Assessment of Knowledge, Strains and Coping of the Family Care Givers Having Autistic Children.

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ABSTRACT

Background: Autism is a lifelong disability and, a broad spectrum disorder of unknown cause appears during the first three years of life. ***Aim:*** The present study aimed to assess the knowledge, strains and coping of the family caregivers having autistic children (descriptive study). ***Setting:*** The study was conducted in Children & Adolescent Psychiatric Outpatient Clinic in Suez Canal University Hospital, El-Terbia El-Fekria, El-Salam El-Engelia, Gamal El-Din El-Afghani and Ard El-Mashtl Primary Schools, Wyana Institution for Integration and Rehabilitation, El-Aml Center for Children with Special Needs, El-Tathkief El-Fekri Institution and the Psychiatric Measures Clinic at Ismalia city. ***Sample*:** Included 36 caregivers and 36 autistic children. Data were obtained through an interview with the studied caregivers using three tools: structured interview questionnaire, caregiver strain questionnaire-short form and brief cope scale. ***Results:*** Revealed that 44.4% of the studied caregivers had unsatisfactory total knowledge regarding autism, 77.8% of the studied caregivers' total strains mean scores were high and the 97.2% of the studied caregivers had high total coping mean scores. ***Conclusion*:** The studied caregivers had unsatisfactory total knowledge mean score (regarding autism, strains and coping), had high total strains mean scores and had high total coping mean scores. ***Recommendation:*** Emphasize the importance of carrying out educational programs to improve knowledge of autistic children's care givers regarding their autistic children's needs and care. Also regular assessment and monitoring of the studied family care givers' strains and coping is recommended.

Key words: Autism, knowledge, strain, coping, caregivers, children, pediatric nurse

INTRODUCTION

Children are highly appreciated by the society because of their potential future contributions. Autistic children having long term disability, impaired communication & social contact and difficulties in achieving independence could affect the overall health and general production of their societies ***(****Abdullah, 2013).*

Autistic children represent about 1% overall the world. In the United States, autism occurs in one per 68 births; autism more common among boys than girls (5:1); (*Buescher et al., 2014 and Centre for Diseases Control and Prevention (CDC), 2014)*. In Egypt, the prevalence rate of autism as reported by the study of *Haffiz, (2007**),*** is one child in every 870 children.

The inexperienced caregivers of newly diagnosed autistic children are left in shock, disbelief and grief because of losing an expected typical child and not knowing what course of action should be taken to help their autistic child. The family care givers having autistic children have different sources of stressors experiencing either objective or subjective strains or both of them at the same time. Caregivers have high levels of strain may lead them to high morbid condition which requires coping *(Kashif, 2013).*

The caregivers of autistic children have varied reactions when informed with their children's diagnosis ranging from feeling shock, anxiety, depression, anger, denial, frustration and feeling guilt. Coping has two aspects either positive\effective or negative\ineffective. The positive coping patterns give higher chances for both autistic children and their care givers to act more smoothly with less rejection and more acceptances on the part of each other and the society. The coping response of the caregivers of autistic children towards the perceived strains depends on the situation/threat being faced, in addition to the caregivers' personality traits, health, optimistic beliefs, culture, social support networks, problem-solving capabilities and religion *(Abdullah, 2014 and Greene et al., 2012).*

There is also a call to engage in certain activities and studies to promote awareness about autism among caregivers of autistic children in Africa to recognize the autistic children early and consequently provide prompt intervention, thus, have better prognosis. As Most caregivers know little about autism and its implications *(CDC, 2015, Hockenberry and Welson, 2013 and World Health Organization (WHO), 2013).*

The pediatric nurse must give the caregivers of autistic children complete necessary correct information regarding autism, coordinate to meet their needs and give them a chance to exchange their information & experiences. The pediatric nurse must teach the family caregivers of autistic children how to provide care for their children without or with little strain, in addition to providing them with psychological support and helping them identify the factors that mediate a positive coping pattern **(***Wallace, 2010).*

The ASDs account for 0.3% of all disabilities-adjusted life years (*WHO, 2013*). Autism is a lifelong disability which imposes huge emotional and financial burdens. Furthermore, the costs for raising an autistic child are three times more than those for a typically-developing child. Caregivers of autistic children suffer from inadequate access to services and support. Worldwide, most autistic children and their family caregivers do not receive any care from health or social care systems *(Scheffer et al., 2012).* In Africa, studies are required to increase the awareness of the professional personnel and the caregivers of autistic children regarding autism, its consequent strain and coping. The chances of having a second autistic child among parents already having an autistic child is 2-18% **(*CDC, 2015)***. So, the present study will shed light on strains/stressors that caregivers having autistic children face it and their coping strategies.

