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STRESS AND COPING STRATEGIES AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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Abstract

Having a child with autism is a major event that negatively affects families, and force families to re-evaluate its plans, goals, and relationships in light of restrictions and limitations associated with child's disability, and resultant stresses in parents and their efficiency in coping with these stresses. This study aimed to assess stress and coping strategies among parents of children with autistic disorder. A purposive sample of thirty Parents of Autistic Children was recruited from the Center for Social and Preventive Medicine (child psychiatry out-patient clinic) in Abou-El-Rish University Hospital. Three tools were used to conduct the current study, demographic and medical data sheet, parent stress scale and coping strategies scale. The results indicated that, sixty percent of the studied parents had moderate level of stress. The results also showed that, more than fifty percent were using seeking information, avoidance and denial coping strategies. And finally, the results indicated high positive and significant correlation and acceptable predictable relation between levels of stress and coping strategies. In conclusion, children with autism require lifelong provision, management and service coordination.

Keywords

Autism, Parents, Stress and Coping Strategies

1. Introduction

Autism is a complex developmental disability that emerge early in childhood with severe and long lasting effects for individuals and their families (Autism Speaks, 2015). As reported by

the Center for Disease Control & Prevention, the number of children diagnosed with ASD estimated to be 1 in 68 (CDC, 2014).

The effect of having a child with autism in a family can generate severe psychological stressors. From the initial diagnosis to the continuous demanding everyday caretaker responsibilities, for some families, caretaking can be devastating. Parents of children diagnosed with autism encounter with the many obstacles associated with the disorder cause in more stress (Bilgin & Kucuk, 2010). The stressors include problems associated with the characteristics of the disorder, which include social skills, communication, and in diverse cases, behavioral difficulties. Parents, particularly mothers, are more liable to psychological and emotional problems due to the demanding day-to-day tasks of caring for a child with autism (Sawyer, et al. 2010).

Carrying a child with disability is major events that negatively disturb families, and power families to re-arrange its plans, goals, and relationships in light of limitation and constraint associated with child's disability, and resultant stresses in parents, and their capability in coping with these stresses. During re-evaluation process, families tend to utilize available support resources, or look for choices, as an trial to adopt strategies to gain balance between family's resources and disability need to cope with stresses combine with the child's disability (Woodman, & Hauser, 2013).

Strains of caring a child with disabilities will raise levels of stress in parents, which guide them to look for, develop, and use strategies to deal with these stresses. Conforming to (Seymour, et al., 2013) the consequences of using such strategies may be in behavioral presentation such as neglecting responsibilities at home and work, or cognitive manifestation such as defect in problem-solving or emotional presentation which includes negative feelings regarding the child with disability. In this view, (Woodman, & Hauser, 2013) indicate to coping strategies as constant change in cognitive and behavioral act by person to manage the growing external and/or internal needs of caring the child with disability. As stated in (Picci, et al., 2015), parents of children with disabilities contribute to use different strategies to cope with stress such as, looking for support, avoidance strategies, self-blame, drug abuse, making jokes, rebuilding of stressful situation in positive manner.

Parents of children with autism use a range of coping strategies and resources when encounter with parenting stress (Hall & Graff, 2011). Parents use both adaptive (e.g. cognitive reframing, seeking social support) and maladaptive (e.g. avoidance and disengagement) coping strategies with a tendency regarding adaptive coping approaches such as seeking social support and positive reinterpretation (Lai & Oei, 2014).

Families need to know they are not confronting their challenging adventure alone. Accepting and approve their matters may be one of the most important things nurses can do to handle parent's feelings of isolation, denial, and anger. Parents need to master their feeling of grief and loss is normal. They should be inspired to explore their feelings, and find way to handle their grief and loss so, they can turn ahead rather than continuing to live in them (Sommer, 2013).

The basic goal of the nurse is to determine problems and develop a plan of intervention to decrease the prevalence and severity of symptoms. Interventions involve building the nurse-child relationship, strengthen the coping skills of the child and family, determining maladaptive responses, and decline the negative effect of the symptoms of hyperactivity, impulsivity, and inattention, and engage in program application. The nurse also performs a crucial role in assessing the adequacy of interventions and can work as a liaison between the child and family and the other members of the treatment team, containing the child's teachers (DeNisco, Tiago, and Kravitz, 2012).

Nurses can also guide parents to determine which services and treatment are better for the children and those that are not beneficial. Being available to guide the parents as they face the demands that may become devastating will help them become resilient and attain a more valuable conclusion for the family. Instructing the public is one more important form of advocating for families confronting autism (Grove, Burns, Gray, 2013).

