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Caregiver Stress, Burden, And Coping In Families Of Children With Intellectual Disabilities: A Comprehensive Review

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ABSTRACT

Families serve as the lifelong support system for children with intellectual disabilities (ID). The responsibilities of caregiving frequently lead to stress, heavy burden and unhealthy coping mechanisms, which, in turn impact caregivers' physical, mental and social health. This review examines the aspects of caregiver stress and burden theoretical frameworks describing caregiver results elements affecting evaluation and coping methods employed by caregivers of children with ID. The evidence highlights the urgent need for structured family support, coping-skills training, respite services, and community-based interventions to maintain caregivers' health and resilience

Keywords: Intellectual disability; Caregiver stress; Caregiver burden; Coping strategies; Psychological well-being; Family caregivers

1. INTRODUCTION

Providing care for a child with disability (ID) is understood as a lifelong duty that impacts all aspects of family life. Although caregiving may be fulfilling it frequently results in stress because of the child's difficulties with communication, learning, social abilities and everyday tasks. Families often encounter distress, trauma and sorrow upon receiving a diagnosis of intellectual disability followed by prolonged emotional adaptations marked by guilt, stigma and worries, about the child's unpredictable future.

Intellectual disability is characterized by significant limitations in intellectual functioning and adaptive behaviors, with onset during the developmental period. It is often accompanied by comorbid conditions—including epilepsy, behavioral dysfunction, and mental health symptoms—which elevate the complexity of caregiving demands. These multifaceted care needs, particularly when severe, result in heightened stress among caregivers, notably parents who shoulder the primary role.



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In nations with middle incomes like India relatives deliver up to 90% of prolonged care for people with chronic mental disorders and developmental disabilities because formal support systems are scarce. As a result those providing care face heightened strain in emotional, social and financial aspects. Ongoing supervision, behavior control and managing healthcare needs can ultimately cause fatigue role struggles and a decline, in both psychological well-being.

Conceptual frameworks, like the Stress-Appraisal-Coping model developed by Lazarus and Folkman highlight that caregiver results are influenced not by the concrete challenges of caregiving but also by the personal perception of stress and the success of employed coping methods. When caregiving demands surpass personal, social and financial resources caregivers tend to face psychological strain such, as anxiety, depression and emotional exhaustion. On the hand effective coping and increased social support enhance resilience and help maintain the ability to provide care.

Given the central role of families in disability care, it is essential to understand the nature of caregiver stress, the resulting burden, and the coping mechanisms adopted by parents of children with ID. Such evidence is crucial for guiding clinical, psychosocial, and policy interventions aimed at strengthening family well-being and enhancing quality of life for both caregivers and children with intellectual disabilities.

2. CAREGIVER STRESS

Caregiver stress refers to the psychological and physiological strain experienced when caregiving demands surpass the caregiver's available emotional, social, and material resources. This mismatch results in chronic stress reactions that affect daily functioning and long-term health outcomes.

In households with children who have disabilities (ID) stress arises from various interconnected elements. The intensity of the child's behavioral challenges, such, as aggression, hyperactivity, communication problems and self-harm behaviors greatly increases the stress experienced by caregivers. The ongoing reliance and constant monitoring requirements lead to strain and exhaustion especially when children cannot manage daily living activities on their own.

Emotional pressure increases as caregivers observe their child's difficulties and social isolation. Parents often express anxiety and doubt about their child's adult life, future care plans and overall well-being, without family assistance.

Caregiver stress is understood in terms of two types of stressors:

2.1 Primary Stressors

- These come directly from the responsibilities of caregiving and the traits of the child:
- Developmental limitations and delayed milestones
- Assistance with activities of daily living (ADL)



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- Challenging or unpredictable behaviors
- These stress factors are closely linked with mental distress.

2.2 Secondary Stressors

- These take place within the caregiver's communal surroundings:
- Work or career disruptions
- Marital conflict and reduced social participation
- Loss of personal identity and leisure

Additional stressors amplify the pressure of caregiving responsibilities and add to the total load.

