

ASSESSMENT OF THE LEVEL OF STRESS OF PARENTS OF CHILDREN WITH AUTISM IN A SELECTED SPECIAL SCHOOL AT ERNAKULAM

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DOI: <http://doi.org/10.47211/idcij.2020.v07i02.015>

ABSTRACT:

Autism is a pervasive developmental disability meaning that the impact of the disorder affects multiple aspects of a child's life and is a major stressor for parents. A descriptive survey design was adopted to assess the stress of parents of children with Autism. The samples were collected from Adarsh Charitable Trust Ernakulam. Kerala. A sample of 30 parents was selected through convenient sampling for the study. The majority (36.7%) of them were in the age group of 26 – 30 years and more than half were holding a degree. Most (83.3%) of the parents belonged to a nuclear family and just 33.33 % were full time employed. Less than half (36.7%) of the parents had a monthly income of 30,000 and the majority (70%) were having just two children. Data analysis was done using descriptive statistics and chi-square statistics to find the association between variables. Based on the study, Majority (86.67%) were having a moderate amount of stress and 3.3 % had severe stress. There was no association between the level of stress and selected demographic variables at $p < 0.005$.

Keywords: Stress, Parents, autism, children.

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INTRODUCTION

The autism spectrum disorder affects multiple aspects of a child's life and is a major cause of stress for mothers. The incidence of autism spectrum disorders has increased significantly to 78% among American children in recent days. The stress of raising a child with autism negatively impacts the family structure and is very stressful for the parents. The most recent estimate from CDC indicates that 1 out of 88 (1.13%) American children have autism with the rate among boys estimated to be 1 in 54.¹

The stress of raising a child with autism has greatly increased the divorce rate among parents of children diagnosed with an ASD. Poverty and loss of social support may affect single mothers raising children with autism, ultimately contributing to poorer outcomes over time. If they were pushed to interact socially the children frequently reacted with tantrums and aggression. Once upset, the children were extremely difficult to calm and the results of interfering with their goal-directed behavior could continue for a long period. Attempts at discipline were frequently ineffective as the children were noted to show 'no' to teach through punishment and these were consistently met with failure as there was no subsequent evidence of learning or reduction of problematic behavior, they could often be destructive. Their parents were noted to be either aloof and disengaged or highly stressed as a result of the difficulties inherent in raising these children.

An additional concern of the parents included increasing concern about the future, lack of services for adults with Autism, the fears about what would happen to their children when parents were no longer be able to care for them at home due to advancing age, and the increasing probability of being harmed during child's aggressive outbursts.²

The cost of caring for a person with autism across a life span was estimated in 2006 to be \$ 3.2 million. The stress associated with caring for a child with autism takes a significant toll on the marriages of their parents, with divorce rates speculated to be 80 % or higher in the media. In addition to the financial stress of caring for a child with autism, parents may be limited in their ability to apply effective coping skills.³

Need for the study

The stress and coping behavior among parents of children with autism have to be assessed to rule out for any health hazard mushroomed out of this type of parenting. From the moment parent begins to suspect that their children with Autism Spectrum Deficit (ASD) are not developing in a neurotypical way, families of children with ASD begin to face challenges that set them apart from other family groups.

This disorder can be emotionally devastating for parents, especially just before and after the child is diagnosed. Additionally, there's the stress of navigating complicated therapy schedules following through on treatment at homes, juggling family commitments with job responsibilities, and many other issues.

The investigator from reviewing the literature and from their personal experience in dealing with parents having children with autism came to know about the difficulty parents face through different means while caring for a child with autism. The high-stress level can lead to burnt-out syndrome among parents and ultimately can affect the child's health in turn.⁴

STATEMENT OF THE PROBLEM

Assessment of the level of stress and coping of parents of children with autism in a selected special school at Ernakulam.

OBJECTIVES:

The objectives of the study were

- To assess the level of stress of parents of children with autism.
- To find the association between the level of stress and selected socio-demographic variables.

METHODOLOGY

A quantitative descriptive survey design was conducted to identify the stress of parents of children with Autism in January 2015. The study included 30 parents of children with autism who were between 20 and 50 years of age. The setting for the study was Adarsh Charitable trust school at Ernakulam. The sampling was selected by convenience sampling method. The demographic proforma and parental stress assessment scale was administered and was supervised by the investigator.

Based on the objectives, a self-administered parental stress assessment scale was prepared and was utilized in the current study. The prepared tool with the blueprint was given for the subject experts, and the reliability was established by using the split-half method.

Description of the tool:

The tool used for data collection consisted of three parts. Part 1 was the demographic proforma, Part II consisted of a self-administered parental stress assessment scale highlighting the key areas of stress as 1. related to the family, 2. related to personal problems, 3. related to social problems, 4. related to the child, and according to the total score obtained it was arbitrarily classified into three sections as mild (26- 59), moderate (60 – 94) and severe (95-130) stress.