AIM OF THE STUDY:-

The aim of the present study was to assess the knowledge, strains and coping of the family caregivers having autistic children.

Research questions:

What is the knowledge of the family care givers having autistic children regarding autism?
What are the strains faced by the family care givers having autistic children?
What are the coping patterns adopted by the family care givers having autistic children?

SUBJECTS & METHODS:

Research design: A descriptive research design was utilized for the current study.

Setting of the study: The present study was conducted at the available established settings providing care to the autistic children in Ismailia city, namely: Children & Adolescent Psychiatric Outpatient Clinic in Suez Canal University Hospital (SCUH), Wyana Institution

for Integration & Rehabilitation of Children with Special needs, The Psychiatric Measures Clinic, El-Aml Center for Children with Special Needs, El-Tathkief El-Fekri Institution, El-Terbia El-Fekria, Gamal El-Din El-Afghani, El-Salam El-Engelia and Ard El-Mashtl Primary Schools.

Subjects: This study comprised convenient sample of all caregivers of autistic children (36 caregivers and 36 autistic children).

Inclusion criteria:

1. Family caregivers (mothers) of autistic children, regardless their age, level of education and residence.
2. Children aged between 3-18 years old with confirmed diagnosis of autism, from both genders.

Exclusion criteria:

Family caregivers (mothers) having any chronic or psychiatric illness.

Tools of data collection:

Three tools of data collection were used as the following:

Tool I. Structured Interview Questionnaire: This was designed by the researcher and composed of three parts including; data regarding the studied family care givers, data regarding the studied children and data regarding the studied care givers' knowledge regarding autism (in relation to definition, factors affecting, clinical manifestations, treatment methods and needs of autistic children), strains (in relation to definition & clinical manifestations) and coping (in relation to definition, coping patterns, factors affecting and source of knowledge).

Scoring system of Tool I: The knowledge of the studied caregivers was scored as follows: unknown answer was scored (0), incomplete correct answer was scored (1) and complete correct answer was scored (2). For each area of knowledge, the scores of the items were summed-up and the total was divided by the number of items, giving a mean score of this area of knowledge. The scores were converted into a percentage score. The knowledge of the mothers was considered satisfactory if their score was ≥ 65%, partially satisfactory if their score was 50% - <65% and unsatisfactory if the score was < 50%.

Tool II: Caregiver strain questionnaire-short form (CGSQ-SF): The CGSQ-SF was developed by Platt (1985), to assess the extent to which caregivers and families of children

with emotional and behavioral problems experience additional demands, difficulties and psychological consequences as result of their caregiving role. The CGSQ-SF was adapted by the researcher then validity and reliability were done.

Scoring system of Tool II: The CGSQ-SF assessed a total score of caregiving strain and 2 related but distinct subscales: objective strain (6 items) and subjective internalized strain (4 items), their scores were represented as means. The CGSQ-SF total score was calculated as the sum of 2 subscales. Subscale responses ranged from not at all\ a little (A) to quite a bit\ very much (C). The subscale scores ranged from 1:5 and the total score can range from 2:10. The score was classified into low or high. The higher score meant more strain experienced. The CGSQ-SF total score, objective strain subscale and subjective internalized strain subscale were considered low if the scores were < 50% and high if the scores were ≥ 50%.

Tool III: - Brief cope scale:

A brief cope scale was developed by Carver (1997), to assess the family caregivers'\parents' patterns of coping with strain associated with raising autistic children. The brief cope scale was adapted by the researcher and then validity and reliability were done. A brief cope scale consisted of 28 items; with 2 items under each subscale based on strong loadings from previous factor analyses, item clarity and meaningfulness to the patients in a previous study.

Scoring system of Tool III: The responses ranged from: I have not been doing this at all (1), to I have been doing this a lot (4).The total score was obtained by summing up the scores of each pattern. The higher summed scores indicated greater use of the coping pattern. For each area of coping, the summed scores were divided by the number of items, giving a mean score of the part. Standard deviations were computed. The scores were converted into a percentage score. The coping pattern of the caregivers of autistic children was considered low if the score was < 50 % and high if the percent score was ≥ 50%.

