International Journal of Transdisciplinary Research and Perspectives
Volume 2, Issue 5, May 2026
www.ijtrp.com | E-ISSN: 3107-7935 | RESAIM Publishing | www.resaim.com

Parental Psychological Distress in Pediatric Cancer Care: A Narrative Review with Focus on the Indian Context

K. A. Sneha*
School of Liberal Studies, CMR University, Bangalore, India

***Abstract*: Pediatric cancer is a severe and life-altering condition that affects not only the child but also the psychological functioning of parents who provide continuous care throughout the treatment process. Although advances in medical care have improved survival outcomes, the psychological distress experienced by parents remains highly prevalent and is often under-recognized, particularly in low- and middle-income countries such as India. This narrative review critically synthesizes existing literature on parental psychological distress in pediatric oncology, emphasizing its multidimensional nature, which includes emotional, financial, social, cognitive, and systemic dimensions. Common psychological manifestations such as anxiety, depression, post-traumatic stress symptoms, and chronic stress-related reactions are examined. The review also highlights structural and systemic barriers that limit access to psychological care, including inadequate psychosocial services, financial strain, stigma, and healthcare accessibility challenges. Special attention is given to the Indian context, where these barriers are more pronounced. Additionally, emerging evidence related to step-parent caregiving is briefly discussed as an underexplored area within pediatric psycho-oncology. Overall findings suggest that parental distress is most intense during diagnosis and early treatment stages, although psychological burden often persists long after treatment completion. The review emphasizes the importance of integrating structured, culturally sensitive, and family-centered psychosocial care within pediatric oncology services.**

***Keywords*: Pediatric cancer, caregiver distress, parental burden, psycho-oncology, India, narrative review.**

1. Introduction

Pediatric cancer represents one of the most emotionally challenging medical conditions for families, as it disrupts not only the child's physical health but also the emotional, social, and financial stability of the entire family system. While improvements in treatment have significantly increased survival rates, the psychological burden experienced by parents remains substantial and persistent. Following diagnosis, parents are often required to rapidly process complex medical information, engage in urgent treatment decisions, and adjust to prolonged hospital-based care routines. At the same time, they are expected to maintain emotional stability for their child while managing their own psychological distress. Research consistently reports elevated levels of anxiety, depressive symptoms, and stress during this period, largely due to uncertainty and reduced perceived control (Pai et al., 2007; Kazak et al., 2010). In addition to emotional strain, caregiving responsibilities extend into financial management, treatment coordination, and family role adjustment. In India, these difficulties are further intensified by delayed diagnosis, limited access to specialized oncology services, high out-of-pocket expenditure, and inadequate psychosocial support systems (Arora et al., 2010). Although existing literature predominantly focuses on biological parents, particularly mothers and fathers, limited attention has been given to step-parents and blended family systems. Step-parents may face unique challenges such as unclear caregiving roles, limited participation in medical decisions, and emotional boundary difficulties, which remain underexplored in pediatric oncology research. This review therefore aims to synthesize literature on parental psychological distress in pediatric cancer care, focusing on its dimensions, causes, assessment methods, and contextual challenges in India.

2. Parental Psychological Distress in Pediatric Cancer Care

Parental psychological distress in pediatric oncology is a complex and evolving condition that extends beyond emotional reactions to include financial strain, social disruption, cognitive burden, and existential concerns. It develops throughout the illness trajectory and varies depending on treatment phase and family circumstances. Emotional responses such as fear, helplessness, sadness, and shock are most prominent at the time of diagnosis and during intensive treatment phases. Parents often struggle to regulate their emotions while providing support to their child, which can lead to long-term emotional exhaustion and psychological fatigue (Kazak et al., 2010). Financial pressure represents a major source of chronic stress, particularly in resource-limited settings. Costs associated with treatment, hospitalization, travel, accommodation, and loss of income contribute to sustained economic strain, commonly referred to as financial toxicity (Zafar & Abernethy, 2013). Social functioning is also significantly affected, as caregivers frequently reduce engagement in social networks due to time

*Corresponding author: snehaanil747@gmail.com

constraints, emotional exhaustion, and perceived stigma. Cognitive and existential concerns, including guilt, worry, and catastrophic thinking, further intensify distress (Phipps et al., 2014).