Sustained caregiving without adequate support has been shown to increase vulnerability to anxiety, depression, somatic complaints, and emotional burnout among caregivers.

As stress accumulates over time, caregivers may experience declining coping abilities, reduced quality of life, and diminished capacity to provide effective care to the child.

3. CAREGIVER BURDEN

Caregiver burden refers to the cumulative physical, psychological, social, and financial strain experienced by family members as a result of prolonged caregiving responsibilities for a child with intellectual disability (ID). It represents not only the observable disruptions in daily functioning but also the subjective emotional hardships associated with the caregiving role.

Parents, mothers frequently assume the role of main caregivers and as a result bear a greater burden of caregiving responsibilities than other relatives. The ongoing need, for monitoring participating in therapy and managing behaviors leads to exhaustion and enduring stress responses.

The tangible burden of caregiving encompasses impacts like higher household costs more frequent medical appointments, job loss decreased social participation and role tensions within the family. These systemic difficulties are especially notable in resource- environments where access, to professional rehabilitation and respite care is scarce compelling caregivers to adjust family priorities and forego individual aspirations. Often siblings are impacted well because of split parental focus and restricted leisure or educational assistance.

The subjective burden is just as significant, involving caregivers' reactions to their responsibilities. Numerous caregivers share experiences of guilt, frustration, sorrow and helplessness as they deal with problems and developmental difficulties in their child. The social stigma linked to disability can amplify psychological stress causing social isolation and decreased willingness to seek assistance. Parents often voice concerns, about their child's future. Fear that their child may be abandoned when they are no longer capable of caregiving.

The intensity of the child's condition serves as an indicator of burden. Kids displaying tendencies, hyperactivity and limited adaptive abilities need continuous supervision leading to physical tiredness and emotional strain. Research indicates that caregivers of children with disabilities or



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several comorbid conditions experience notably worse health-related quality of life than those caring for children with mild to moderate disabilities. Extended caregiving further increases the risk of insomnia, high blood pressure and mental health issues, like anxiety and depression.

When burden becomes overwhelming and coping resources are insufficient, caregivers may experience burnout, reduced caregiving efficiency, and decreased emotional availability toward the child. This cyclical relationship underscores the importance of early recognition of caregiver burden and timely psychosocial interventions. Strengthening institutional support, promoting respite services, ensuring inclusive education, and empowering parents through skill-building programs are essential to reduce caregiver burden and enhance family resilience.

4. APPRAISAL OF CAREGIVING

Appraisal is crucial in shaping how caregivers emotionally and mentally understand the difficulties of raising a child with disability (ID). As per Lazarus and Folkman's Stress–Appraisal–Coping Theory (1984) the results of caregiving rely not on the actual demands but also, on the personal interpretations of those demands. If caregivers view the situation as intimidating or unmanageable they are more likely to experience distress (Keller & Honig 2004). Conversely, perceiving caregiving as meaningful or manageable supports positive adjustment and stronger resilience (Gupta & Singhal, 2005).

In the appraisal caregivers assess how their child's disability affects family dynamics, future aspirations and social connections. Feelings, like guilt, sorrow and stigma frequently emerge when the disability is perceived as a disturbance (Dyson, 1997). The intensity of behavioral difficulties greatly affects negative judgments since difficult behaviors require ongoing attention and emotional involvement (Hastings, 2002).

Secondary appraisal entails evaluating both external coping resources. Such as family assistance, availability of health and educational services, financial security and parenting abilities. In settings with resources, like India, the scarcity of professional support resources amplifies negative appraisal and exacerbates enduring stress (Kaur et al., 2018). Caregivers possessing robust social connections and greater self-confidence generally perceive caregiving in a more favorable light thus diminishing adverse emotional impacts (Peshawaria & Venkatesan 2005).

Appraisal is not static; it changes over time with the child's developmental progress and family adaptation patterns. Parents of children with severe intellectual disability often report ongoing uncertainty and fear about lifelong dependency, which contributes to sustained threat appraisal and poorer mental health outcomes (Hassall et al., 2005).

