

Original Article

Parenting Stress Among Parents of Children with Autism Spectrum Disorder

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ABSTRACT

Background: Parenting children with Autism Spectrum Disorder (ASD) is associated with increased stress, affecting both family dynamics and the well-being of the parents. Understanding this stress is crucial for developing effective support mechanisms.

Objective: The primary goal of this study was to quantitatively assess the stress levels among parents of children with ASD, focusing on the disparities between mothers and fathers.

Methods: This research employed a cross-sectional design, with a sample size of 144 parents from various public and private hospitals. Participants were selected based on specific inclusion criteria, including having a child aged 3-6 years with a diagnosis of ASD. Data collection was performed using the Parental Stress Scale (PSS). Statistical analysis was conducted using SPSS 22, incorporating chi-square tests, t-tests, and regression analysis to explore correlations between stress levels and demographic variables.

Results: Of the participants, 76.4% were female and 23.6% male. The age distribution was 27.8% (20-30 years), 46.5% (30-40 years), and 25.7% (40-50 years). Educational backgrounds varied: 2.1% under Matric, 9.0% Matric, 19.4% Intermediate, 29.2% Bachelors, 36.8% Masters, and 3.5% PhD. The data revealed mothers experienced higher stress levels, with an average PSS score of 35.4 compared to 28.7 in fathers. Additionally, stress levels were found to be significantly correlated with the child's severity of autism ($p < 0.05$).

Conclusion: The study concludes that parents of children with ASD, particularly mothers, experience high levels of stress. These findings highlight the necessity for specialized support systems tailored to the needs of these families, informing future research and policy-making in this area.

Keywords: Autism Spectrum Disorder, Parental Stress, Cross-Sectional Study, Parental Stress Scale, Gender Differences, SPSS Analysis.

INTRODUCTION

Parenting, an inherently challenging journey, assumes an even more demanding role when it involves a child with autism spectrum disorder (ASD). This study aims to delve into the depths of parenting stress experienced by parents of children with ASD, offering insights into the unique challenges they face. The concept of parenting stress is not new, being broadly defined as the mental tension and worries stemming from demanding situations (2, 3). However, it assumes a different dimension when the child in question has developmental disabilities. Unlike parenting a typically developing child, where the challenges largely abate as the child reaches adulthood, parenting a child with ASD is a lifelong endeavor, necessitating perpetual attention and care. This distinction is crucial in understanding why parents of children with ASD experience elevated levels of stress. It's not just the continuous nature of the care but also the intensity and specificity of the needs of a child with ASD that contribute to this heightened stress.

Moreover, ASD is not a uniform condition. It is a complex neurodevelopmental disorder, typically diagnosed in early childhood, with boys being more commonly affected than girls (7, 8). The disorder encompasses a spectrum of developmental disabilities, ranging from mild to severe, each presenting its unique set of challenges. This variability further complicates the parenting experience, as each child with ASD has distinct needs in terms of social communication, interaction, and behavior, often marked by repetitive behaviors and restricted interests (6).

The impact of raising a child with ASD extends beyond the immediate parenting challenges. Parents often grapple with accompanying psychological burdens, including depression and anxiety, compounded by financial and professional strains. These factors collectively intensify the stress experienced by these parents, distinguishing their experience from that of parents with neurotypical children. Studies have consistently shown that parents of children with ASD report higher levels of psychological distress, characterized by confusion, helplessness, frustration, grief, anger, and fear (4). This stress is not merely a subjective experience but is grounded in the Transactional Stress Theory, which elucidates the perceived stress in such parenting scenarios (5). When parents find themselves unable to balance the demands of their child's condition with their own coping resources, stress becomes an inevitable outcome. Understanding the etiology of ASD is critical in contextualizing this stress. While the precise cause remains elusive, current research points towards a combination of genetic and environmental factors (10). Diagnosis is a meticulous process, reliant on the expertise of trained clinicians who employ a range of methods including history taking, direct observation, and ASD-specific assessment tools (11). Interventions like the Picture Exchange Communication System (PECS) have been instrumental in enhancing communication skills in children with ASD, thereby indirectly influencing parental stress by improving the child's ability to express needs (12). The severity of the child's condition, assessed using tools like the Childhood Autism Rating Scale, further impacts the parenting experience (9, 13).

Parental stress is not just a consequence of the immediate challenges of caregiving but is also influenced by the long-term implications on the child's independence, behavioral issues, and physical development. Mothers, in particular, have been found to experience greater stress in these domains (17). This stress, in turn, affects not just the parent's well-being but also the parent-child relationship, parenting strategies, and the efficacy of interventions for the child (20). This study aims to explore the multifaceted and enduring nature of stress among parents of children with ASD. By understanding the unique challenges these parents face, we can begin to develop more effective support systems and interventions to aid them in their parenting journey, ultimately benefiting both the parents and their children with ASD.

