Self- Reliance of Parents Caring for Children with Autism

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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 their self-reliance. *Design:* A quasi-experimental research design was used in the present study, two groups (pre\ posttest). **Setting:** The study was carried out at children outpatient clinics of Suez Canal University Hospital & 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 children with autism from the mentioned settings that treat autism. **Tools of data collection:** A Structured interview questionnaire included four tools; Part 1: Socio-demographic characteristics of parents, Part 2: Characteristics of the studied children with autism. Tool II Assessment of parents' knowledge tool III: Assessing the parents reported practice regarding to self-reliance. Results: Revealed that more than two thirds (68%) of parents were mothers. The majority (88%) of studied parents had significant differences regarding their knowledge about identification of autism, causes, predictors and symptoms and management, in addition to improvement of their children self- reliance (84& 82%) regarding body shower and feeding post program implementation compared to preprogram. *Conclusion:* There was a statistically significant improvement in total knowledge of parents about autism and children self. *Recommendations:* Increase awareness through mass media about importance of early recognition of autism, seeking management and avoid neglect.

Keywords: Autism, Program, Parent Children,, Nursing intervention, Self-Reliance

1. Introduction

The term autism spectrum disease (ASD) covers a wide variety of neurologically varied symptoms. It is challenging to define the disease in a way that makes sense given how various people are affected by it. Many autistic kids fail to communicate, have trouble interacting with others, and exhibit behaviors that are harmful in certain situations *(Mottron, 2021).*

Although individuals who also have an intellectual handicap are more likely to demonstrate this link, about 10% of children with autism have particular genetic, neurologic, ror metabolic abnormalities that may be deemed to be etiologic. Mother's age and the immigration status of the parents are other risk variables that have been researched. A research based on parental reports, however, revealed no connection between maternal age

and diagnosis *(Happé & Frith, 2020).*

The primary source of support for kids with autism spectrum disorder (ASD) is their families. Although ASD affects everyone it affects, families may be notably affected to a greater extent than other groups. Having a child with ASD is frequently viewed as a risk factor intern of family well-being due to the additional strain placed on family relationships as well as on family members' roles and responsibilities. The affected family unit must work together to negotiate around the many challenges associated with supporting the affected child *(Legg et al., 2022).*

Caring for children with ASD is challenging and affects family life. Meeting the high care demands of affected children requires much time, effort and patience. Parenting stress is theoretically defined as a psychological **AIM OF THE STUDY**

The present study was aimed to assess the effect of nursing intervention program for parents caring of children with autism regarding their self-reliance.

Research hypothesis:

Nursing intervention program is expect to positive effect on self-reliance of parents caring children with autism.

phenomenon that results from an imbalance between the demands of the parenting role and

the available resources required to fulfill the parenting responsibility. Parents stress can be defined as the aversive psychological reaction to the demand of being a parent *(Cooke et al., 2020).*

Before operations or appointments, nurses may assist the family by going over the anticipated behaviors with them. They can also give regular reminders to the patient while receiving post-intervention care, which can lessen the patient's dread and outbursts while encouraging compliance. The main goal is to modify the patient's treatment in accordance with their sensory sensitivity and their communication skills. Interventions can calm the person with ASD, include lowering the lights, using a weighted vest or blanket, and allowing repetitive movement that doesn't interfere with care *(Dunlap & Filipek, 2020).*

Children with autism may develop self-reliance skills in a different progression than children with neuro-developmental disorders and often require direct intervention to acquire self-reliance skills. Ultimately, it is important for children to develop self-reliance skills to increase their general independence, reduce reliance on caregivers, and promote general health, hygiene, wellness, and safety *(Peterson et al., 2023).*

2. 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.

IV. Statistical design.

I) Technical design:

The technical design composed of research design, setting, subjects and tools of data collection used in this study.

Research design:

A quasi-experimental research design was used in the present study two groups (pre\ posttest).