RESULTS**Percentage distribution of samples according to demographic variables of parents of children with Autism.**

The majority (36.7%) of the parents were in the age group of 26-30 years of age. Most (66.7%) of the parents were educated. The majority (83.3%) belonged to a nuclear family type. Almost half (33.3%) of the parents were not working whereas 33% worked full time. The majority of the families had a family income above 30000 Rupees every month. The majority (70%) were having only two children whereas just 3.3% had more than two children. Half of the parents (50%) had access to health services within a 5 km radius. Around 56.7% of families had a support group available. The majority (36.7%) of them had children between 3 – 5 years and 80 % of the children were males.

Table 1: Description of the level of stress of parents of children with Autism

To assess the level of stress of parents of children with autism, a self-administered stress assessment scale was administered. Based on the tool the stress levels were arbitrarily classified into three levels as Mild, Moderate, and Severe.

		N = 30
Level of stress	Percentage (%)	
Mild	10	
Moderate	86.67	
Severe	3.34	

Data presented in Table 1 shows that the majority (86.67%) of the parents had a moderate level of stress and (10%) experienced mild stress whereas (3.34 %) had a severe form of stress

Area wise range of level of stress

The stress assessment tool assessed the different areas of stress related to family, related to personal problems, related to social problems, and related to the child. The data revealed the stress related to the child was major stress (69.34%). The stress related to personal and family problems were (55.9%) and (57.5%) respectively. Stress-related to social problems were less (4.7%) comparatively.

Table 2: Maximum score obtained, range of score, mean, median, and SD of the level of stress of parents of children with autism.

Max Score	Range	Mean	Median	SD
130	49 - 104	78.2	80	421.119

The data presented in Table 2 shows that the Maximum score, range of score, mean, median, and standard deviation of the level of stress of parents of children with autism were estimated as 130, 49- 104, 78.2, 80, 421.119 respectively.

Association of the level of stress of parents of children with Autism with selected demographic variables.

Chi-square was computed between the level of stress of parents and the selected variables showed that there existed no significant association between the level of stress and the selected demographic variables. The calculated Chi-Square value (age in years 1.3, type of family 0.6048, employment status 0.51, number of children 0.460, and availability of support group 0.16) were less than the tabled value at 0.05 level of significance. Thus, the null hypothesis H_0 was accepted.

DISCUSSIONS

In the current study, 3.34 % of parents had a severe level of stress and 86.67% of them were experiencing moderate stress. The findings are supported by another study conducted to examine the relationship between the daily parental stress and coping of parents of children with autism. The findings revealed that 82% of mothers and 46% of fathers have severe stress.⁵

This study is further supported by another longitudinal study conducted by grey which observed the period of early childhood is one of the most stressful full times for parents of children with autism. He writes that during a child's early development stage after when the parents realize that something is not right with their children parents go through a period of intense stress as a result of watching their child's problems and become more pronounced in comparison to their normally developed peer.⁶

CONCLUSION

Autism is a pervasive developmental disability and the impact of the disorder affects multiple aspects of a child's life. Almost half (36.7%) of the mothers were between the age group of 26 – 30 years of age and the majority of them (66.7%) had a degree. The maximum (83.3%) parents belonged to the nuclear family and the majority (80%) of their children were boys. Almost half, 50% of the samples were unemployed whereas the majority of spouses of participants were employed with 63.3% with an average family income of 20000- 30000 for 30% of families. The majority (70%) of the families had two children and there was a support group available for just above half (56.7%) of the parents. The current study concluded that the majority (86.67%) of the samples had a moderate level of stress and 3.34 % had severe stress and just 10 % with mild stress.

There existed no association between the level of stress with selected demographic variables like age, educational level, occupational status, family income, the gender of the child, and availability of support groups.

IMPLICATIONS

The findings of the study had several implications for nursing practice, nursing administration, and research.

Nursing practice:

The knowledge of the level of stress of parents is important in nursing practice as the nurses must provide appropriate professional support and other social support systems to families with children with ASD. It helps nurses to educate parents on sound therapies and approaches to provide them with skills needed to directly address the parent's confidence level and to reduce stress.

Nursing education

The preparation of student nurses in the development of skills to be an excellent professional nurse is based on the implementation of the curriculum. The current evidence enables us to revise the curriculum and educate student nurses.

Nursing research

In nursing research, these are helpful to develop new knowledge and approaches towards the stress management strategies as well as help to develop quality nursing care through evidence-based approaches.

Nursing administration

The findings in the nursing administration can help to provide appropriate health care system with appropriate relaxational and rehabilitation facilities to ease the stress and enhance the coping of parents of children with autism.

Limitations

1. Since the samples were conducted on a small sample generalization is restricted.
2. The study was conducted only in one setting as Adarsh charitable trust, Kerala.

Recommendations

1. The study can be done on a large sample for the generalization of findings
2. An interventional study can be done on a stress management program on parents of children with Autism.
3. The study can be done on multiple settings for generalization of findings .

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