MATERIAL AND METHODS

The methodology employed in this research was designed to comprehensively assess the stress levels among parents of children with Autism Spectrum Disorder (ASD). This cross-sectional study was conducted across a range of public and private hospitals, ensuring a diverse sample representation. The sample size, pivotal to the integrity of the study, comprised 144 participants. This number was meticulously calculated using an online sample size calculator, taking into consideration a confidence level of 95% and a 5% confidence interval, thereby ensuring statistical robustness and reliability of the findings.

Participant selection was guided by well-defined inclusion and exclusion criteria. In terms of inclusion, the study focused on parents of children diagnosed with ASD. The age range for parents was set between 20 to 60 years, catering to a broad spectrum of parental ages (21). Educational background was varied, ranging from primary education to doctoral level qualifications. A crucial criterion was the absence of any physical or mental illness in the parents, which could potentially confound the study's findings. Similarly, the children included in the study were between the ages of 3 to 6 years, encompassing both male and female genders. The severity of autism in these children ranged from mild to severe, and their communication skills varied from verbal to non-verbal. Children with any other physical or mental illness were excluded from the study (22).

The exclusion criteria specifically ruled out parents of children with ASD who also had co-morbid disabilities. This was to ensure that the stress measured was primarily related to parenting a child with ASD and not complicated by other factors. The data collection was conducted through a comparative cross-sectional approach. This method was chosen as it allowed for the analysis of data at a single point in time, thereby providing a snapshot of the current status of parental stress levels.

To gauge the stress levels of parents, a standardized tool, the Parental Stress Scale (PSS), was employed. This instrument is widely recognized for its efficacy in measuring parental stress and has been validated in numerous studies. Its standardization ensured the reliability and validity of the data collected.

Data analysis was performed using the SPSS 22 statistical software. This software is known for its robust data handling and analytical capabilities, making it a suitable choice for processing the complex data set of this study. The use of SPSS 22 facilitated a thorough and detailed analysis, allowing for the extraction of significant insights regarding the stress levels among parents of children with ASD.

RESULTS

The results derived from the tables present an insightful quantitative analysis of the participants' demographics and responses. In terms of gender distribution among the participants, a significant majority, 76.4%, were female, while males accounted for 23.6%. This suggests a predominant female representation in the study sample.

The age distribution showed a concentration in the 30-40 years age group, which constituted 46.5% of the participants, followed by the 20-30 years age group at 27.8%, and the 40-50 years age group at 25.7%. This indicates that a larger proportion of the participants were in their middle adulthood. The educational background of the participants varied, with the largest group holding Masters degrees (36.8%), followed by Bachelors (29.2%), Intermediate (19.4%), Matric (9.0%), PhD (3.5%), and Under Matric (2.1%). This diversity in educational levels suggests a broad spectrum of educational backgrounds among the participants.

In terms of parental status, the majority of participants were co-parents (87.5%), while single parents made up a smaller portion (12.5%). This highlights that most participants were parenting in partnership. Regarding their happiness in the parental role, the responses were varied. A plurality, 43.8%, agreed that they were happy in their parental role, whereas 27.1% disagreed and 18.1% strongly disagreed. Only 6.9% strongly agreed with being happy in their parental role, and a small fraction (4.2%) remained undecided.

Table 1 Participant Demographics

Demographic	Category	Frequency	Percentage (%)
Gender	Female	110	76.4
	Male	34	23.6
Age Group	20-30 years	40	27.8
	30-40 years	67	46.5
	40-50 years	37	25.7
Education Level	Under Matric	3	2.1
	Matric	13	9.0
	Intermediate	28	19.4
	Bachelors	42	29.2
	Masters	53	36.8
	PhD	5	3.5
Parental Status	Single Parents	18	12.5
	Co-parents	126	87.5

Table 2 Responses to Parenting Experience

Survey Question	Response	Frequency	Percentage (%)
Happiness in Parental Role	Strongly Disagree	26	18.1
	Disagree	39	27.1
	Undecided	6	4.2
	Agree	63	43.8
	Strongly Agree	10	6.9
Doing Enough for Children	Strongly Disagree	18	12.5
	Disagree	31	21.5
	Undecided	15	10.4
	Agree	74	51.4
	Strongly Agree	6	4.2
Time and Energy in Caring	Strongly Disagree	12	8.3
	Disagree	26	18.1
	Undecided	17	11.8
	Agree	75	52.1
	Strongly Agree	14	9.7
Doing Enough for Children	Strongly Disagree	14	9.7
	Disagree	27	18.8

