

A Study of Psychological Distress and Perceived Social Support among Caregivers of Children with Intellectual Disability and Autism Spectrum Disorder

Ms. Parul¹, Dr. Suman Kumari²

¹Post Graduate Diploma in Rehabilitation Psychology Student, State Institution for Rehabilitation Training & Research (SIRTAR), Gandhi Nagar, Rohtak-124001, Haryana, India

²Senior Scientific Officer, Forensic Science Laboratory, Forensic Psychology, Dept. of Police, Madhuban, Karnal, 132001, Haryana, India

ABSTRACT

Caregivers of children with neurodevelopmental disorders often experience substantial psychological burden due to prolonged caregiving demands, social stigma, and limited support systems. Psychological distress, comprising depression, anxiety, and stress, is commonly reported among caregivers of children with Intellectual Disability (ID) and Autism Spectrum Disorder (ASD). Perceived social support has been identified as an important protective factor that may buffer the adverse psychological effects of caregiving stress. The present study aimed to assess psychological distress and perceived social support among caregivers of children with ID and ASD and to examine the relationship between these variables. The study employed a comparative correlational research design on a sample of 100 caregivers, consisting of 50 caregivers of children with ID and 50 caregivers of children with ASD. Psychological distress was measured using the Depression Anxiety Stress Scales-21 (DASS-21), and perceived social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS). Results indicated that caregivers of children with ASD reported significantly higher levels of depression, anxiety, and stress compared to caregivers of children with ID. Perceived social support was significantly lower among caregivers of children with ASD. A significant negative correlation was found between psychological distress and perceived social support, indicating that higher perceived social support was associated with lower psychological distress. The findings highlight the importance of strengthening social support systems and integrating caregiver-focused mental health interventions into clinical and rehabilitation services.

Keywords: psychological distress, perceived social support, caregivers, intellectual disability, autism spectrum disorder

INTRODUCTION

Caregiving for children with neurodevelopmental disorders is associated with significant emotional, psychological, and social challenges. Parents and primary caregivers often experience long-term stress due to continuous caregiving responsibilities, uncertainty about the child's future, and limited access to support services. Psychological distress, including symptoms of depression, anxiety, and stress, has been consistently reported among caregivers of children with developmental disabilities (Benson, 2010; Dabrowska&Pisula, 2010).

Intellectual Disability (ID) is characterized by deficits in intellectual functioning and adaptive behavior originating during the developmental period (American Psychiatric Association [APA], 2022). Autism Spectrum Disorder (ASD) is defined by persistent difficulties in social communication and restricted, repetitive patterns of behavior (APA, 2022). Although both conditions demand extensive caregiving, studies suggest that caregivers of children with ASD experience higher levels of psychological distress due to behavioral problems, communication difficulties, and social isolation (Singh et al., 2015).

In the Indian socio-cultural context, caregiving responsibilities are primarily managed within the family system, often with limited professional support. Social stigma and lack of awareness further intensify caregiver burden (Chakraborty& Das, 2017). Perceived social support has been identified as a critical protective factor that reduces psychological distress and enhances coping among caregivers (Zimet et al., 1988). Therefore, examining psychological distress and perceived social support among caregivers of children with ID and ASD is essential for planning effective psychosocial interventions.

REVIEW OF LITERATURE

Research indicates that caregivers of children with Autism Spectrum Disorder report significantly higher stress and depressive symptoms compared to caregivers of children with other disabilities (Benson, 2010). Dabrowska and Pisula (2010) found that parents of children with ASD experienced greater parenting stress than parents of children with Down syndrome, largely due to behavioral and communication challenges.

Studies conducted in India have also documented elevated levels of psychological distress among caregivers of children with ASD. Singh et al. (2015) reported high levels of anxiety, stress, and depressive symptoms among Indian parents of children with ASD, emphasizing the role of socio-economic and cultural stressors. Similarly, Chakraborty and Das (2017) observed significant psychological distress among caregivers of children with ASD attending tertiary care centers.

Caregivers of children with Intellectual Disability also experience considerable emotional strain. Somashekhar and Puranik (2018) reported moderate to high caregiver burden among parents of children with ID, which was significantly associated with lower perceived social support. However, comparative findings suggest that distress levels may be higher among caregivers of children with ASD due to the unpredictable nature of symptoms and greater social challenges (Pisula, 2011). Perceived social support plays a crucial role in mitigating caregiver stress. Zimet et al. (1988) conceptualized perceived social support as support received from family, friends, and significant others. Higher perceived social support has been linked to lower depression and stress among caregivers in both Indian and international studies (Kaur & Arora, 2018). These findings support the stress-buffering model, which proposes that social support protects individuals from the adverse effects of stress.

