TITLE

" PARENTAL STRESS: A COMPARATIVE STUDY BETWEEN PARENTS OF CHILDREN WITH MODERATE INTELLECTUAL DISABILITY AND AUTISM SPECTRUM DISORDER"

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ABSTRACT

This study conducts a comparative analysis of stress levels between parents of children diagnosed with Autism Spectrum Disorder (ASD) and those with moderate Intellectual Disabilities (ID). A total of 40 parents participated, equally divided into two groups: 20 parents of children with ASD and 20 parents of children with Moderate ID. Standardized psychological assessments were employed to measure perceived stress and coping mechanisms. Preliminary findings suggest that parents of children with ASD experience significantly higher levels of stress compared to parents of children with Moderate ID. Contributing factors to this heightened stress include challenges in communication, social integration difficulties, and the need for specialized care associated with ASD. These results underscore the importance of developing tailored support systems and interventions to address the unique needs of these parents, aiming to enhance their overall well-being and coping strategies.

Keywords: Stress, Parental Stress, Moderate intellectual disability (ID), Autism Spectrum Disorder (ASD).

1. INTRODUCTION AND LITERATURE

1.1 Intellectual disability (ID)

Intellectual disability (ID) is a developmental condition characterized by significant limitations in both intellectual functioning and adaptive behaviour, affecting various conceptual, social, and practical skills. These challenges emerge during the developmental period, typically manifesting before the age of 18, and can impact a child's ability to learn, communicate, and function effectively in daily life.

1.1.1 Diagnostic Criteria:

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the diagnosis of intellectual disability involves:

1. **Deficits in Intellectual Functions:** This includes impairments in reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and

experiential learning, as confirmed by clinical evaluations and standardized intelligence testing.

2. **Deficits in Adaptive Functioning:** These are limitations in conceptual, social, and practical skills that hinder the individual's ability to perform activities of daily living, such as communication, social participation, and independent living.
3. **Onset During the Developmental Period:** The intellectual and adaptive deficits must originate during the developmental phase, leading to functional limitations in various life settings.

1.1.2 Classification of Severity:

Intellectual disability (ID) is categorized into various levels according to the degree of cognitive impairment.

- Independent living with little assistance and rudimentary academic and vocational abilities is usually possible for those with **mild ID (IQ 55–69)** (APA, 2013).
- People with **moderate ID (IQ 35–54)** can learn self-care and communication skills, but they need greater assistance with everyday tasks (APA, 2013).
- According to WHO (2019), **severe ID (IQ 20–34)** entails severe limits and necessitates extensive assistance with everyday tasks.
- The most severe type of ID, known as **profound ID (IQ <20),** requires lifelong, comprehensive care for all facets of communication and everyday living (WHO, 2019).

1.2 Prevalence and Demographic Considerations:

Intellectual disability affects approximately 2–3% of the global population, with mild ID being the most prevalent. The condition is more commonly diagnosed in males and is observed across all socioeconomic and cultural groups. Environmental factors, such as prenatal care and early childhood nutrition, play significant roles in the prevalence and severity of ID.

Understanding the multifaceted nature of intellectual disability is crucial for developing effective support systems and interventions tailored to the needs of affected individuals and their families.

1.3 Impact on Parental Well-being:

Parenting children with developmental disabilities, such as Autism Spectrum Disorder (ASD) and Intellectual Disabilities (ID), presents unique challenges that significantly impact family dynamics and individual well-being. These challenges often extend beyond the child, affecting parents' emotional, social and financial aspects of life.

Parenting children diagnosed with Autism Spectrum Disorder (ASD) or Intellectual Disabilities (ID) presents unique challenges that significantly impact parental well-being. Various studies suggest that these challenges often manifest as elevated levels of anxiety and stress, affecting various aspects of family life.

1.3.1 Financial Strain:

The financial burden on families is substantial, with costs arising from specialized therapies, medical expenses, and adaptive services. Many parents face difficult choices

between basic necessities, such as heating and food, while also bearing the extra costs for therapies and special diets for their children.