3. Causes of Parental Psychological Distress

Parental psychological distress is influenced by multiple interacting medical, psychological, and systemic factors that operate throughout the illness trajectory. The sudden diagnosis of cancer often creates an intense emotional shock and difficulty in acceptance, followed by persistent uncertainty regarding treatment outcomes and fear of relapse, which together maintain long-term anxiety. In addition, visible physical changes in the child during treatment further intensify emotional burden on caregivers. Financial instability is a major concern, particularly in India, where out-of-pocket expenditure for cancer care is high and often leads to sustained economic strain (WHO, 2023). Psychological distress is further compounded by limited access to structured psychosocial services, stigma associated with both cancer and mental health, and lack of awareness regarding available psychological support, all of which delay timely help-seeking. High caregiving demands, disrupted sleep patterns, and continuous role overload contribute to emotional exhaustion and caregiver burnout. In blended family systems, additional challenges such as unclear caregiving roles and emotional boundary difficulties may further intensify psychological strain (Papernow, 2013).

4. Assessment of Parental Psychological Distress

Assessment of parental psychological distress requires a structured and multidimensional approach that captures emotional, behavioral, social, cognitive, and burden-related domains. Emotional distress is commonly measured using standardized tools such as the Hospital Anxiety and Depression Scale (HADS), the Depression Anxiety Stress Scales (DASS-21), and the State-Trait Anxiety Inventory (STAI), which assess symptoms of anxiety, depression, and stress (Spielberger, 1983). However, despite their availability, routine psychological screening is not consistently implemented in many oncology settings, leading to under-identification of caregiver distress. Behavioral indicators such as withdrawal from communication, reduced self-care, and disruption in occupational functioning provide additional insight into caregiver strain. Social support is typically assessed using instruments such as the Multidimensional Scale of Perceived Social Support (MSPSS) and the General Health Questionnaire (GHQ-12), which evaluate perceived support systems and broader psychological functioning. Cognitive assessment focuses on maladaptive thought patterns, including guilt, catastrophic thinking, and exaggerated fears regarding disease outcomes. Caregiver burden is evaluated using standardized measures such as the Parenting Stress Index (PSI), Zarit Burden Interview (ZBI), and Caregiver Strain Index (CSI), which collectively capture emotional, physical, and financial strain associated with caregiving (Zarit et al., 1980; Abidin, 1995). In addition, psycho-oncology frameworks such as the Pediatric Psychosocial Preventive Health Model (PPPHM) emphasize early identification of high-risk caregivers and the implementation of tiered psychosocial interventions within oncology care systems (Kazak et al., 2010).

5. Indian Context of Caregiver Distress

In India, caregiver distress is strongly shaped by structural inequalities in healthcare access. High out-of-pocket expenditure creates severe financial burden. Many families experience treatment interruption or debt-related stress. Geographic barriers further delay access to specialized pediatric oncology and mental health services. Cultural stigma surrounding cancer and mental illness leads to nondisclosure, social withdrawal, and delayed help-seeking.

Psycho-oncology services in India are still developing. Many hospitals lack structured distress screening protocols, trained psycho-oncology staff, and standardized caregiver interventions. As a result, psychological distress often remains untreated or identified late in the illness trajectory (Chaturvedi, 2016; Kazak et al., 2018). However, emerging multidisciplinary care models and hospital-based counselling services show early promise in improving caregiver coping and emotional adjustment.

6. Conclusion

Parental psychological distress in pediatric cancer is a persistent, multidimensional, and evolving phenomenon shaped by emotional, financial, cognitive, social, and systemic factors. While distress is most acute at diagnosis, it continues throughout treatment due to uncertainty, caregiving demands, and financial strain. In the Indian context, these challenges are intensified by healthcare inequities, high treatment costs, limited psychosocial infrastructure, and sociocultural stigma. Additionally, diverse caregiving systems, including step-parent involvement, remain underexplored, particularly in relation to role ambiguity and emotional adjustment. Overall, this review emphasizes that parental distress should be understood as both an individual psychological response and a systemic healthcare issue. Strengthening psycho-oncology services, implementing routine psychological screening, and adopting family-centered interventions are essential for improving caregiver well-being and pediatric cancer care outcomes.

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