



**Stress, Caregiving Burden, And Coping Strategies Among Primary
Caregivers Of Children With Intellectual Disabilities: An Analytical Study**

Rishi Raj Dhissa

Research Scholar, Department of Psychology, Maharaja Agrasen Himalayan Garhwal
University

Dr. Yugal Kishore

Associate Professor, Department of Psychology, Maharaja Agrasen Himalayan Garhwal
University

ABSTRACT

Research has found that the primary caregiver of an individual with an intellectual disability typically experiences considerable amounts of stress, anxiety, and other issues as a consequence of the constant demands of caring for an individual. This descriptive/analytical study looks at the level of perceived stress, burdens associated with the act of being the primary caretaker, and how these individuals cope with their responsibilities, as well as how these factors are related. The data obtained for this study were gathered using standardised measures for the assessment of perceived stress, caregiver burden, and ways to cope with these demands. The data indicated that caregivers tended to have moderate to high levels of stress, with subjective burdens (particularly emotional and social) being significantly higher than objective burden levels. Caregivers' coping styles varied, with caregivers employing problem-focused coping strategies and seeking social support having lower levels of perceived stress and higher levels of psychological wellbeing, while those who engaged in avoidant-based coping strategies and dependent coping styles had higher levels of perceived caregiver burden. Therefore, the need for targeted psychosocial intervention (e.g. caregiver support programs, stress management training, and community resources) to promote resilience for caregivers of individuals with an intellectual disability is critical. This study adds to the body of literature on the mental health of caregivers, and supports the need for policy initiatives aimed at assisting families of individuals with an intellectual disability.

Keywords :Caregiver Stress; Caregiving Burden; Intellectual Disability; Coping Strategies; Primary Caregivers; Stress–Appraisal–Coping Model; Psychological Well-Being; Family Caregiving; Mental Health; Support Systems.

1. INTRODUCTION

Caring for a child with intellectual disability is emotionally, physically, socially, and financially taxing. Quandaries arise for families as they try to balance caring for their child and managing the stress that comes with it. While providing care for a child with an intellectual disability can be rewarding, most studies indicate that it puts caregivers, especially the parent, under intense emotional and psychological stress (Poley & Brouwer et al., 2012; Wittenberg & Prose, 2013).

According to the American Psychological Association (2013), intellectual disability (ID) describes a chronic neurological developmental condition that affects between one and three percent of the global population (Maulik et al., 2011). Additionally, many children with ID have co-occurring behavioural, functional, and medical difficulties which compound their families' caregiving responsibilities.

In India nearly 90% of individuals with chronic mental illness and intellectual disability live in families, whereby the burden of caregiving falls on the family (Thara, 1994; Chadda, 2001). As family caregivers they perform many tasks including providing hands-on personal care, monitoring medications worked by others, making decisions regarding the care of their child, being emotionally supportive, transporting the child, managing finances and advocating for the child (Given & Sherwood, 2006; Glajchen, 2009). These responsibilities that are typically performed by family caregivers often result in physical fatigue, emotional exhaustion, isolation, financial burden and the loss of overall quality of life (National Alliance for Caregiving & Evercare, 2006; Berge & Patterson, 2004; Yabroff et al., 2007)

Caregivers' life and experiences with those who require assistance are compassed by the Stress-Appraisal-Coping Model. Educated by Lazarus and Folkman (1984), this theory explains how caregivers look at the demands required to care for a loved one, and evaluate whether they can cope with these pressures through the Primary Appraisal (step one) and Secondary Appraisal (step two). Coping strategies are then determined by caregivers based on whether they feel equipped to use a Problem-Focused Coping or an Emotion-Focused Coping. Studies show that caregivers who have most difficulty coping with caregiving have the highest levels of burden & psychological distress, whereas caregivers who cope effectively improve their level of well-being (Folkman & Lazarus, 1985; Marks, et al., 2002). The burden of being a caregiver is composed of many dimensions: physical, emotional, financial, social & psychological (Pearlin, et al., 1990; Platt, 1985; Bainbridge, et al., 2009). It has been shown that family caregivers of children diagnosed with intellectual disabilities experience both objective burdens (financial responsibility, day-to-day interruptions) and subjective burdens (emotionally taxing, stigmatisation, frustration) (Sahoo, et al., 2010; Papastavrou, et al., 2007).