Setting:

The study was carried out in children outpatient clinics in Suez Canal University Hospital which is affiliated to ministry of higher education and scientific research & Outpatient Clinic for children Psychiatric Treatment at Abbasia Mental Health Hospital affiliated to General Secretariat of Mental Health and Addiction in Cairo Governorate

Subjects:

A convenience sampling of 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)* composed of four parts:

Part 1*:* General data of parents included: Age, relation, number of children, marital status, occupation, level of education and monthly income.

Part 2: Family history for children with ASD included: History of mental illness, genetic history and attending educational courses about dealing with children with autism.

Part3: Characteristics of the studied children with autism composed of which included Gender, age, growth and order.

Part 4*:* 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.

Tool II: Assessment of parents' knowledge, included; (25) questions MCQ

regarding to meaning, causes, signs & symptoms and treatment method of autism. This tool adapted from *(Rosi et al., 2019) & (Elsaid et al., 2012).*

Scoring system:

According to the answers obtained from parents their knowledge was scored as (incorrect=0 & correct=1).

Total Scoring system:

Scores of this scale was 25 grades for 25 items were summed up and divided by the number then converted to percentage and accordingly the total parents' knowledge was classified into two categories as follows:

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

Unsatisfactory level of knowledge <60% (mean <15 score).

Tool III: Assessment of parents reported practices regarding to self-reliance during their children daily activities. It consists of **(6) items** MCQ included: Feeding, physical activity, clothing, body showering, oral hygiene and communication. This tool adapted from *(Di Renzo, et al, 2020).*

Scoring system

Total items score of 18 for 16, their rates of dependence classified into three ranks as (0= complete dependence on others, 1= partial dependence on others and 2= independent).

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

Dependence level of self-reliance $\geq$ 60% ($\geq$10.8-18 score)

Independence level of self-reliance <60% (<10.8 score).

Nursing intervention program for parents caring of children with autism during their daily activities

Intervention program was developed and designed by the researchers after a review of recent and related literature through the following phases. It was applied to improve knowledge and self- reliance of parents caring for children with autism. *(Herlina & Susilana, 2017*

1. Assessment phase:

- The researchers constructed the tools. Then data was collected throughout assessing parents individually for Sociodemographic data and family history, children general data and medical history, parents' knowledge, and parents reported practices regarding their self-reliance during providing care foe their children with autism. *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 for start explanation of session consequence and providing the intervention program.

3. Implementing phase

Each session had its own title, objectives and content that had guided by distributing handouts for participated parents.

Accordingly, sessions related knowledge of parents such as: meaning of autism, causes, clinical manifestation, diagnosis, management, problems of autism children and ways to treat it.

Sessions related self-reliance of parents during caring of autistic children included: Feeding, physical activity, clothing, body showering, oral hygiene and communication. Sessions were divided into: theoretical, sessions related knowledge and Sessions related self-reliance and one evaluative sessions were provided for the study parents with the total hours were 4 hours and half for each group include breaks; distributed on two days (Monday & Wednesday) a week for eachgroup each group for all sessions during the first 3 months except for session No. 4 (evaluation session), a half were divided into the two days and a 5-minute break time was given between each session and the other.

Theoretical sessions

Sessions related knowledge of parents:

The1ˢᵗ session:

Interviewing: As part of the pre-assessment data collection, parents were divided to 10 groups, each of which had 5 parents, and each group was questioned individually for gathering information Using the prepared tool to acquire the baseline data, this information was gathered during the first session.

- This session concerned with building rapport relationship.

- Its purpose was to identify and comprehend the program and its goals and discuss the meaning of autism disorder in 15 minutes.

The 2ⁿᵈ session

It is aimed to describe meaning causes of autism, signs of autism, treatment, and purpose of treatment and in 30 minutes.

Sessions related self-reliance of parents:

The 3ᵗʰ session

It is aimed to discuss methods of dealing with autistic child and meet needs of autistic child through items regarding to feeding, physical activity, clothing, body showering, oral hygiene and communication in 30 minutes.

The 4ᵗʰ session

It is aimed to summarize program and its objectives and do post evaluation in 45 minute.