Constructive evaluation, involving acceptance and the creation of meaning promotes motivation improves health and strengthens caregiving connections (Bayat, 2007).



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Thus, appraisal functions as a critical mediator between caregiving demands and caregiver mental health. Structured psychoeducation, supportive counselling, and family empowerment interventions can help modify maladaptive appraisals and strengthen the caregiver's coping capacity, ultimately reducing distress and improving quality of life for both caregivers and their children.

5. COPING STRATEGIES IN CAREGIVERS

Coping strategies are cognitive and behavioral efforts used by caregivers to manage the challenges associated with raising a child with intellectual disability (ID). Effective coping acts as a psychological buffer, reducing stress and preventing caregiver burnout. Lazarus and Folkman (1984) describe coping as dynamic, changing in response to situational demands and personal resilience resources. The type of coping strategy employed—adaptive or maladaptive—significantly influences caregiver health outcomes and overall family functioning (Hastings et al., 2005).

Parents of children with ID often employ a combination of problem-focused and emotion-centered coping methods. Problem-focused coping involves actions like scheduling medical visits implementing behavior management techniques, consulting experts and utilizing educational materials. These approaches tend to be used often when caregivers feel they have more control, over the caregiving circumstances (Hassall et al., 2005). In contrast emotion-centered coping includes strategies like avoidance, denial, self-criticism, prayer and venting emotions—commonly employed when stressors are continuous and, beyond control (Dyson, 1997; Kaur et al. 2018).

Social support emerges as one of the most influential coping facilitators. Parents who maintain supportive relationships with family, peers, and disability organizations experience reduced anxiety and emotional distress (Gupta & Singhal, 2005). Group-based interventions, peer networks, and parental training programs have been shown to strengthen positive coping and improve quality of life (Peshawaria & Venkatesan, 2005).

Conversely insufficient social support is linked to dependence on harmful coping mechanisms, like isolation and drug use, which worsen stress and symptoms of depression.

Furthermore, spiritual coping plays an essential role in many cultural contexts, including India, where families often derive hope, acceptance, and meaning from faith-based practices (Bayat, 2007). Such strategies help caregivers reframe disability not as a burden but as a meaningful life challenge, promoting positive appraisal and psychological resilience.

Caregiver coping is affected by disability-associated variables. Mothers, the main caregivers tend to use emotion-centered coping more because of sustained emotional engagement while higher education and availability of services correlate with an increased use of problem-centered coping methods (Keller & Honig 2004; Hastings, 2002). Throughout time caregivers might change their



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coping approaches depending on the child's progress experiences, with school inclusion and how the family adjusts.

In summary, coping strategies serve as a critical moderator between caregiver burden and mental health. Enhancing adaptive coping through structured training, counseling support, and strong social network development is essential for maintaining caregiver well-being and sustaining high-quality care for children with intellectual disabilities.

6. THEORETICAL PERSPECTIVES

Several theoretical models explain the psychological processes that influence caregiver stress, burden, and coping when raising a child with intellectual disability (ID). The Stress–Appraisal–Coping Model by Lazarus and Folkman (1984) remains the most widely applied framework. It emphasizes that caregiving stress is shaped not only by the objective caregiving demands but also by caregivers' cognitive appraisal and coping strategies. When situations are interpreted as threatening or uncontrollable, caregivers experience heightened distress and reduced resilience (Keller & Honig, 2004).

Likewise Pearlin's Stress Process Model (1990) differentiates stressors—like demanding behaviors and caregiving requirements—from secondary stressors stemming from role conflicts, economic pressure and social withdrawal. This framework emphasizes the mediating effect of coping strategies and social support, on the well-being of caregivers (Hastings, 2002).

Role Theory additionally clarifies caregiver strain through concepts, like role overload, captivity and identity disturbance. Parents frequently give up job prospects, recreational pursuits and personal connections to fulfill caregiving responsibilities, which heightens stress and lowers life satisfaction (Dyson, 1997).