Pilot study: A pilot study was carried out after the development of the study tools and before starting the data collection. This study included 10% (4 caregivers) of the expected sample size to test the clarity, applicability, efficiency and validity of the study tools and to estimate the required time to gather data. Afterwards, minor changes (item modifications, omissions and additions) were done and the final form was developed. All participants in the pilot study were excluded later from the study sample.

Content validity of the tools: Content validity of data collection were revised by seven

expert professors, as juries to test the tools' validity.

Reliability of the tools: Furthermore, the reliability of tools was assessed with the following results:

Scale	**Cronbach alpha value**
Brief Cope scale	
Positive coping pattern	0.7
Negative coping pattern	0.7
Strain Questionnaire-Short Form (CGSQ-SF)	0.8

Field of the work: The actual field work was carried out over a period of six months; two months for preparation, three months for the actual data collection and one month for statistical analysis of the collected data. The researcher collected the data from 36 caregivers having autistic children and 36 autistic children. The researcher interviewed each caregiver of an autistic child individually using the previously mentioned study tools for 15-20 minutes according to their physical and mental readiness. Regarding the data collection: the researcher rotated in each study setting as follows: El-Aml Center, Saturday and Wednesday from 2:00 PM to 7:00 PM; Children and Adolescent Psychiatric Outpatient Clinic in Suez Canal University Hospital (SCUH): Sunday from 8:30 AM to 2:00 PM; and for the remaining study settings, the researcher rotated for the rest of the week (from Monday to Thursday) from 8:30 AM to 2:00 PM.

Administrative design: An Official permission was obtained from the director of each study setting.

Ethical consideration: Written consent was taken from each mother prior to her participation in the study after simple explanation of the aim and expected outcomes of the study. The researcher assured voluntary participation, anonymity and confidentiality of the collected information.

Statistical Analysis:

The collected data were organized, revised, coded and entered to statistical package of social science (SPSS) program version (18), tabulated, analyzed and interpreted using number and

percentage distribution. The following statistical descriptive statistics (frequencies, distribution, mean score degree and standard deviation) to describe different characteristics were used. The significance level was set at $p < 0.05$.

Limitations of the study:

Some of the studied family care givers didn't complete the study tools.

RESULTS:

Table (1): represents distribution of the studied family caregivers according to their characteristics. It was found that 44.4% of the studied mothers' age was < 35 years old, with mean age of 36.7 ± 6.0 years. In relation to the studied mother's education, it was revealed that 52.8% of the studied mothers had university and post-graduate education. Regarding the studied caregivers' occupation, it was found that 55.6% of the studied mothers were housewives. Furthermore, 63.9% and 61.1% of the studied children's parents had enough income and were non-consanguineous respectively. Also, 91.7% of the studied caregivers had negative family history of autism.

Table (2): shows distribution of the studied children according to their characteristics. It was clarified that 58.3% of the studied children were aged 6 < 12 years, with mean age 8.4 ± 3.6 years. 91.7% were males. Regarding their level of education, 63.8% of the studied children were educated in different educational levels, while 30.6% of them were uneducated.

Table (3): shows that 50% and 55.6% of the studied family caregivers had complete correct answers regarding the psychological signs & symptoms of strains and patterns of coping respectively. While had complete correct answers regarding the risk factors of autism related to parents, prenatal, perinatal and postnatal 5.6%, 0.0%, 2.8%, 5.6% respectively .

Figure (1): shows that 41.7%, 38.9% and 22.2% of the studied caregivers had unsatisfactory knowledge regarding autism, strains\stressors and coping. The total knowledge scores of the studied caregivers were unsatisfactory among 44.4% of them. This figure also shows that 58.3% of the studied caregivers had satisfactory knowledge regarding coping.

Table (4): clarifies that 77.8% of the studied family caregivers' total strains were high. Also, the same table clarifies that 97.2% of the studied family caregivers had high total coping scores.

Table (5): shows that there was a statistically significant relation regarding the studied caregivers' total knowledge mean scores and their ages ($P < 0.05$); the caregivers <35 years old were the most knowledgeable with mean 62.5 ± 17.2. This table also shows that there was a statistically significant relation regarding the studied caregivers' total knowledge mean scores and their occupation ($P > 0.05$). The housewives were more knowledgeable than the working mothers with mean score 61.0 ± 20.6.

Table (1): Distribution of the studied caregivers according to their characteristics (n= 36).