Need for the Study

Caregivers of children with Intellectual Disability (ID) and Autism Spectrum Disorder (ASD) face continuous emotional, physical, and social demands that place them at increased risk for psychological distress. Several studies have documented elevated levels of depression, anxiety, and stress among caregivers of children with neurodevelopmental disorders (Benson, 2010; Dabrowska & Pisula, 2010). In the Indian context, caregiving responsibilities are largely family-based, with limited access to formal mental health and social support services, which further intensifies caregiver burden (Chakraborty & Das, 2017).

Although both ID and ASD present caregiving challenges, caregivers of children with ASD often report higher stress due to behavioral difficulties, communication impairments, and social stigma (Singh et al., 2015). Perceived social support has been identified as a crucial protective factor that can buffer the negative effects of caregiving stress and improve psychological well-being (Zimet et al., 1988). However, there is limited Indian research that comparatively examines psychological distress and perceived social support among caregivers of children with ID and ASD using standardized tools. Therefore, the present study aims to address this gap.

Method

Objectives of the Study

1. To assess psychological distress among caregivers of children with Intellectual Disability.
2. To assess psychological distress among caregivers of children with Autism Spectrum Disorder.
3. To assess perceived social support among caregivers of children with Intellectual Disability and Autism Spectrum Disorder.
4. To compare psychological distress between caregivers of children with Intellectual Disability and Autism Spectrum Disorder.
5. To examine the relationship between psychological distress and perceived social support among caregivers.

Hypotheses

1. There will be a significant difference in psychological distress between caregivers of children with Intellectual Disability and caregivers of children with Autism Spectrum Disorder.
2. There will be a significant difference in perceived social support between caregivers of children with Intellectual Disability and caregivers of children with Autism Spectrum Disorder.
3. There will be a significant negative relationship between perceived social support and psychological distress among caregivers.

Variables

1. **Independent Variable:** Type of care giving group (Caregivers of children with Intellectual Disability vs. Caregivers of children with Autism Spectrum Disorder)

2. Dependent Variables:

- a. Psychological distress (Depression, Anxiety, Stress)
- b. Perceived social support (Family, Friends, Significant Others)

Sampling

The sample consisted of 100 caregivers, including:

1. 50 caregivers of children with Intellectual Disability
2. 50 caregivers of children with Autism Spectrum Disorder

Caregivers were parents or primary family members actively involved in the daily care of the child. Purposive sampling used from special schools, rehabilitation centers, pediatric/psychiatric outpatient services, and caregiver support networks.

Inclusion Criteria

1. Primary caregiver (mother/father/guardian) providing care for at least 6 months
2. Child diagnosed with ID or ASD by qualified professionals
3. Caregiver aged 18 years and above
4. Ability to understand the language of tools (English/Hindi/regional translation as available)

Exclusion Criteria

1. Caregivers currently diagnosed with severe psychiatric illness requiring immediate clinical care (self-reported/record-based screening)
2. Caregivers of children with multiple severe co-morbid neurodevelopmental disorders

Tools Used

1. **Depression Anxiety Stress Scales 21 (DASS-21)** Developed by Lovibond and Lovibond (1995), the DASS-21 is a self-report scale measuring depression, anxiety, and stress. The scale has demonstrated good reliability and validity and has been widely used in Indian populations (Chauhan et al., 2020).
2. **Multidimensional Scale of Perceived Social Support (MSPSS)** Developed by Zimet et al. (1988), the MSPSS measures perceived support from family, friends, and significant others. The scale has shown adequate psychometric properties in Indian samples (Kaur&Arora, 2018).
3. **Socio-Demographic Data Sheet** A self-prepared form used to collect information such as age, gender, education, family type, residence, and duration of caregiving.

Research Design

A comparative correlational research design was adopted to compare psychological distress and perceived social support between the two caregiver groups and to examine the relationship between the variables.

RESULTS

Table 1: Mean and Standard Deviation of Psychological Distress Scores

Dimension	ID Caregivers (M \pm SD)	ASD Caregivers (M \pm SD)	t	p
Depression	10.4 \pm 5.9	15.2 \pm 6.4	3.82	< .001
Anxiety	9.6 \pm 5.4	13.8 \pm 6.1	3.59	.001
Stress	13.1 \pm 6.2	18.4 \pm 6.9	3.94	< .001

Table 1 presents the mean scores and standard deviations of psychological distress specifically depression, anxiety, and stress among caregivers of children with Intellectual Disability (ID) and Autism Spectrum Disorder (ASD). Independent samples *t*-tests were conducted to examine group differences.