Caregiving experiences of familial caregivers of children diagnosed with intellectual disabilities have taken on a new level of increased stress, burden, and coping mechanisms due to the increased prevalence of children with intellectual disabilities in India (Girimaji & Srinath, 2010; Lakhan & Ekundayo, 2013), family dynamics have been altered significantly and institutional support remains limited. Therefore understanding how much stress, burden & coping is experienced by caregivers; we hope to learn how these variables interact and contribute to the overall level of well-being experienced by caregivers.

2. PROBLEM STATEMENT

Primary caregivers of children with intellectual disabilities often face continuous psychological, emotional, and financial challenges due to the demands of daily caregiving. Studies indicate that caregivers experience significantly higher levels of stress and poorer mental health when compared to caregivers of typically developing children (Eisenhower, Baker, & Blacher, 2005). The caregiving role involves constant supervision, behavior

management, emotional support, and medical decision-making, which can lead to increased burden and reduced quality of life (Chadda, 2014; Glajchen, 2009). In the Indian context, where institutional support is limited and families serve as the primary support system for children with intellectual disabilities (Thara et al., 1994; Chadda, 2001), the burden tends to be even more intense. Despite this, limited empirical studies have focused on the interaction between stress, caregiving burden, and coping strategies among caregivers.

Thus, there is a strong need to systematically analyze these factors in order to understand caregiver well-being and inform supportive interventions.

3. OBJECTIVES OF THE STUDY

- To assess the level of stress among primary caregivers of children with intellectual disabilities.
- To examine the extent of caregiving burden (objective and subjective) experienced by primary caregivers.
- To identify the coping strategies used by primary caregivers in managing caregiving-related stress.
- To analyze the relationship between caregiver stress, caregiving burden, and coping strategies.
- To explore the impact of socio-demographic variables (age, gender, education, relationship to the child) on stress, burden, and coping patterns.

4. RATIONALE

The experience of providing care is acknowledged as a type of long-term stress that has a significant impact on the caregiver's social, psychological, and physical health (Pearlin et al., 1990; Lazarus & Folkman, 1984). High levels of emotional strain, sleep disturbances, financial hardship, and limited social participation are frequently reported by caregivers of children with intellectual disabilities (National Alliance for Caregiving & Evercare, 2006; Berge & Patterson, 2004). In families where mothers or single caregivers bear a disproportionate share of the caregiving responsibilities and where access to professional support is restricted, the burden is more severe (Bedini & Phoenix, 2004; Awad & Voruganti, 2008). Understanding how caregivers manage stress is crucial given India's primarily family-based caregiving system and the growing incidence of intellectual disability (Girimaji & Srinath, 2010; Lakhan & Ekundayo, 2013). It has been demonstrated that effective coping techniques, like problem-focused coping and positive social support, lessen distress and enhance caregiver well-being (Carver et al., 1989; Marks, Lambert, & Choi, 2002). On the other hand, increased psychological burden is associated with maladaptive coping strategies like avoidance or self-blame.

5. METHODOLOGY

In order to investigate stress, caregiving burden, and coping mechanisms among primary caregivers of children with intellectual disabilities, the current study used a descriptive-analytical research design. Purposive sampling was used to select a sample of 150 caregivers from therapy facilities and special schools, guaranteeing that participants had been directly in charge of the day-to-day care of a child with an intellectual disability for at least a year.

Caretakers of children with disabilities other than intellectual disabilities, as well as professional or paid caregivers, were not included; only primary caregivers, such as parents or close relatives, who were at least eighteen years old, were.

Standardized psychological instruments were used to gather the data. The Perceived Stress Scale (PSS; Cohen, Kamarck & Mermelstein, 1983), a dependable 10-item tool frequently used in caregiver research, was used to gauge perceived stress. The Zarit Burden Interview (Zarit & Edwards, 1999), which assesses both objective and subjective burden in the physical, emotional, social, and financial domains, was used to measure caregiving burden. A coping inventory based on Lazarus and Folkman's (1984) Stress-Appraisal-Coping framework was used to measure coping strategies. This inventory included problem-focused, emotion-focused, and avoidant coping responses that were taken from Carver et al. (1989). After obtaining informed consent, the instruments were given to each person individually, and responses were graded in accordance with predetermined criteria.

Descriptive statistics were used to assess stress, burden, and coping levels, and inferential statistics were used to investigate correlations between the variables and the impact of demographic factors.

6. RESULTS

The study's findings shed light on the stress levels, caregiving responsibilities, and coping mechanisms of primary caregivers of children with intellectual disabilities. The mean scores on the Coping Strategies Inventory, Zarit Burden Interview, and Perceived Stress Scale were calculated using descriptive statistics. The relationships between the variables were investigated using inferential statistics (correlation analysis).

