education. Also, this result in disagreement with Saini et al., (2023), who reported that more than one third of studied mothers had university degree.

The present study reported that, more than one third of studied fathers had university education and technical institute. This finding was supported with Zorčec, (2020), who found that less than one guarter of studied fathers had university degree. Also, this result in agreement with Malla & Taha, (2022), who reported that more than one third of studied parents had bachelor degree.

Regarding total knowledge of the parents caring of children with autism pre and post program implementation, the present study reported that, about three quarters of studied parents caring of children with autism had unsatisfactory level of knowledge regarding autism preprogram which improved to become most of them had satisfactory level of knowledge post program implementation, it related to that the current program increased the parents' knowledge regarding autism.

This finding on line with Bassam & Tork (2019), who revealed that most of mothers had unsatisfactory and low levels of knowledge and awareness regarding the care provided to autistic children before implementation of the program, meanwhile, after implementation of the program, the majority of mothers had satisfactory and moderate levels of knowledge and awareness with a statistical significance differences.

Concerning total practice of the parents caring of children with Autism pre and post program implementation, the present study mentioned that, there was a statistically significant improvement in total reported practice of parents caring of children with autism pre and post program implementation, this could be due to effectiveness of this program on improving parents reported practice regarding care of their autism children. This study on the same line with Zhang *et al.*, (2019), who revealed that there was a statistically significant improvement in parents' practice regarding care of autism children post program.

The present study reported that more than two thirds of parents had unsatisfactory level of reported practice regarding care of their autism children preprogram which improved to become most of them had satisfactory level of reported practice post program. This result was disagreed with Abd El-momiem et al., (2020), who reported that more than two thirds of studied parents had satisfactory level of reported practice post program with statistically significant improvement. Also, the current study reported that, most of studied parents had satisfactory level of reported practice regarding caring of their autistic children post program. This result supported by Bassam & Tork, (2019), who mentioned that a majority of studied mothers had satisfactory and moderate levels of knowledge, practice and awareness with a statistical significance differences post implementation of educational program.

In the result finding correlation between total parents' knowledge score and total parents reported practice score in posttest, the current study reported that, there positive correlation between total parents' knowledge score and total practice posttest. This study in agreement with Rutherford *et al.*, (2019), who reported

that there was positive correlation between parents' knowledge and practice.

CONCLUSION

There was a statistically significant improvement in studied parents' knowledge and practice regarding caring of autism children post program implementation on preprogram. Finally, there was strong positive correlation between total parents' knowledge score and total parents' practice score in posttest.

RECOMMENDATIONS

In the light of these findings the following recommended was:

Recommendations for parents:

- Health education through mass media concerning how to deal with and care for autism children.
- Provide the current Arabic intervention program for large numbers of parents having autistic child to increase their knowledge and practice regarding caring of autistic children.
- Replication of the same study on larger probability sample at different geographical locations for data generalizability.

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Cite This Article: Marwa Mohammed Abo Baker, Safy Salah Eldin Al-Rafay, Faten Fathi Ahmed Mahfoz (2023). Effect of Nursing Intervention Program for Parents Caring of Children with Autism Regarding to their Daily Activities. *EAS J Nurs Midwifery*, *5*(5), 90-97.