The results indicate that caregivers of children with Autism Spectrum Disorder reported significantly higher levels of depression ($M = 15.2$, $SD = 6.4$) compared to caregivers of children with Intellectual Disability ($M = 10.4$, $SD = 5.9$). The obtained *t* value ($t = 3.82$, $p < .001$) suggests a statistically significant difference between the two groups.

Similarly, anxiety scores were found to be significantly higher among caregivers of children with ASD ($M = 13.8$, $SD = 6.1$) than among caregivers of children with ID ($M = 9.6$, $SD = 5.4$). The difference was statistically significant ($t = 3.59$, $p = .001$), indicating that ASD caregivers experience greater anxiety-related symptoms.

With respect to stress, caregivers of children with ASD again showed significantly higher mean scores ($M = 18.4$, $SD = 6.9$) compared to caregivers of children with ID ($M = 13.1$, $SD = 6.2$). The t value of 3.94 with $p < .001$ confirms that this difference is statistically significant.

Overall, the findings from Table 1 demonstrate that caregivers of children with Autism Spectrum Disorder experience greater psychological distress across all three dimensions—depression, anxiety, and stress than caregivers of children with Intellectual Disability.

These findings are consistent with previous research. Benson (2010) reported higher psychological distress among parents of children with ASD due to persistent behavioral challenges, communication difficulties, and social isolation. Similarly, Dabrowska and Pisula (2010) found that parents of children with ASD experienced significantly higher parenting stress compared to parents of children with intellectual disabilities. Indian studies have also supported these findings, indicating elevated depression, anxiety, and stress among caregivers of children with ASD (Singh et al., 2015).

The present findings further support the literature suggesting that the unpredictability of symptoms, behavioral issues, and higher caregiving demands associated with ASD contribute to increased psychological distress among caregivers. These results emphasize the need for targeted mental health interventions and enhanced support services for caregivers of children with Autism Spectrum Disorder.

Table 2: Mean and Standard Deviation of Perceived Social Support Scores

Dimension	ID Caregivers ($M \pm SD$)	ASD Caregivers ($M \pm SD$)	t	p
Family	5.2 ± 1.1	4.5 ± 1.2	2.87	.005
Friends	4.7 ± 1.2	4.1 ± 1.3	2.34	.021
Significant Others	4.9 ± 1.0	4.2 ± 1.1	3.01	.003

Table 2 presents the mean scores and standard deviations of perceived social support across three dimensions family, friends, and significant others among caregivers of children with Intellectual Disability (ID) and Autism Spectrum Disorder (ASD). Independent samples t -tests were used to examine differences between the two caregiver groups.

The results indicate that caregivers of children with Intellectual Disability reported significantly higher perceived family support ($M = 5.2$, $SD = 1.1$) compared to caregivers of children with Autism Spectrum Disorder ($M = 4.5$, $SD = 1.2$). The obtained t value ($t = 2.87$, $p = .005$) indicates a statistically significant difference between the two groups. This suggests that caregivers of children with ID perceive greater emotional and instrumental support from family members.

Similarly, perceived support from friends was found to be significantly higher among caregivers of children with Intellectual Disability ($M = 4.7$, $SD = 1.2$) than among caregivers of children with ASD ($M = 4.1$, $SD = 1.3$). The difference was statistically significant ($t = 2.34$, $p = .021$), indicating reduced peer-based support for caregivers of children with ASD. With regard to support from significant others, caregivers of children with Intellectual Disability again reported significantly higher levels ($M = 4.9$, $SD = 1.0$) compared to caregivers of children with Autism Spectrum Disorder ($M = 4.2$, $SD = 1.1$). The t value of 3.01 with $p = .003$ confirms that this difference is statistically significant. Overall, the findings from Table 2 demonstrate that caregivers of children with Autism Spectrum Disorder perceive significantly lower social support across all three domains family, friends, and significant others compared to caregivers of children with Intellectual Disability.

These findings are consistent with earlier research. Zimet et al. (1988) emphasized that perceived social support plays a critical role in psychological well-being, particularly in stressful life situations. Previous studies have reported that caregivers of children with ASD often experience social isolation and reduced support due to stigma, lack of understanding of the disorder, and demanding caregiving routines (Benson, 2010). Indian studies have similarly noted lower perceived social support among parents of children with ASD compared to other disability groups (Kaur & Arora, 2018). In contrast, caregivers of children with Intellectual Disability may have better access to extended family support and community acceptance, which enhances perceived social support (Gupta & Singhal, 2004). The present findings support the stress-buffering model, suggesting that reduced social support among caregivers of children with ASD may contribute to their higher psychological distress.