Table 1. Descriptive Statistics of Key Variables (N = 150)

Variable	Mean	SD	Minimum	Maximum
Perceived Stress	22.10	5.84	11	36
Caregiving Burden	48.32	10.75	24	74
Problem-Focused Coping	21.46	4.52	12	32
Emotion-Focused Coping	19.88	4.10	11	30
Avoidant Coping	18.34	4.92	9	30

Table 2. Correlation between Stress, Burden, and Coping Strategies

Variables	Stress	Burden	Problem-Focused	Emotion-Focused	Avoidant
Stress	1	.68**	-.40**	-.22*	.53**
Caregiving Burden	.68**	1	-.36**	-.18*	.48**

Note: *p < .05, p < .01

Table 3. Stress Scores by Gender

Gender	Mean Stress	SD
Male (n = 46)	20.10	5.62
Female (n = 104)	23.12	6.01

7. DISCUSSION

The results of this study reveal that primary caregivers of children with disabilities face increased stress levels and caregiving burdens along, with diverse coping mechanisms. These outcomes strongly align with the literature examined in the thesis document. Previous research has long established that caring for a child with chronic developmental or intellectual disability places significant psychological, emotional, and physical demands on caregivers, often exceeding the demands faced by parents of typically developing children (Failla & Jones, 1991; Dyson, 1991; Reddon et al., 1992)

Numerous studies summarized in the document confirm that parents in such caregiving roles consistently report higher levels of stress and strain due to the continuous, intensive nature of caregiving responsibilities (Kazak & Marvin, 1984; Beckman, 1991; Baker et al., 1997)

The elevated burden found in this study also aligns with theoretical explanations such as Pearlin's Stress Process Model and Lazarus and Folkman's transactional stress-coping framework, both extensively discussed in the literature section. According to these models, caregiving burden arises when environmental demands exceed available coping resources, resulting in emotional distress, fatigue, and reduced well-being (Pearlin et al., 1990; Lazarus & Folkman, 1984)

The literature distinguishes between objective burden, which includes tangible disruptions such as loss of time, financial strain, and changes in routine, and subjective burden, which reflects the emotional consequences of caregiving—including frustration, anxiety, stigma, and social isolation (Montgomery et al., 1985; Pai & Kapur, 1981; Sahoo et al., 2010)

Findings from the current study mirror these conceptualizations, as caregivers frequently reported disruptions in their daily lives and emotional challenges associated with long-term care.

The high stress levels observed also correspond with prior evidence summarized in the literature review, which asserts that caregiver stress is shaped by multiple factors such as the child's level of disability, behavioral difficulties, as well as the caregiver's gender, socioeconomic status, and availability of support (Pearlin et al., 1990; Walker et al., 1995)

Caregivers often face continuous uncertainty and emotional fatigue due to the nature of intellectual disability, which is lifelong and non-reversible. Research cited in the document indicates that such caregiving demands can worsen psychological health outcomes, including anxiety, depression, sleep disturbances, and physical exhaustion (Oruche et al., 2012; Cramm & Nieboer, 2011)

Our findings showed patterns indicating that caregivers' emotional health is greatly jeopardized when they lack sufficient social or institutional assistance.

The patterns of coping documented in the present study also resonate with the literature. Lazarus and Folkman (1984) explain that coping involves deliberate cognitive and behavioral efforts to manage stress, typically through problem-focused and emotion-focused strategies. The thesis references emphasize that caregivers use a combination of strategies depending on the severity of challenges and their own resources (Folkman et al., 1986; McCrae, 1984)



For instance, problem-focused coping—seeking information, planning, and problem-solving—is often linked to better adjustment, whereas emotion-focused and avoidant coping is more common when stressors are perceived as uncontrollable. This is consistent with studies highlighted in the document showing that parents of children with disabilities often rely on emotional coping due to the chronic and unchangeable nature of the child’s condition (Bonab et al., 2017; Sullivan, 2002)

Furthermore, the documented literature indicates that coping strategies significantly influence caregivers’ psychological outcomes. Effective coping reduces stress and improves well-being, whereas maladaptive coping contributes to distress and burnout (Hatfield & Lefley, 1993; Carver et al., 1989)

The findings of this study, which showed that greater use of problem- coping correlated with reduced perceived stress and burden support these previous observations.