Characteristics:	**No.**	**%**
Age of mother (in years):		
<35	16	**44.4**
35 - <40	10	27.8
40 - <45	6	16.7
≥ 45	4	11.1
$\bar{x}$ ± SD	**36.7 ± 6.0**	
Level of education:		
Elementary\Basic	4	11.1
Less than university	13	36.1
University or higher	19	**52.8**
Occupation:		
Worker	16	44.4
Housewives	20	**55.6**
Family income:		
Enough	23	**63.9**
Not enough	13	36.1
Consanguinity of parents:		
Negative	22	**61.1**
Positive	14	38.9
Family history of autism:		
Negative	33	**91.7**
Positive	3	8.3

Table (2): Distribution of the studied children according to their characteristics (n= 36).

Characteristics:	**No.**	**%**
Age (years):		
3 < 6	7	19.5
6 < 12	21	**58.3**
12 ≤ 18	8	22.2
$\bar{x}$ **± SD**	**8.4 ± 3.6**	
Gender:		
Male	33	**91.7**
Female	3	8.3
Educational level:		
Underage	2	5.6
Uneducated	11	**30.6**
Kindergarten	8	**22.2**
Primary schools	12	**33.3**
Preparatory schools	3	**8.3**

Table (3): Percentage distribution of the studied family caregivers' knowledge (complete correct answers) regarding autism, strains and coping (n= 36).

Complete correct answer about:	**No.**	**%**
Autism:		
Definition of autism	15	41.7
Risk factors of autism related to:		
parents	2	**5.6**
Pre-natal	0	**0.0**
Perinatal	1	**2.8**
Post-natal	2	**5.6**
Clinical manifestations of autism regarding:		
Social communication\interaction	13	36.1
Verbal and non-verbal communication	13	36.1
Behaviors (activities, concerns and games)	13	36.1
Needs of autistic children	29	**80.6**
Treatment methods of autistic children	15	41.7
Strains:		
Definition of strain	13	36.1
Sources of strains	14	38.9
Warning signs and symptoms of strain:		
Physical signs and symptoms	11	30.6
Psychological signs and symptoms	18	**50.0**
Coping:		
Definition of coping	14	38.9
Patterns of coping	20	**55.6**
Factors affecting coping with strains	6	16.7

*Statistically significant difference, (P-value of McNemar's test of significance).