Recent studies have additionally applied Family Systems Theory indicating that a child's disability affects the family system necessitating adjustments in communication styles, familial roles and support networks (Gupta & Singhal 2005). When family unity is robust stress is lessened, while disagreements increase the strain, on caregivers (Bayat, 2007).

In essence, theoretical models reinforce that caregiver outcomes arise from a dynamic interaction between child-related stressors, caregiver perceptions, coping strategies, and social context. These models guide the design of holistic and preventive interventions tailored to family needs.

7. IMPACT OF CAREGIVING

The impact of caring for a child with ID extends across multiple domains of caregiver well-being. Psychological consequences are among the most prevalent, including anxiety, depression, emotional exhaustion, and lowered self-esteem (Hassall et al., 2005). Chronic stress diminishes coping abilities and increases susceptibility to psychiatric disorders (Hastings et al., 2005).



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Emotional distress can also arise from stigma, criticism by others and societal bias, against disabilities (Kaur et al. 2018).

Caregivers often experience health issues such as headaches, disrupted sleep, backaches and high blood pressure, which stem from the demanding physical tasks involved in caregiving and less time available, for personal care (Keller & Honig 2004). Ongoing tiredness diminishes function and raises the likelihood of premature illness (Hastings, 2002).

In addition, caregiving affects family and social relationships. Parents may limit social activities due to the child's behavioral challenges or fear of negative reactions from others. This isolation adversely impacts marital harmony and sibling adjustment (Dyson, 1997). Peer networks, once strong, often shrink as caregiving becomes more restrictive (Peshawaria & Venkatesan, 2005).

Economic pressure is another result with families facing higher costs, for medical care therapies, special education and travel while caregivers—particularly mothers—might cut back on work hours or stop working altogether (Gupta & Singhal 2005). Gradually this financial load contributes to stress and uncertainty regarding the child's future prospects (Bayat, 2007).

In spite of these difficulties certain caregivers recognize effects including personal development, closer family relationships, increased empathy, patience and a deeper sense of meaning and purpose. Research indicates that positive reframing and acceptance can improve resilience and emotional health (Hassall et al., 2005).

Overall, the impact of caregiving is multifaceted, containing both risk and resilience pathways. Supportive interventions must therefore aim not only to reduce burden but to enhance positive caregiver identity and family empowerment.

8. IMPLICATIONS FOR PRACTICE

Assisting caregivers of children with disabilities demands a holistic family-focused strategy. Psychoeducation alongside parent-training initiatives can enhance behavior management abilities. Alleviate stress (Hastings et al., 2005; Peshawaria & Venkatesan 2005). Bolstering health provisions via routine screening and counseling is essential for averting anxiety, depression and burnout (Gupta & Singhal 2005). Improved social support—such, as peer networks and community engagement—contributes to diminishing isolation and stigma (Bayat, 2007). Policy measures such as financial subsidies, accessible rehabilitation, and inclusive education ease economic burdens and promote care continuity (Dyson, 1997; Kaur et al., 2018). Finally, interventions that foster positive coping and meaning-making improve resilience and overall caregiving sustainability (Hassall et al., 2005).

9. CONCLUSION

Providing care for a child with an intellectual disability presents ongoing difficulties that profoundly affect the caregiver's physical health, mental state, social life and financial stability. The caregiving journey is influenced by the extent of the child's disabilities the caregiver's



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perception of the challenges and the access, to coping mechanisms and support networks. When the pressure surpasses resources the burden escalates, causing emotional strain, diminished life quality and an increased likelihood of health issues. However, caregivers can show remarkable resilience when supported with effective coping strategies, strong social networks, and accessible services. Strengthening psychoeducation, mental health care, financial assistance, and community inclusion is essential to protect caregiver well-being and ensure sustainable care for children with intellectual disabilities. A comprehensive, family-centered approach—grounded in supportive policies and evidence-based interventions—remains critical to improving outcomes for both caregivers and children.

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