1.3.2 Social and Emotional Challenges:

Beyond financial and physical demands, parents often encounter social isolation and emotional distress. The stigma associated with developmental disabilities can lead to exclusion from social networks, exacerbating feelings of isolation. Additionally, the stress of caregiving can strain marital relationships and limit opportunities for personal time and self-care.

1.3.3 Need for Support and Intervention:

Addressing these challenges necessitates comprehensive support systems, including accessible healthcare services, financial assistance, and community-based programs. Parent-mediated interventions have shown promise in improving parent-child interactions and reducing stress. A 2013 Cochrane Review found that while there was no evidence of gains in most of the primary measures, there was strong evidence for a positive pattern of change in parent-child interactions.

In conclusion, understanding and addressing the multifaceted challenges faced by parents of children with ASD and ID are crucial for promoting family well-being. This includes recognizing the emotional, social, and financial strains and implementing supportive interventions tailored to their unique needs.

1.4 Autism Spectrum Disorder (ASD):

The neurodevelopmental disease known as autism spectrum disorder (ASD) is typified by limited or repetitive behaviours as well as poor social interaction and communication (American Psychiatric Association [APA], 2013). Intellectual disability is not the best explanation for symptoms, which must appear early in development. The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) states that this disease has very variable clinical symptoms and that its severity ranges from mild to severe, with three severity levels: 1–3. The degree of severity is determined by limited and repetitive behavioural patterns as well as poor social communication.

Adaptive capacities are impaired in individuals with ASD, independent of their intellectual level, and this impairment can worsen with growth (Kanne et al., 2011; Chatham et al., 2018; Precenzano et al., 2020; Pastorino et al., 2021).

1.5 Parental Stress:

In a similar vein, parents of children with ID deal with a lot of stress from their caregiving duties. The level of stress faced can vary depending on the severity of intellectual disabilities; parents of children with moderate ID frequently need more assistance with everyday tasks. Since many parents cut back on their work hours or quit their jobs to give the care they need, these difficulties can cause financial difficulties as well as damaged family ties. Given that children with autism spectrum disorder (ASD) exhibit limited and stereotyped behavioural patterns and have

considerable impairments in social interaction and communication, parents may experience particular problems in raising a kid with ASD (APA, 2000).

Another study suggested, children with ASD often exhibit intellectual disability (ID), anxiety, eating and sleeping disorders, temper tantrums, aggressive behaviour and self-harm, social isolation, and self-care issues. These issues pose significant daily challenges for parents (e.g., Cotton and Richdale, 2010, Matson and Shoemaker, 2009, Rodrigue et al., 1991, Schreck et al., 2004, White et al., 2009).

2. MATERIALS AND METHOD

2.1 Research Design:

This study employs a mixed quantitative and qualitative research design to analyse and compare 'Parental Stress' between Parents of Children with Moderate Intellectual Disability and Autism Spectrum Disorder using 20 samples from each group.

2.2 Sample and Data Collection:

The study involved 40 parents of children diagnosed with Autism Spectrum Disorder (ASD) and Moderate Intellectual Disabilities (ID), comprising 20 parents of children with ASD and 20 parents of children with ID. Participants were recruited from the National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID) and Rainbow Children's Hospital in Secunderabad, Telangana with prior approval obtained from both institutions. Data collection focused on assessing parental stress levels.

2.3 Variables and Measures:

In this comparative study of parental stress between parents of children with Autism Spectrum Disorder (ASD) and Moderate Intellectual Disabilities (ID) using the Parental Stress Scale (PSS), the primary variable under investigation is **Parental stress**.

2.3.1 Parental Stress Scale (PSS):

- **Description**: The PSS, an 18-item self-report questionnaire created by Berry and Jones (1995), measures how parents feel about their parenting role, taking into account both positive (such as emotional rewards and personal growth) and negative (such as resource demands and stress).
- **Usage**: A 5-point Likert scale, with 1 denoting "strongly disagree" and 5 denoting "strongly agree," is used to grade each topic; higher scores correspond to higher levels of stress.
- **Scoring**: Reverse scores for certain items (1, 2, 5, 6, 7, 8, 17, and 18) are computed (1=5, 2=4, 3=3, 4=2, 5=1), and then added up to determine the overall stress score. Higher scores indicate higher levels of parental stress; the total possible scores range from 18 to 90.

