

ASSESSMENT OF PARENTAL STRESS AMONG MOTHERS AND FATHERS OF CHILDREN WITH AUTISM

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Abstract

Having a child with developmental disabilities brings life changing implications and long-lasting effects in the life of the whole family. Parenting is inherently challenging, even in relation to normative events experienced by every parent. A number of studies conducted on this area show that parents of children with developmental disabilities experience higher levels of stress compared to parents of children with typical development. The present study is designed to assess and compare the perceived stress among the fathers and the mothers of 30 individuals with ASD. All the children with autism were of moderate- to- severe level of impairment. The Perceived Stress Scale (PSS) was administered on the parents of children with ASD. For statistical analysis, mean, median and t-test were used. Results show that, there is no significant difference between the perceived stress by the mothers and fathers. But the mean perceived stress among this group is higher than the means of the norms provided by the developer of the test. Literature review has revealed that some parents also have reported positives effects of having a young child with an ASD.

Key Words: Perceived stress, Perceived Stress Scale (PSS), Autism Spectrum Disorder (ASD), Parental stress.

Introduction

While parenting stress has been studied in many developed countries, few formal studies have been conducted in developing countries. Having a child with developmental disabilities brings life changing implications and long-lasting effects in the life of the whole family [1, 2].

Research has shown bringing up a young child with a disability gives parents a unique set of challenges that impact their family including relationships among family members [3].

Parenting is inherently challenging, even in relation to normative events experienced by every parent [4] and potentially more so for parents of children with additional needs. Parents of children with Autism Spectrum Disorder (ASD) have also been found to report poorer health and more illnesses than parents of children with typical development [5, 6] and children with other disabilities [7]. Many studies conducted on this area show that parents of children with developmental disabilities experience higher levels of stress compared to parents of children with typical development [8].

In comparison to parents of neuro-typical children, parents of autistic children show an inclination to report higher family stress, and they experience severe physical and psychological problems [9]. The enduring stress eventually shows in the form of various psychological difficulties such as depression, anxiety and lack of satisfaction in life [10 – 13]. These problems not only lead to parents having an anxious life, but also decrease the effect of early educational and therapeutic interventions for autistic children [14]. Researchers have demonstrated that this is in part a result of the severity and ongoing nature of the characteristics of ASD [15]. There also are characteristics that are associated with several diagnoses but may be more pronounced in children with ASD. According to previous researchers, parents of children diagnosed with Autism Spectrum Disorders (ASD) consistently report more stress than parents of typically developing children [16, 17]. and children with other developmental disorders like Down's syndrome [18].

Perceived Stress:

Based on a theory of stress and coping developed by Lazarus and Folkman [19], stress is not simply events that trigger negative emotional responses but it is a two-way process where individuals interact with their environment. In other words, stress can impact individuals' well-being or functioning negatively only when individuals perceive the situation as stressful and their resources are inadequate to handle environmental stimuli. Perceived stress is a concept which focuses on the individual's interpretation of any difficult situation. Perceived stress is explained as experiencing difficulty in meeting demands within important life domains [20]. Lazarus and Folkman [19] further proposed the concepts of cognitive appraisal (i.e., primary appraisal and secondary appraisal) in order to explain individual differences in coping with stressful life events. Primary appraisal is the process in which individuals evaluate situations as threatening, neutral-positive, or not-relevant whereas secondary appraisal is explained as the process in which individuals assess their coping resources in response to the primary appraisal, Folkman and Lazarus in 1985 [21]. . Depending on how individuals perceive the threat level of the environmental stimuli (i.e., primary appraisal), individuals will determine whether their coping resources are adequate or inadequate (i.e., secondary appraisal), and this secondary appraisal will consequently affect individuals' well-being. . Thus, Lazarus cognitive evaluation theory focuses on the individual, the environment and on the simultaneous cognitive evaluation of environmental demands and stimulus response options [22]. According to this theory, cognitive evaluation of the internal and external stimuli plays a vital role in determining the individual's response to them. Cognitive evaluation is the process of judgment by which, the level of adjustment methods available that each person has, is recognized. It includes identifying available resources and options, which will help the person to negotiate with potential or actual demands [23]. This perceived stress determines the individual's reaction to the environmental demands and how do they

cope with it. Lazarus further explained two coping strategies; emotion-focused and problem-focused- which can be developed in individuals to cope with the situational demands.