2. Significance of the Study

Parents of children with disabilities suffer from stress, which invest them in demand to employ different strategies to cope. Several studies investigated the primary role of coping strategies employed by parents to manage these stress, but conclusion of these studies did not add enough evidence about adequacy of these strategies in decreasing levels of stress in light of disability's type, or rational in which parents choose specific coping strategy but not other. One may propose that type of disability and related limitation and constraint in child and family life, parents' characteristics, and cultural differences may impede with their preference of strategies they used to cope.

3. Aim of the Study

The aim of this study was to assess stress and coping strategies among parents of children with autism spectrum disorder.

4. Research Methodology

4.1 Research Questions

1. What are the stress levels experienced by parents of children with autism?
2. What are the coping strategies used by parents of children with autism?
3. Is there a relationship between Parent stress and coping strategies of parents of children with autism?

4.2 Research Design

The design used in this study was a descriptive exploratory design. The aim of descriptive studies is to notice, explain, and record aspects of a phenomenon as it naturally occurs and at times to aid as a starting point for hypothesis generation or theory development (Polit & Hungler, 2010).

4.3 Setting

The Center for Social and Preventive Medicine (Child Psychiatry Out-patient Clinic) in Abou-El-Rish University Hospital. This unit is receiving children from all over Egypt. The unit includes five rooms and a waiting place for children and their parents, one room for IQ test, one room for nurses to arrange the patient's sheets, two rooms for interview and examination by doctors and one room for group therapy, play therapy, and for children play during waiting examination, and also for social workers' interviews. The clinic provides services for 20-30children/day. The clinic works 6/days/week for behavioral disturbance, developmental delays, and follow up for psychiatric disturbance in children.

4.4 Sample

A purposive sample of (30) Parents of Autistic Children. The sample size of (30) participants was measured using a power analysis. A Power of0.80 ($\beta = 1-.80 = .20$) at alpha. .20(one-sided) was used as the significance level, because these levels have been implied for use in the most areas of behavioral science research (Ellis, 2010), high effect size (.5). Sample was selected according to the following criteria:

A. Inclusion Criteria:

1. Both genders.
2. Children diagnosed by psychiatrists with ASD
3. Ages of all caregivers were 18 years old and more
4. Parents who provide care directly and attached to child with ASD

B. Exclusion Criteria:

1. Parents who didn't fill the questionnaire completely.
2. Parents of children with ASD under 18 years old.

4.5 Data Collection Tools

1- **Demographic and Medical Data Sheet**

This tool was developed by the researchers to elicit information about child information and medical data it included; code, age, gender, number of siblings, order of child between siblings, degree of autism, family history of autism.

2- **Parent Stress Scale (PSS)**

The Parent Stress Scale was developed by Hosny, (2006). The scale was designed to measure level of stress directly associated with the parenting role. The PSS consists of a 72 items divided into six subscales: somatic symptoms (15 item), psychological symptoms associated with child disability (12 item), psychological stress resulting from child communication problems (10), psychological stress resulting from child behave disturbance (17 item), psychological stress resulting from child social skills deficit (13), and psychological stress resulting from financial aspects (5). All items were answered by using 5- point Likert scale. The scoring ranged from (0-4), (0) = Never occurs, (1) = rarely occurs, (2) =sometimes occurs, (3) = often occurs, (4)= always occurs. The total score of the scale is (0- 288). When the parent has a score from Zero to 69 it means that the parent has a mild stress level, from 97 to 192 it means the parent has a moderate level of stress and score from 193 to 288 it means that the parent has a severe stress level. Reliability was assessed by Cronbach's Alpha and it was 0.93 display a high degree of internal consistency and validity was tested 0.78. The tool response duration is within 15-20 minutes.

3- **Coping Strategies Scale**

This scale was developed by Bustami, (2013). the scale used to assess the coping strategies that used by the parent having especial need children. It consists of 64 question (Arabic version), divided into 7 subscale: social support (12 items), performing exercise (7 items), problem solving (8 items), seeking information (11 items), avoidance and denial (13 items), and religious strategies (7 items). All items were answered by using a 5- point Likert scale. The scoring ranged from (1-5), strongly agree = (5), agree = (4), somewhat = (3), disagree = (2), strongly disagree = (1). The total score of the scale is (64- 320). The total scoring system range from (64 to 320), the cutoff point is (160) the higher the score the higher the frequency of using the coping strategies. Reliability and validity were tested (0.72 and 0.93) respectively. The tool response duration is within 15-20 minutes.