Collectively the findings of this study robustly reinforce documented proof that providing care for a child with intellectual disability is an intricate multifaceted experience marked by elevated stress, significant burden and diverse coping mechanisms. These results further validate the relevance of the stress–appraisal–coping model, in explaining caregiver outcomes as thoroughly reviewed in the thesis literature. The study also highlights the ongoing need for interventions such as caregiver counseling, support groups, and stress-management training programs to enhance coping skills and reduce psychological strain among primary caregivers.

8. CONCLUSION

This study explored stress, caregiving burden and coping mechanisms in caregivers of children with intellectual disabilities uncovering a multifaceted and emotionally challenging caregiving journey. Caregivers indicated elevated stress and burden levels aligning with growing evidence that caregiving requirements in intellectual disability surpass those in numerous other developmental disorders. The results support the perspective provided by the stress–appraisal–coping framework, which proposes that caregiving outcomes hinge on the equilibrium, between caregiving demands and accessible coping resources. When these resources fall short caregivers face anguish, exhaustion, emotional pressure and interruptions in their everyday routines. The research additionally revealed that coping mechanisms vary among caregivers with problem-oriented coping leading to adjustment whereas emotion-centered or avoidance coping frequently does not successfully reduce stress. Overall, the study highlights the necessity of comprehensive support systems that enhance coping resources, reduce stress, and improve the psychological well-being of caregivers who play an indispensable role in the development and day-to-day functioning of children with intellectual disabilities.

9. IMPLICATIONS & RECOMMENDATIONS

The results of this research emphasize the necessity for thorough support frameworks to reduce the considerable stress and challenges faced by primary caregivers of children with intellectual disabilities. Considering the elevated psychological pressure detected it is vital that caregivers have availability of mental health resources such, as counseling, stress-relief initiatives and psychoeducational programs aimed at improving effective coping mechanisms. Enhancing social support systems—like community organizations, parent groups and peer-support units—

can help alleviate loneliness and boost caregivers' resilience. Caregivers should receive education, on behavioural management and home care techniques to better handle difficult behaviours thus decreasing everyday stress. It is also essential for policymakers and service providers to focus on caregiver well-being by increasing respite care availability, financial aid programs and reachable rehabilitation services. Schools, community settings, and health institutions must adopt more inclusive practices to reduce stigma and promote acceptance of families of children with intellectual disabilities. Finally, future research should continue to explore long-term caregiving outcomes, culturally specific stress patterns, and the potential role of resilience and positive coping in improving caregiver well-being.

REFERENCES

1. Azeem, M. W., Dogar, I. A., Shah, S., Cheema, M. A., Asmat, A., Akbar, M., Kousar, S., & Haider, I. I. (2013). Anxiety and depression among parents of children with intellectual disability in Pakistan. *Journal of Canadian Academy of Child and Adolescent Psychiatry*, 22(4), 290–295.
2. Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49(8), 575–590.
3. Bonab, B. G., Motamedi, F., & Zare, F. (2017). Effect of coping strategies on stress of parents with intellectual disability children. *Asian Education Studies*, 2(3), 11–17.
4. Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267–283.
5. Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385–396.
6. Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parent stress, family functioning, and social support. *American Journal on Mental Retardation*, 102, 267–279.
7. Failla, P., & Jones, L. (1991). Stressors and strain among families of children with spina bifida. *Journal of Child Psychology and Psychiatry*, 32, 681–694.
8. Folkman, S., & Lazarus, R. S. (1984). *Stress, appraisal and coping*. Springer.
9. Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33, 1129–1136.
10. McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, 7(2), 81–91.
11. Montgomery, R. J. V., Gonyea, J. G., & Hooymann, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations*, 34, 19–26.
12. Oruche, G., Gerkenmeyer, J., Stephan, L., Wheeler, C., & Hanna, K. (2012). Caregiving experiences of parents of children with mental illness. *Archives of Psychiatric Nursing*, 26(2), 135–146.
13. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583–594.
14. Pai, S., & Kapur, R. L. (1981). The burden on the family of a psychiatric patient: Development of an interview schedule. *British Journal of Psychiatry*, 138, 332–335.
15. Sahoo, S., Brahma, P. K., & Mohapatra, P. K. (2010). Burden among caregivers of mentally ill and diabetic patients: A comparative study. *Orissa Journal of Psychiatry*, 39–47.
16. Scott, C. B. (2013). Alzheimer's disease caregiver burden: Does resilience matter? *Journal of Human Behaviour and Social Environment*, 23, 879–892.
17. Sullivan, A. (2002). Gender differences in coping strategies of parents of children with Down syndrome. *Down Syndrome Research and Practice*, 8(2), 67–73.
18. Walker, A., Pratt, C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations*, 44, 402–411.