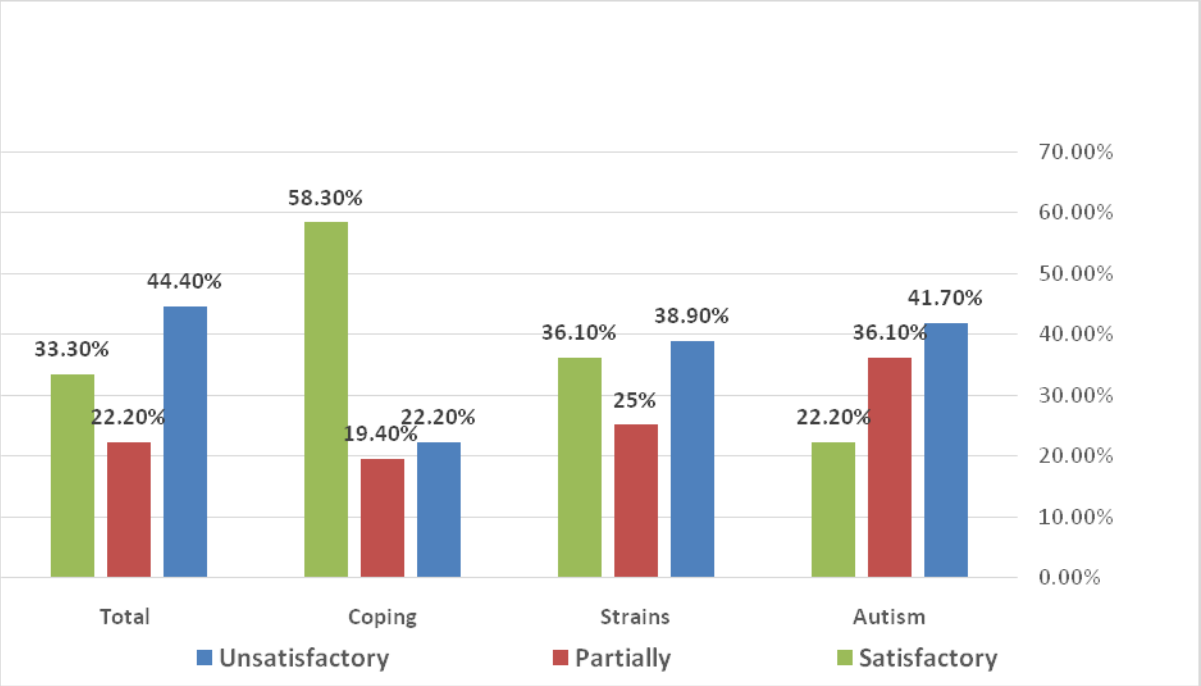

Figure (1): Percentage distribution of the studied caregivers' total knowledge scores regarding autism, strains and coping (n= 36).

Table (4): Distribution of the total scores of the studied caregivers' total strains and coping (n=36).

The total scores of the studied caregivers' total strains and coping:	**Low (< 50%)**		**High (≥ 50%)**	
	No.	**%**	**No.**	**%**
The studied caregivers' strains: Objective strain	13	36.1	23	**63.9**
Subjective strain	1	2.8	35	**97.2**
Total strain	8	22.2	28	**77.8**
Total coping score	1	2.8	35	**97.2**

Mac NX^2: Mac Nemar's test

Table (5): Relationship between total mean score of knowledge of the studied family caregivers and their characteristics (n=36).

Characteristics:	No.	Knowledge Mean Score		
		$\bar{x}$±SD	Test	P-Value
Age (years):				
<35	16	**62.5 ± 17.2**	**F=**	**P=0.033***
35 - <40	10	40.5 ± 23.8	**3.30**	
40 - <45	6	50.8 ± 8.6	**6**	
≥ 45	4	45.6 ± 13.3		
Level of education:				
Elementary	4	53.8 ± 36.5	F=	
Less than university	13	46.3 ± 13.1	1.04	P= 0.364
University or higher	19	56.6 ± 19.5	1	
Occupation:				
Worker			**t=**	
Ho Housewives	16	42.0 ± 12.9	**3.21**	**P=0.003***
	20	**61.0 ± 20.6**	**5**	

*Significant at P ≤ 0.05.

DISCUSSION:

The caregivers of autistic children are usually the first to notice the unusual behaviours of their children. The autistic children create a situation that requires understanding and support from their caregivers. The inexperienced caregivers having newly diagnosed autistic children need to be understood, as they are left in shock, disbelief and grief because of losing a typical expected child and not knowing what course of action should be taken. The pediatric nurse must teach the caregivers to provide care for their autistic children without or

with little strains. The pediatric nurse must also provide the caregivers with psychological support and identify the factors mediating positive coping patterns (Hockenberry and Welson, 2013 and Kashif, 2013).

The results of the current study found that the mean age of the studied mothers was 36.7 ± 6.0 years. More than half of the studied mothers had university and post-graduate education. More than half of the studied mothers were housewives and the majority were married. Furthermore, less than two thirds of the studied children's parents were non-consanguineous. Also, the majority of the studied caregivers had negative family history of autism.

The findings of the current study revealed that less than two thirds of the studied children's parents had enough income were supported by the study of Bilder (2009), entitled "Prenatal, perinatal and neonatal factors associated with autism spectrum disorders" and that of El-Baz et al. (2011), who found that less than half of autistic children were of a high social class as most of their parents were professional doctors and engineers. However, this contradicted with Bauomey (2012), who found that the monthly income of the majority of caregivers of autistic children was inadequate.

The results of the current study clarified that the majority of the studied caregivers had negative family history of autism, which came in agreement with Bauomey (2012), who found that most caregivers of autistic children had a negative family history of autism. However, this contradicted with El-Baz et al. (2011), who found that positive family history of autism was statistically associated with risk of autism in 16% of autistic children versus 1% of controls. The contradiction between the researcher's expectations and the findings of the current study may have been due to the fact that genetic factors represent only 10%-15% from the known factors contributing to occurrence of autism ***(Talkowski et al., 2014)***, and the contradiction between the findings of the current study and the previous study may be due to the difference in the sample size and the study research settings.