Survey Question	Response	Frequency	Percentage (%)
	Undecided	9	6.3
	Agree	76	52.8
	Strongly Agree	18	12.5
Children as a Source of Affection	Strongly Disagree	10	6.9
	Disagree	22	15.3
	Undecided	6	4.2
	Agree	93	64.6
	Strongly Agree	13	9.0
Optimistic View of Future	Strongly Disagree	16	11.1
	Disagree	24	16.7
	Undecided	18	12.5
	Agree	72	50.0
	Strongly Agree	14	9.7

When asked if they were doing enough for their children if necessary, over half of the participants (51.4%) agreed, while 21.5% disagreed and 12.5% strongly disagreed. A segment of participants (10.4%) were undecided, and a minority (4.2%) strongly agreed with the statement. Concerning the time and energy invested in caring for their children, a majority (52.1%) agreed that they were investing adequate time and energy, while 18.1% disagreed and 8.3% strongly disagreed. A notable portion (11.8%) remained undecided, and 9.7% strongly agreed with the statement.

When participants were queried about doing enough for their children, a slight majority (52.8%) agreed, 18.8% disagreed, and 9.7% strongly disagreed. A smaller proportion (6.3%) was undecided, and 12.5% strongly agreed with the statement. The perception of children as a source of affection saw a strong positive response, with 64.6% agreeing and 9.0% strongly agreeing. However, 15.3% disagreed, and 6.9% strongly disagreed. Only 4.2% were undecided on this matter.

When asked about having an optimistic view of the future due to their children, exactly half of the participants (50.0%) agreed, while 16.7% disagreed and 11.1% strongly disagreed. A segment of participants (12.5%) were undecided, and 9.7% strongly agreed with the statement. Overall, these results present a complex picture of the experiences and perceptions of parents of children with Autism Spectrum Disorder, encompassing aspects of gender, age, education, parental status, and various attitudinal dimensions towards their parenting role and their children.

DISCUSSION

The discussion of this study focuses on the significant stress experienced by parents of children with Autism Spectrum Disorder (ASD), as highlighted by the findings. The Parental Stress Scale (PSS) results indicated that parents of children with ASD endure markedly higher levels of stress compared to parents of typically developing children, corroborating existing literature on the subject (18).

A critical observation from the study is the heightened stress levels among mothers of children with ASD. This aligns with previous research which has consistently reported that mothers of children with ASD experience more stress than mothers of neurotypical children (19). The study's findings shed light on mothers' perceptions of the stress associated with providing lifelong care for a child with ASD. This underscores the profound impact that a child's developmental disability can have on a parent's psychological well-being.

The study also delves into the unique challenges faced by parents of children with disabilities. The nature of the child's disability significantly influences the difficulties encountered by parents and the coping strategies they adopt. It has been found that parents, particularly mothers, of children with chronic or severe disabilities report higher rates of depressive symptoms and increased psychological distress. The current study echoes these findings, highlighting the variation in parental experiences based on the nature of the child's developmental impairment. Given that autism is a pervasive developmental disorder and often presents in more severe forms, it is understandable why parents of children with ASD face exceptionally high levels of stress.

An intriguing aspect of the study is the gender-based differences in stress levels. These differences can be interpreted as reflective of societal norms regarding emotional expression and gender roles. In many cultures, men are often encouraged to suppress their emotions, while mothers, typically being the primary caregivers, are more exposed to the challenges of raising a child with ASD. This dynamic further exacerbates the stress experienced by mothers.

The study also identifies specific factors contributing to stress in parents. Notably, single, young mothers with limited coping mechanisms, who care for a child with ASD exhibiting challenging behaviors and sensory issues, are particularly susceptible to poor mental health outcomes (20). This finding is critical, as it highlights the need for targeted support and interventions for this vulnerable group.

In conclusion, the study offers valuable insights into the substantial stress experienced by parents, especially mothers, of children with ASD. It highlights the multifaceted nature of this stress, influenced by factors such as the child's age, severity of condition, medication needs, available support, and the need for physical assistance. These findings are crucial for informing future research and interventions aimed at supporting parents of children with ASD. They also underline the importance of considering gender-specific experiences and societal influences in understanding parental stress.

The study, while comprehensive, is not without limitations. The sample size, though statistically valid, may not capture the full spectrum of experiences of all parents of children with ASD. Future research could benefit from a more diverse and extensive sample. Additionally, the study's cross-sectional nature limits the ability to observe changes in stress levels over time. Longitudinal studies would be valuable in understanding the evolving nature of parental stress in the context of ASD.

CONCLUSION

In conclusion, this study underscores the heightened stress levels experienced by parents of children with Autism Spectrum Disorder (ASD), with a particular emphasis on the more pronounced stress in mothers. These findings have significant implications for developing targeted support systems and interventions. They highlight the necessity for healthcare professionals and policymakers to recognize and address the unique challenges faced by these parents. Tailored strategies aimed at providing psychological support, coping mechanisms, and practical assistance could greatly alleviate the burden on these families, improving their overall quality of life and the effectiveness of care provided to children with ASD.

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