Table 3: Correlation between Psychological Distress and Perceived Social Support

Variable	Social Support
Depression	-.49**
Anxiety	-.42**
Stress	-.46**

Note. $p < .01$

Table 3 presents the correlation coefficients between psychological distress variables depression, anxiety, and stress and perceived social support among caregivers. Pearson's product moment correlation analysis was used to examine the relationship between these variables.

The results indicate a significant negative correlation between depression and perceived social support ($r = -.49, p < .01$). This finding suggests that caregivers who perceived higher levels of social support reported lower levels of depressive symptoms. Conversely, caregivers with lower perceived social support experienced higher levels of depression.

Similarly, anxiety was found to be significantly and negatively correlated with perceived social support ($r = -.42, p < .01$). This indicates that increased perceived social support is associated with reduced anxiety among caregivers. The negative direction of the correlation reflects the protective role of social support in managing anxiety related to caregiving responsibilities.

With respect to stress, a significant negative correlation was also observed between stress and perceived social support ($r = -.46, p < .01$). This suggests that caregivers who perceive greater emotional and practical support from family, friends, and significant others experience lower stress levels.

Overall, the findings from Table 3 demonstrate that perceived social support is significantly and inversely related to all components of psychological distress—depression, anxiety, and stress. Higher levels of perceived social support are associated with lower psychological distress among caregivers.

These findings are consistent with the stress-buffering model proposed by social support theories, which posit that social support mitigates the negative effects of stressful life events (Zimet et al., 1988). Previous studies have similarly reported significant negative associations between social support and psychological distress among caregivers of children with developmental disorders (Benson, 2010; Kaur & Arora, 2018). Indian research has also emphasized that strong family and social networks play a crucial role in reducing caregiver stress and improving psychological well-being (Gupta & Singhal, 2004).

The present findings reinforce the importance of enhancing perceived social support through family counseling, peer support groups, and community-based interventions to reduce psychological distress among caregivers of children with Intellectual Disability and Autism Spectrum Disorder.

CONCLUSION

The present study examined psychological distress and perceived social support among caregivers of children with Intellectual Disability and Autism Spectrum Disorder. The findings revealed that caregivers of children with Autism Spectrum Disorder experienced significantly higher levels of psychological distress, including depression, anxiety, and stress, compared to caregivers of children with Intellectual Disability. Additionally, caregivers of children with Autism Spectrum Disorder reported significantly lower levels of perceived social support across family, friends, and significant others.

A significant negative relationship was observed between perceived social support and psychological distress, indicating that higher levels of perceived social support were associated with lower levels of depression, anxiety, and stress among caregivers. These findings highlight the crucial role of social support as a protective factor in mitigating psychological distress among caregivers. The results emphasize the need for caregiver-focused mental health interventions, particularly for caregivers of children with Autism Spectrum Disorder. Strengthening family support systems, facilitating peer support networks, and integrating psychosocial services within clinical and rehabilitation settings may help reduce caregiver distress and improve overall family well-being.

LIMITATIONS

Despite its contributions, the present study has certain limitations that should be considered while interpreting the findings:

1. The study employed a cross-sectional research design, which limits the ability to establish causal relationships between psychological distress and perceived social support.
2. Purposive sampling was used, which may restrict the generalizability of the findings to the broader caregiver population.
3. The study relied on self-report measures, which may be influenced by response bias and social desirability.
4. The severity of the child's condition, behavioral problems, and duration of caregiving were not controlled, which may have influenced caregiver distress levels.
5. The study was limited to a relatively small sample size, which may reduce statistical power.

FUTURE SUGGESTIONS

Based on the findings and limitations of the present study, the following suggestions are proposed for future research and practice:

1. Longitudinal studies should be conducted to examine changes in psychological distress and perceived social support over time among caregivers.
2. Future research should include larger and more diverse samples across different socio-economic, cultural, and geographical backgrounds.
3. Intervention-based studies focusing on enhancing social support, coping skills, and resilience among caregivers should be undertaken.
4. Additional variables such as coping strategies, caregiver burden, resilience, and quality of life may be included to gain a more comprehensive understanding of caregiver mental health.
5. Mental health screening and counseling services for caregivers should be incorporated into routine clinical and rehabilitation programs for children with Intellectual Disability and Autism Spectrum Disorder.

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