The main aim of the present study was to examine the profile of stress of mothers and fathers of the children with ASD and also to compare their perception of stress with the community population.

Literature Review

The nature of challenges resulting from the child's developmental deficits affects the type of coping strategies used by parents. Successful adaptation of parents depends on a range of factors, including their coping strategies and styles [24]. Stress experienced by parents may significantly affect their adaptability to the demands of bringing up a child with developmental disability. Recent intervention plans are geared towards strengthening and maintaining family resources and the appraisal process of the parents to protect them from demands of stressful encounters and reduce the sources of stress. Cognitive reappraisal techniques help parents to evaluate the environmental demands and resources available to deal with them; which in turn empower the parents.

In spite of the increased recognition of the fact that both mothers and fathers have significant challenges in bringing up a child with ASD, even in the western countries, very few studies have compared the profile of their stress [25]. The majority of studies on parental stress associated with raising a child with autism have focused on mothers. Although mothers historically have been the primary caregivers of children in India, the importance of the role of fathers belonging to younger generation and the necessity of their involvement in the process of assessment and intervention of children with ASD are clinically obvious. However, our knowledge of how they experience problems related with the child's developmental deficits is still limited. In a previous study Rodrigue *et al.* in 1992 [26] demonstrated that fathers noticed the child's effect on family members' opportunities to satisfy their own needs and on overall family activity. Later studies found that the level of stress in fathers of children with autism is higher than in fathers of typically developing children [27]. Very few research projects to date have compared the stress profiles of mothers and fathers. Tehee *et al.* in 2009 [28] found that mothers were significantly more stressed than fathers while no such finding was reported in fathers [25]. They reported no significant differences in the perceived stress among fathers and mothers of children with ASD. Other researchers, Knusen & Sloper, in 1992 [29] have also shown that mothers were particularly affected by behavioural problems demonstrated by the child, as well as his/her dependency, anxiety and poor communicative skills, while fathers, apart from communication problems, were most affected by the child's physical disability and presence of other stressful life events (e.g. career-related or associated with family finances).

Previous research has shown that the stress of bringing up a child with ASD is much higher than the stress of bringing up a neuro-typical child. However in most studies maternal stress was assessed. There are few studies where stress among both parents was assessed. For example, behaviors related to self-regulation generally are delayed or impaired in children with ASD. These behaviors increase the time and energy demands of caring for these children, thus leading to a greater likelihood of parental stress [30]. In addition, the stress of having a child with ASD can negatively influence the couple relationship [31].

Objective of the study: The present study is designed to assess and compare the perceived stress among the fathers and the mothers of 30 individuals with ASD. All the children with autism were of moderate- to- severe level of impairment.

Methods

Participants: The subjects in this study included 60 (30 mothers and 30 fathers) parents with children with ASD. Participants were the biological parents of their children. The age of the children ranged from 7years to 12years. All the children had clinical diagnosis of mild to moderate level of ASD and they have been receiving intervention for their condition in a centre for intervention. The centre used Applied Behaviour Analysis (ABA), developmental approach viz. Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH), or mixed or eclectic forms of developmental support for the children. Participants' age range varied from 32years to 42years. They all belonged to middle-to high socio-economic status and all had graduation as the minimum qualification status. The results were compared to the response of parents who do not have a child with disability.

Table 1: Subjects' demographic variable

Variable	Mothers	Fathers
n	30	30
Age range	32-37years	35-42years
Level of education		
Graduation	26	21
Masters	4	9
Employment Status		
Employed	6	30
Unemployed	24	-

Table 2: Children's age and gender

Variable	Girls	Boys
n	7	23
Age range	9-12years	7-12years

Materials: Two measures were included in the present research: a brief demographic questionnaire was used to obtain basic information about the parents and their children and a self-report questionnaire, the Perceived Stress Scale (PSS) was used to measure the perceived stress.