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.

Content validity and reliability

To achieve the criteria of trust worthiness of the tools of data collection in this study, tool tested and evaluated for content validity by group of four experts professors in the field of Pediatric Nursing to ascertain relevance, clarity, and completeness of the tools experts

The required corrections and modifications were done. Some repeated statements related to tools were deleted or modified..

The reliability of the tools was assessed through Cronbach Alp.

Scale reliability of parent's knowledge

was 0.79

Pilot study:

In April 2020, a pilot study was completed, in order to guarantee the clarity of the questions, the application of the tools, the time needed to complete them, and the capacity to undertake the necessary adjustment in accordance with the available resources, it was conducted on 10% (5) of the sample size (they are excluded from the research sample Under the supervision of the researcher supervisors, a pilot study using "revised each tool and deleted repeated statements and modified some statement" was conducted. The researcher changed the items to include things like asking a minister for assistance, getting feedback from family members, and looking for solutions to difficulties.

Field work:

The researchers was contacted the directors of the mentioned sitting as well as administrative staff to explain the purpose of the study. Parents informed that they have pre and post nursing 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 December 2021 at the end of May of 2021.

III. Administrative design:

An official letter requesting Permission

to conduct the study was submitted from the Dean of the Faculty of Nursing, Suez Canal University to all persons in charge of the settings. This letter included the aim of the study and a photocopy from the data collection tools in order to get the permission and help for collection of data.

IV. Statistical design:

The collected data were coded and entered into the Statistical Package for the Social Science (SPSS V 0.26). Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables. Qualitative variables were compared using chi-square test. Pearson correlation co-efficient (r) was used for assessment of the inter-relationship among quantitative variables. The confidence level chosen for the study was 95%. Statistical significance was considered at p value <0.05.

3. 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. While 41.2% of fathers had university education and technical institute. Also half (50%) of mothers had technical institute education.

Table (2) shows that, two thirds (66%) of children were malesThe majority (92%) of children had ages more than 3 years, more than half (60%) of them had abnormal child growth rate compared to his/her peers. Almost (36%) of children had second child birth order in the family.

Table (3) reveals that; the majority of studied parents (86%,84% & 82% & 78% respectively) identification of autism, causes, predictors and symptoms of autism and management of autism post program implementation compared to 12%, 14% & 16% & 16% respectively of preprogram where (p<0.001). So, there was a statistically significant improvement in parents' knowledge regarding autism post program implementation on of the studied parents.

Figure (1) illustrates that, about three quarters of studied parents caring of children with autism had unsatisfactory level of knowledge regarding autism pre-program which improved to become most of them had satisfactory level of knowledge post program implementation.

Table (4) illustrates that: the majority of studied children (84% &82% respectively) had improved self-reliance about body shower and feeding post program implementation compared 10% & 16% of preprogram where (p<0.001). So, there was a statistically significant improvement

parents levelof self-reliance post program

4. DISCUSSION

Autism is developmental disorder with impairment of language and social communication skills, as well as repetitive or restrictive interests. Autism is spectrum disorder because there is wide variation in types of symptoms and severity *(Barbera, 2022)*. The nursing care to the autistic child is based on qualified listening, once that nurses are the eyes and ears of the health team and the voice for parents. The nurse becomes a link between the multiprofessional team and the parents of the autistic child *(Magalhães et al., 2020).*

This study aimed to assess the effect of nursing intervention program for parents caring of children with autism regarding to their self-reliance To fulfill this aim one research hypothesis was stated.

In relation to characteristics of studied children and their parents, the current study found 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 more than half of studied parents were females. Contrariwise, this result was disagreed with *Mohamed et al., (2020* who founded that more than two thirds of study

implementation than preprogram. group 2 was males.

The present study revealed that, more than two thirds of fathers' ages were ranged from 30-50 years, this may be related to age of mothers and children. This result supported by *Hosseinpour et al., (2022)* who reported that mean age of fathers was 36.79 years. Contrariwise, this finding in disagreement with *Di Renzo et al., (2020)* who mentioned that fathers' age ranged from 27-68 years.