In addition to parental stress, several **demographic variables** are typically considered to provide context and control for potential confounding factors. These include:

2.3.2 Demographic Variables:

- **Parent-Related Variables:**
  - Socioeconomic Status: Economic and social position based on income, occupation.
  - Educational Background: Highest level of education completed.
- **Child-Related Variables:**
  - Autism Spectrum Disorder (ASD)
  - Moderate Intellectual Disabilities (ID).

Collecting data on these demographic variables helps control for potential confounding factors, providing a comprehensive understanding of the influences on parental stress levels.

2.4 Hypotheses:

- **Null Hypothesis (H_0):** There is no significant difference in the stress levels between parents of children with ASD and parents of children with moderate ID.
- **Alternate Hypothesis (H_a):** Parents of children with ASD experience significantly higher stress levels than parents of children with Moderate ID.

2.5 Inclusion and Exclusion Criteria for the Study

- **Inclusion Criteria:**
  1. Parents of children diagnosed with ASD
  2. Parents of children diagnosed with Moderate ID
- **Exclusion Criteria:**
  1. Parents of children Mild, Severe and Profound ID cases
  2. Parents of children with physical disability and other associated comorbid conditions like fits.

2.6 Data Analysis and Tools used in the Study:

The collected data were analysed using the following statistical methods:

- **Mean (M):** Calculated to determine the means of Parental Stress Scale score for both of the Autism Spectrum Disorder (ASD) and Moderate Intellectual Disabilities (ID) groups.
- **Standard Deviation (SD):** Computed to assess the variability of Parental Stress Scale score within each group.
- **Independent Samples t-Test:** Conducted to compare the individual means of Parental Stress Scale scores from both groups, evaluating if observed differences are statistically significant.
- **Pearsons's Correlation Coefficient (r):** Calculated to examine the strength and direction of the relationship between each age group.

All statistical analyses were performed using SPSS software, with significance set at $p < 0.01$.

3. RESULTS AND DISCUSSION

This chapter presents the analysis and results from the study (N=40) conducted on Parents with children diagnosed with Moderate Intellectual Disabilities (ID) and Autism Spectrum Disorder

(ASD), all of whom were participants from a school under the National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID), Rainbow Children's Hospital in Secunderabad, Telangana with prior approval obtained from both institutions.

3.1 Parental Stress Scale (PSS) Test Analysis on Parents of children with ASD and Moderate ID respectively:

- **Table 1:** Shows the Individual Analysis of scores of **Parental Stress Scale Response Checklist** conducted on all 20 parents of children with ASD (N=20) and Moderate ID (N=20) respectively.

	ASD PSS Score	Mod ID PSS Score
Mean	65.6	58.8
Std. Deviation	7.17	9.36
Variance	51.41	87.64
Minimum	51	43
Maximum	76	76
Skew	-0.22	0.09
95% Confidence interval of Mean	62.24 - 68.96	54.42 - 63.18
Mean ± Std.	65.6 ± 7.17	58.8 ± 9.36

Table 1: PSS Test Scores of Parents with children with Moderate ID (N=20)

3.2 t- test Analysis:

- **Table 2:** Shows the analysis of t-test scores on independent Parental Stress Scale (PSS) means of Parents of children with ASD (N=20) and Moderate ID (N=20):

	ASD (N=20)	Moderate ID (N=20)	t- test value
Mean	65.6	58.8	2.58 T-value Calculation $s^2_p = ((df_1/(df_1 + df_2)) * s^2_1) + ((df_2/(df_2 + df_2)) * s^2_2) = ((19/38) * 51.41) + ((19/38) * 87.64) = 69.53$ $s^2_{M_1} = s^2_p/N_1 = 69.53/20 = 3.48$ $s^2_{M_2} = s^2_p/N_2 = 69.53/20 = 3.48$ $t = (M_1 - M_2)/\sqrt{(s^2_{M_1} + s^2_{M_2})} = 6.8/\sqrt{6.95} = 2.58$
Std. Deviation	7.17	9.36	
Variance	51.41	87.64	

Table 2: t-test scores of Parents with children with ASD (N=20) and Moderate ID(N=20)