Assessment Instruments

Perceived Stress Scale (PSS) (Cohen, 1995): The Perceived Stress Scale (PSS) developed by Cohen, Kamarck and Mermelstein [32]. It is a well-established self-report measure based on the psychological conceptualization of stress. The scale assesses “the degree to which situations in one’s life are appraised as stressful.” It measures the degree to which life has been experienced as unpredictable, uncontrollable and overloaded in the past month. Later Cohen and Williamson in 1988 [33] defined perceived stress as a one-dimensional construct. The scale is easy to complete and can be administered in only a few minutes providing an economic measure for research and practice.

PSS is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one’s life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress. The items are answered on a 0 (Never) to 4 (Very often) Likert scale. The validity and reliability is found to be very high. The PSS was designed for use in community samples with at least a junior high school education. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way. The norm for the community population is also available.

Procedure: The parents were contacted through the therapy centre. Those who agreed to take part in the study were given consent forms and the questionnaires. They completed them at home and returned them personally. The instructions were given on the top of the questionnaire. After getting the filled-up questionnaires they were scored according to the scoring manual and the data were tabulated. Then statistical analysis was done by SPSS.

Results:

Descriptive statistics and t-test was conducted to analyze if there is a significant difference between the perceived stress level of fathers with children with ASD and perceived stress level of mothers with children with ASD.

Table 3: Table depicting Mean and SD of scores of fathers and mothers

	Mothers	Fathers
Mean	18.66	16.66
SD	3.72	4.45

Table 4: Table depicting scores of t-test and df

	t	df	Significance level (2-tailed)
Score	1.88	58	0.64

The t-score is found to be 1.88 which is significant at 0.64 level of significance ($p > 0.05$). Thus, it is seen that there is no significant level of differences between the scores of PSS of

mothers and fathers of children with ASD. However, the mean score of the mothers is slightly higher than the mean score of the fathers.

Table 5: Table depicting the Mean of scores of males and females of community population and of parents of ASD children

Sex	Parents with children with ASD	Community Population
Male	16.66	12.1
Female	18.66	13.7

The scores indicate that the parents with children with ASD perceive more stress in the environment, than the other members of the community.

Discussion:

The current study suggests that the parents with children with ASD have a higher level of perceived stress than the community which in accordance with what is predicted by the previous researchers [34 – 38]. But it is interesting to explore the fact that there is no significant difference between the fathers' perceived stress and the mothers' perceived stress level. Thus, though our culture focuses more on the mothers' role on the child's development but the fathers are equally involved in the developmental process of their children. They share the same amount of distress as the mother. The environmental demands are perceived as more or less same stressful by both of them. There might be some differences among them on the nature of stressors perceived by them which must be explored in future research.

In many different studies, parents have reported positives effects of having a young child with an Autism Spectrum Disorder [39, 40]. Mothers have reported an increase in spiritual connectedness, social support, a sense of purpose, and a community network of support [39, 41]. Also, parents report raising their child with ASD has led to greater meaning to their lives, and enhanced empathy for others [40]. One must keep in mind that when examining families who have a child with ASD, cultural factors are also very important to consider [42]. Various studies have pointed out that parent of children with ASD present significantly higher levels of chronic stress than parent of children with typical development [43-46].

Limitations: The Parental stress was measured using a self administered test. Although these instruments have very good psychometric properties and high reliability and validity in the constructs they measure, they are subjective measures, which can lead to possible biases. Moreover children with ASD with serious behavioral problems or very low cognitive functioning were not part of this sample, so the sample did not represent the entire autism spectrum.

Conclusion: Despite the limitations the study confirmed that parents of children with ASD have stress in their lives. The present study leaves us with the scope to explore the different stressors perceived by parents and also the coping strategies they employ; so that any psychotherapeutic or interventional strategies can be planned accordingly. The exploration of the stressors can also lead to some insight into the social norms and attitudes which might need a

reformation. Parenting children with autism spectrum disorder (ASD) can be more stressful and challenging than parenting children with typical development, especially in countries where there is a dearth of various support resources. Results show that, there is no significant difference between the perceived stress by the mothers and fathers. But the mean perceived stress among this group is higher than the means of the norms provided by the developer of the test. Future research could be on the comparative effectiveness of intervention programs and their influence on the stress level of the parents of children with ASD. It would be interesting to see whether parent empowerment and training programs have an effect on the coping strategies of the parents and their subsequent stress levels.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this work.

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