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 disagreed 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 reported that, more than one third of studied fathers had university education and technical institute; this may be due to that more than two thirds of studied parents from urban areas. This finding was supported with *Zorčec, (2020)* who founded that less than one quarter 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.

The constant study mentioned that, half of mothers had technical institute education, this may be related to education of fathers 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 less than one quarter of studied mothers had university degree.

Regarding general data about the studied children, the current study revealed that, two thirds of children were males, this related to that autism is male-to-female ratio is 3:1 ***(Loomes et al., 2017)***. This result on line with ***Saad et al. (2020)*** who reported that about two thirds of studied children were males. Also, this finding in agreement with ***Samadi, (2020)*** who mentioned that more than two thirds of studied children were boys.

The present study mentioned that, the majority of children had ages more than 3 years, it might be related to that more than two thirds of studied parents had young age from 30-50 years. This study was agreed with ***Oneib et al. (2022),*** who stated that more than half of studied children their age were more than 5 years. Also, this result on line with ***Narayan, (2020)*** ,who revealed that more than two thirds of studied children

their age more than 3 years.

The current study revealed that, more than half of studied children had abnormal child growth rate compared to his/her peers, it may be related to alterations in the expression level of GFs during embryogenesis are linked to the pathophysiology and clinical manifestations of autism spectrum disorders (ASD) ***(Galvez-Contreras et al., 2017)***. This study supported by ***(Regev et al., 2020)*** who reported that most of studied children had abnormal fetal head growth which is a familial trait of ASD disagreement with ***Li et al. (2022)*** who mentioned that less than one quarter of studied children has development disorders.

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The current study mentioned that, more than one third of children had second child birth order the family.This finding in disagreement with ***Samadi, (2020)*** who revealed that more than half of studied children were the first child. Also, this study was disagreed with ***Martins et al. (2021)*** who found that more than one third of studied children were the single children for their parents.

According knowledge of the Parents Caring of Children with Autism regarding identification, causes, symptoms and

management of Autism pre and post program implementation, the present study reported that, there was a statistically significant improvement in parents' knowledge of Autism post program implementation compared with preprogram this might be due to the positive effect of the educational program.

This study supported by *Keshk et al. (2020),* who mentioned that there was a statistically significant improvement in studied mothers knowledge regarding definition of autism, causes, symptoms and treatment. Also, this study in agreement with *Rochyadi et al. (2019),* who revealed that there was highly statistically significant elaboration in parents' knowledge regarding definition of autism, causes, symptoms and health and care of autistic children.

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 may be 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**.**

According parents evaluation of a child's level of self-reliance, the current study reported that, there was a statistically significant improvement in child's level of self-reliance post program implementation than preprogram, more than two thirds had improved self-reliance about body showering and feeding post program implementation compared to preprogram. In addition, there was a statistically significant improvement in total score of child' slevel of self-reliance post program thanpreprogram, it related to good effect of current study on improving children self-reliance.

This study on the same line with ***Abdel Hamid, (2020)*** who presented that there were statistically significant differences between the pre and post-tests on the independence behavior skills scale for autistic children in favor of the post-test. The improvement in the skills of independence were evident in the autistic children's ability to use eating and drinking tools independently, to walk properly,

to control urination and defecation, and to depend on themselves for dressing and other needs.

5. CONCLUSION

The present study showed that there was a statistically significant improvement in studied parents' knowledge and regarding caring of autism children post program implementation than preprogram Additionally, there was a statistically significant improvement in child' level of self-reliance post program implementation on preprogram. there was strong positive correlation between total parents' knowledge score, total parents reported practice score and total level of child's self-reliance score in posttest.

6. RECOMMENDATIONS

In the light of these findings the following recommended was:

Recommendations for parents:

- Increase public awareness about autism to reduce social stigma.

- Health education through mass media concerning how to deal with and care for autism children.