❖ Below **figure 1** depicts the **t-test Scores** of Parental Stress Scale **PSS** conducted on Parents with children with ASD (N=20)

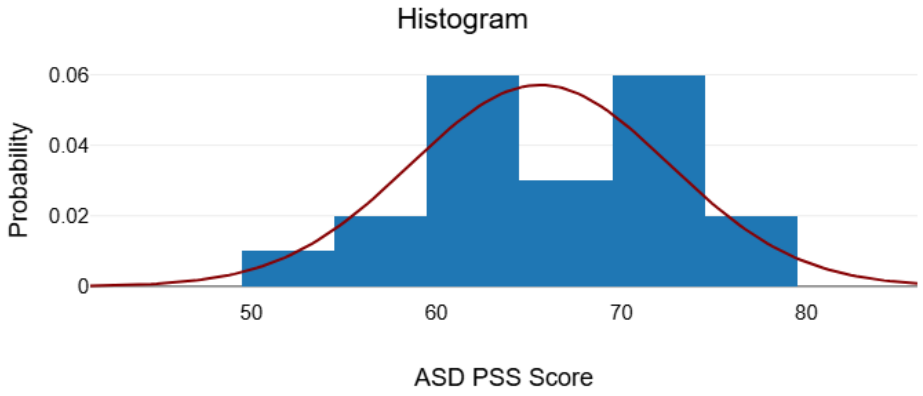

Fig1: t-test Scores of Parental Stress Scale PSS conducted on Parents with children with ASD (N=20) at Significance Level (0.01)

❖ Below **figure 2** depicts the **t-test Scores** of Parental Stress Scale **PSS** conducted on Parents with children with ASD (N=20)

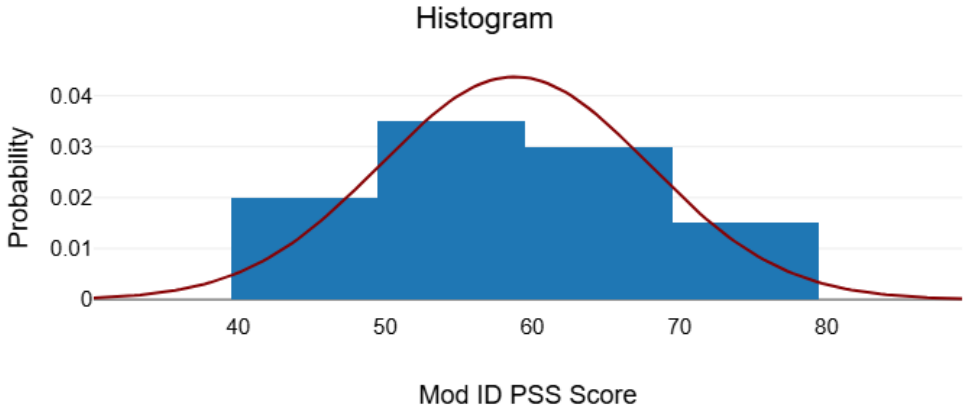

Fig2: t-test Scores of Parental Stress Scale PSS conducted on Parents with children with Moderate ID (N=20 at Significance Level (0.01)

Result Analysis:

- The results of the descriptive statistics show that the ASD PSS Score group has higher values for the dependent variable (M = 65.6, SD = 7.17) than the Moderate ID PSS Score group (M = 58.8, SD = 9.36).
- A two-tailed t-test for independent samples (equal variances assumed) showed that the difference between ASD PSS Score and Mod ID PSS Score with respect to the dependent variable was statistically significant, $t(38) = 2.58$, $p = .014$, 95% confidence interval [1.46, 12.14].
- Thus, the null hypothesis is rejected and alternative Hypothesis is accepted i.e., 'Parents of children with ASD show significantly higher Parental stress levels than parents of children with Moderate ID.'

3.3 Correlation Analysis:

❖ **3.3.1 Table 3:** Depicts the **Correlation scores** of PSS on Parents of children with ASD (N=20) and Moderate ID (N=20).