4.6 Procedure

Necessary official permission was granted from the director of The Center for Social and Preventive Medicine (Child Psychiatry Out-patient Clinic) in Abou-El-Rish University Hospital

to conduct the proposed study. Full explanation of the rational of the study and its importance was done. The researchers begun data collection by introducing themselves to parents of autistic children who met the inclusion criteria, the researcher clarifies the aim of the study and the content of questionnaires. All questions were answered and detailed explanation was given to taken their acceptance and cooperation during conducted interview sessions.

Each child's mother was interviewed individually from 60-90 minutes for each, after describe the aim of the study and getting approval to participate in the study. The investigators insured voluntary participation and confidentiality to each subject who agreed to participate. In this study the questionnaire was read and explained to every participant and the choices were documented by the researcher in case of incapability of the participants to read and write .For more verification of the mothers' information, the children's files were checked to complete the needed information. Data were collected over a period of three weeks from the end of March up to April, 2018 using the previously mentioned tools.

4.7 Ethical Consideration

Primary permission was obtained from The Director of the Center of Social and Preventive Medicine (Child Psychiatry Out-patient Clinic). All participants signed a written informed consent and acquainted that cooperation in the current study is voluntary; no names were included in the data collection sheets. Anonymity and confidentiality for each participant were secured by the allocation of a code number. Subjects were informed that they can withdraw at anytime during the study without giving reasons. Subjects were notified that in case of withdrawal no risk for stopping the care that they are receiving as well as their relationship with the investigator. Confidentiality was confirmed and subjects were acquainted that the results of this study only for the research purpose.

4.8 Pilot Study

A pilot study was conducted at the beginning of the study. A total of 10 % of the sample consisted of 3 parents. The study tools were submitted to those subjects, who fulfilled the inclusion criteria. The main aim of the pilot study was to ensure clarification and simplicity of data collection tools, and their applicability and relevance, to estimate the time needed to complete the tools, and to find out any problems that might interfere with the process of data collection. The pilot study revealed that, no modifications are needed to be made. Subjects who shared in the pilot study were included in the main study sample.

4.9 Statistical Design

Data were analyzed using the Statistical Package for Social Sciences (SPSS), version 21. Frequency and percentage were used for numerical data as well as mean and standard deviation. Probability (value) less than 0.05 was considered significant and less than 0.001 considered as highly significant.

4.10 Limitations of the Study

1. The investigators faced many difficulties in assembling health statistics related to autistic children in Egypt.
2. There was no specific area for meeting parents of autistic children. So the researchers identified the most suitable time for parents to meet them.

5. Results

Table 1: *Frequency distribution of the studied children according to their demographic Characteristics (n = 30)*

Items	Frequency	Percentage
Child age (years)		
2-<4	8	26.8
4-<6	7	23.3
6-<8	11	36.6
8-10	4	13.3
Total	30	100
Mean ± SD	5.20 ±2.04	
Gender		
Male	18	60.00
Female	12	40.00
With whom child comes		
Mother	29	96.7
Father	1	3.3

Table (1) stated that, age range were 2 to 10 years with mean of 5.20±2.04years. As well, 36.6% of the studied children were in the age ranged between 6 to less than 8years. In relation to gender, 60% of the studied children were males and 40% of them were females. Also, 96.7% of them were coming with his\her mother.

Table 2: *Frequency Distribution of the Studied Parents according to their Age (n=30)*

Item	Frequency	Percentage
Parent age (years)		
20-<24	18	60.0
24-<28	2	6.6
28-<32	10	33.4
Total	30	100.0

Table (2) revealed that, 60.0% of the studied parents were in the age ranged between 20 to less than 24 years.

Table 3: *Frequency Distribution of the Studied Children according to their Medical Data (n = 30)*

Items	Frequency	Percentage
Degree of autism		
Mild	6	20.0
Moderate	9	30.0
Severe	15	50.0
Total	30	100.0
Family history of autism		
Yes	4	13.4
No	26	86.6

Table (3) reveled that, 50.0% of the studied children had severe degree of autism. Also, 86.6% of the studied children had a negative family history of autism and 13.4% had positive family history of autism.

Table 4: *Distribution of the Studied Parents according to their Total Stress Level (n=30)*

Item	Frequency	Percentage
Parent stress level		
Mild	1	3.3
Moderate	19	63.3
Severe	10	33.3
Total	30	100.00

It is noticed from table (4) that, 63.3% of studied parents had moderate level of stress, while 3.3 of them had mild level of stress.