The results of this study showed that half and more of the studied caregivers had complete correct answers regarding the psychological signs & symptoms of strains and patterns of coping respectively. While the minority of them had complete correct answers regarding the risk factors of autism. The findings of the current study came in agreement with Mohammed (2013), who revealed that the studied care givers' knowledge regarding the risk factors of autism were incomplete pre-intervention. This may be due to the fact that the family care givers having autistic children may be concerned with the already confirmed diagnosis of

autism and their autistic children's abnormal behaviors, so they focus on how to relive the strains they are facing rather than the risk factors of the autism.

The present study results revealed that the studied caregivers had unsatisfactory knowledge regarding autism, strains\stressors, coping and total knowledge scores. More than half of the studied caregivers had satisfactory knowledge regarding coping. The findings of the current study were consistent with those of the study by Mohammed (2013), who revealed that the majority of family caregivers of autistic children lacked knowledge about autism pre-nursing counseling. This may be due to the fact that the family care givers having autistic children didn't attend any training courses regarding autism, strain and coping.

The present study results clarified that the total scores of the objective, subjective and total caregivers' strains were high, which came in line with Lan (2015), who found that total mean scores of the objective, subjective and total caregivers' strains were high. This may have been due to autism being a long-term disorder. Usually, mothers face stressful challenges of raising autistic children and become concerned with their children’s communication, education, relationships and the independence of their futures.

The findings of the current study however, contradicted with Bauomey (2012) and Mohammed (2013), who found that the majority of the caregivers of autistic children had high parental pressure pre-nursing guidance\intervention. The contradiction may have been due to the difference in the ages of the studied children, where in the Mohammed (2013) study, the children were aged from 1.5 up to 10 years old, while in the study of Bauomey (2012), they were aged from 3-5 years, meaning that the studied caregivers had not begun to think about their autistic children's education, social interaction with friends, their arousals or high sexual desires, and other problems and stressors. Also, these autistic children were free from any chronic physical or neurological disorders. The findings of the current study showed that the majority of the studied caregivers had high total coping scores.

The results of this study demonstrated that the younger the studied mothers the more knowledgeable they are. The researcher interpreted that to be related to the believe that the younger the mother the more eager and enthusiastic to be acknowledged with their children's health problems generally and autism disorder specifically. The findings of the current study contradicted with Parvin et al. (2015), the descriptive study entitled "Knowledge on care of autistic child among the mothers attending Protibondhi foundation, Dhaka", who found a

highly significant relation between the studied mothers' ages and their knowledge about autism ($P < 0.001$), as the majority of mothers who were <30 years old had unsatisfactory knowledge regarding autism. The contradiction may be due to the differences in the cultural back grounds and the study settings.

The findings of the current study contradicted with the researcher's expectations that; the highly educated caregivers, should have more knowledge. This contradiction may have been due to the fact that all the studied caregivers were very interested and curious to know autism as a disability overall and how to deal with it effectively. The current study findings were supported by Hassb-Roubo (2010), in the study entitled "Parental awareness regarding care of their children suffering from autism", who found that although the majority of the studied mothers had high education, most of them had inadequate and incorrect knowledge regarding autism.

The current study findings were also in the same line with Parvin et al. (2015), who found that there was no statistically significant relationship regarding the studied mothers' level of education and their total knowledge mean scores ($P > 0.05$), as although the majority of the studied mothers had post graduate education, their knowledge regarding autism was unsatisfactory.

The current study results revealed that there was a statistically significant relationship regarding the studied caregivers' occupation and their total knowledge mean scores ($P < 0.05$). This may have been due to that housewives had more time to search and gain information about autism. However, this findings of the current study contradicted with Parvin et al. (2015), who found that nearly half of the studied mothers were housewives and there was no statistically significant difference regarding the studied mother's occupation and their total knowledge mean scores ($P > 0.05$).

The current study findings also contradicted with Bauomey (2012), in the study entitled "Counseling intervention for parents caring for children with autism", which involved 60 parents of 3-5 year-old children, free from any chronic physical or neurological disorders, who found that the highest percentage of the studied mothers were housewives and most of them had inadequate and incorrect knowledge regarding autism before the counseling intervention.

CONCLUSION & RECOMMENDATIONS:

In the light of the current study, it can be concluded that the studied caregivers had unsatisfactory total knowledge mean scores regarding (autism, strains and coping), had high total strains mean scores and had high total coping mean scores.

The study recommends emphasize the importance of carrying out educational programs to improve knowledge and care of autism in children & their care givers. The study also recommends conducting further researches on large study sample size in different areas to generalize the results. Also regular assessment and monitoring of the studied family care givers' strains and coping is recommended.

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