Pearson Correlation	r	p
ASD PSS Score vs Mod ID PSS Score	-0.03 *R Calculation* $r = \sum((X - M_y)(Y - M_x)) / \sqrt{((SS_x)(SS_y))}$ $r = -42.6 / \sqrt{(976.8)(1665.2)} = -0.0334$ *Meta Numerics (cross-check)* r = -0.0334	.889

Table 3: Correlation Scores of PSS on Parents of children with ASD and Moderate ID

❖ Below **figure** represent the Correlation between the two groups of PSS scores calculated on parents of children with ASD and Moderate ID

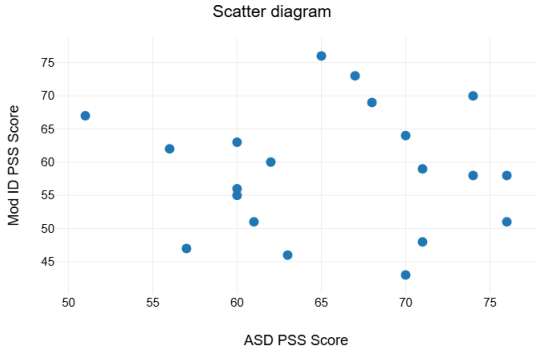

Fig3: Parental Stress Scale PSS conducted on Parents with children with ASD(N=20) and Moderate ID (N=20)

Result Analysis:

- A Pearson correlation was performed to determine if there is a correlation between variables ASD PSS Score and Mod ID PSS Score. As the r value depicts a negative correlation between groups ASD PSS Score and Mod ID PSS Score i.e., **r = -0.03**, signifying a very weak/almost no association between ASD PSS Score and Mod ID PSS Score in this study.
- Although technically a negative correlation, the relationship between the groups is only weak (the nearer the value is to zero, the weaker the relationship).

4. SUMMARY AND CONCLUSIONS

4.1 Summary and Conclusion:

- Descriptive statistics revealed that Parents of children with Autism Spectrum Disorder (ASD) reported higher stress levels (M = 65.6, SD = 7.17) than Parents of children with Moderate Intellectual Disability (ID) (M = 58.8, SD = 9.36). Further analysis using a two-tailed t-test for independent samples (assuming equal variances) demonstrated that this difference was statistically significant, t (38) = 2.58, p = .014. Consequently, the null hypothesis was rejected in favour of the alternative hypothesis, indicating that parents of children with ASD are prone to significantly higher levels of parental stress compared to parents of children with Moderate ID.

- This study investigated the parental stress levels of parents with children diagnosed with Autism Spectrum Disorder (ASD) compared to those with children diagnosed with Moderate Intellectual Disability (Mod ID). A Pearson correlation analysis was conducted to assess the relationship between the ASD PSS Score and Mod ID PSS Score. The resulting correlation coefficient (r = -0.03) indicates a negligible negative correlation, suggesting a very minimal/weak association between the parental stress scores of the two groups.
- According to the study's findings, parents of children with ASD experience higher levels of stress than parents of children with Moderate ID. Even though there was only a very slight negative association between the two groups' stress scores, the notable variation in mean stress levels emphasizes the particular difficulties faced by parents of children with ASD. These findings are consistent with the body of research highlighting the need for treatments and specialized support for this group.

4.2 Limitations:

- The study's limited sample size may affect the robustness and generalizability of the findings.
- This study did not examine potential comorbidities which are prevalent in both Autism Spectrum Disorder (ASD) and Moderate Intellectual Disability (ID), such as epilepsy, gastrointestinal issues, and psychiatric disorders. The absence of data on these comorbidities limits the understanding of their impact on parental stress levels.

4.3 Ethical Considerations:

- Ensured informed consent to the participants to understand the study's purpose, procedures and potential risks before agreeing to participate.
- Protection of participants' personal information and maintaining data privacy.
- Allowing participants the right to withdraw from the study at any time without facing negative consequences.

4.4 Suggestions for future Research:

- The study did not include to assess the areas comorbidities on ASD and ID conditions. Proper identification and support for comorbidities are essential to prevent additional stress for both parents and children.
- These results align with existing literature emphasizing the need for investigating the effectiveness of support systems and targeted support interventions programs for this demographic.

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