- Replication of the same study on larger probability sample at different geographical locations for data generalizability.

Table (1): Percentage distribution of studied parents regarding their socio-demographic characteristics (n=50).

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 (2): Percentage distribution of studied children regarding their socio-demographic characteristics (n=50).

Children socio-demographic characteristics	No.	%
Gender		
Male	33	66
Female	17	34
Age		
<3 years	4	8
>3 years	46	92
growth		
Normal	20	40
abnormal	30	60
Birth order		
The sole child	12	24
The first	12	24
The second	18	36
The third	8	16
Above the third	0	0

Table (3): Total Knowledge of the Parents Caring of Children with autism pre and post program implementation (n=50).

total Knowledge	Pre				Post				Chi-square	
	Correct		Incorrect		Correct		Incorrect		X^2	P-value
	No	%	No	%	No	%	No	%		
Identification of Autism	6	12	44	88	43	86	7	14	59.052	<0.001*
Causes	7	14	43	86	42	84	8	16	52.64	<0.001*
Predictors and symptoms of autism	8	16	42	84	41	82	9	18	45.543	<0.001*
Management of autism	8	16	42	84	39	78	11	22	41.67	<0.001*

<0.001* Statistical significant difference

Figure(1) Total knowledge of the Parents Caring of Children with autism pre and post program implementation (n=50)
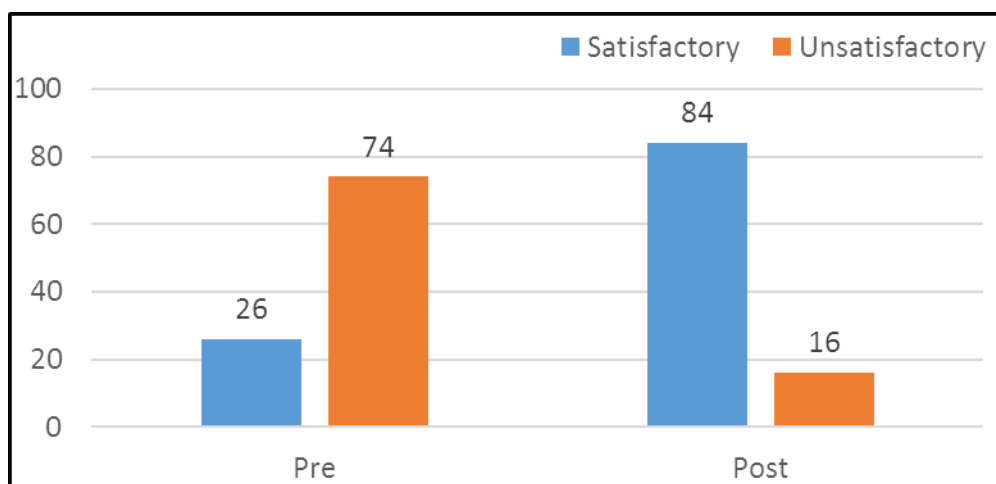
Table (4): The Parents evaluation level pre an of relianced post program implementation (n=50)

The level of self-reliance	Pre						Post						Chi-square	
	Independent		Partial dependence on others		Complete dependence on others		Independent		Partial dependence on others		Complete dependence on others		X²	P-value
	No	%	No	%	No	%	No	%	No	%	No	%		
Feeding	8	16	15	30	27	54	41	82	9	18	0	0	50.724	<0.001*
Physical activity	5	10	13	26	32	64	39	78	10	20	1	2	55.785	<0.001*
Oral hygiene	10	20	9	18	31	62	40	80	5	10	5	10	37.921	<0.001*
Body showering	5	10	12	24	33	66	42	84	6	12	2	4	58.585	<0.001*
Clothing	9	18	14	28	27	54	41	82	7	14	2	4	44.365	<0.001*
Communication	7	14	10	20	33	66	38	76	8	16	4	8	44.308	<0.001*
Total	7	14	12	24	31	62	40	80	8	16	2	4	49.455	<0.001*

<0.001* Statistical significant difference

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