Table 5: *Distribution of the Studied Parents according to their Coping Strategies Style (n = 30)*

Coping Strategies style	Mean	SD	Minimum	Maximum
Seeking information	39.16	8.09	25.00	55.00
Problem solving	30.20	5.11	20.00	37.00
Social support	42.60	8.44	23.00	55.00
Avoidance and denial	43.10	9.78	21.00	59.00
Performing exercise	24.20	5.93	14.00	33.00
Relaxation	21.26	4.00	12.00	28.00
Religious strategy	26.16	5.65	14.00	35.00

Table (5) illustrated that 59% of parents were using avoidance and denial as a coping strategies style. While 55% of them were using seeking information and social support.

Table 6: *Correlation Matrix between the Parents Stress Domains and Coping Strategies Sub Scales among the Studied Parents*

Studied variable	Coping strategies											
	Seeking information		Problem solving		Social support		Avoidance and denial		Performing exercise		Relaxation	
Parent stress domains	R	P	R	P	R	P	R	P	R	P	R	P
Somatic Symptoms	.178	.347										
Child disability			.333	.072								
Child communication problems					.467**	.009						
Child behavioral disorder							.507**	.004				
Child socialization deficit									.435*	.016		
Financial aspect											0.061	0.748

*correlation is significant at the 0.05 level
**correlation is highly significant at the 0.01 level

Table (6) showed that, there is a highly statistically significant correlation were found between psychological stress resulting from child communication problems and social support domain among the studied parents where r=.467 and p= .009. Meanwhile, statistically significant positive correlation were found between psychological stressors resulting from child behavioral

disorder, avoidance and denial where r=0.507 P=.004. Also, statistically significant positive correlations were found between psychological stressors resulting from child socialization deficit and performing exercise as a coping strategies style where r=.435 and p=.016.

6. Discussion

In the light of the current study findings, slightly more than sixty percent of the studied parents have moderate level of stress. This result may be due to that parent's reported feeling exhausted and stressed in regard to the huge responsibilities associated with caring of a child with disability. This result came to be consistent with finding from earlier studies such as (Picci, et al., 2015; & Woodman, & Hauser, 2013; Wang, Michaels, & Day, 2011) which all pointed out high levels of stress in parents of children with autism. According to the literature reviewed before, these high levels of stress came as a result of permanent feelings of crisis of parents' inadequacy to provide effective care to handle developmental and behavioral problems in their child with disability and feelings of segregation and refusal they might face from their societies (Mount & Dillon, 2014).

Moreover, parents are faced with an ambiguous loss when a child is diagnosed as with ASD and the dreams for a healthy child evaporate and the real child cannot live up to the original anticipation. In the same line with this result Karst & Hecke (2012) mentioned that, caring a child with an autism spectrum disorder (ASD) increase parent's stress, physical and mental health problems, family and couple problems, as well as reduce parents efficacy and worse quality of life. Furthermore Silva & Schalock (2012) stated that, difficulties handling challenging behaviors, impaired social communications, and co morbid physical symptoms can place significant burdens on the family. Hayes and Watson (2013) conducted a comprehensive Meta analysis in which the literature on stress in parents with and without children with autism was evaluated. The mean effect size was 1.58, indicating a large and significant effect of raising a child with autism on parenting stress levels. Moreover, Fleishmann (2014) reported that, after a child has been diagnosed with an ASD, parents report that they experience disbelief, shock, and depression.

Coping strategies used by parents of children with autism showed that, seeking information, avoidance and denial were in general the most used ways by those parents. How parents cope with the diagnosis and emotional issues varies, but consistently parents report a strong social support network is a necessary part of being able to cope (Altiere & Von Kluge, 2009). In contrast, Gallagher & Whiteley, 2012 found that, parents of children with ASD reported significantly higher use of a number of coping strategies (i.e., emotional support, positive

reframing, planning, humor, acceptance, and religion) than parents of typically developing children. Conversely, Pisula & Kossakowska, (2016), reported that, parents of children with ASD used less social support seeking strategies than those of typical children.

7. Conclusion

In conclusion, the finding of this study indicated high levels of stress in parents of children with autism, with individual differences in the way parents cope with these stresses.

8. Recommendations

- Future research is needed to investigating the long term effects of various coping strategies on stress.
- Parents of children with disabilities have different levels of stress, and as a result, they use various strategies to cope, and this arouses the need for future investigations for the well-being of parents' life in light of the efficacy of used coping strategies.
- Special education teacher's spotlight on satisfy their students' academic, behavioral and social requirement but it is also equally important to work with and build relationships with parents.

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