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REVIEW ARTICLE

Psychological Distress and Quality of Life Among Parents of Children with Cancer: Implications for Holistic Nursing Care

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ABSTRACT

Childhood cancer represents a devastating diagnosis that not only disrupts the life of the affected child but also profoundly impacts parents, who are the primary caregivers. With nearly 400,000 new pediatric cancer cases reported worldwide each year, and about 50,000 in India alone, the burden extends far beyond medical treatment. Advances in oncology have significantly improved survival outcomes, yet the psychosocial consequences for parents remain underexplored, especially in low- and middle-income countries. Parents of children with cancer face considerable psychological distress, manifested through anxiety, depression, anticipatory grief, and post-traumatic stress symptoms. Such distress is particularly pronounced during diagnosis and active treatment but may persist for years, even after remission.

The quality of life (QoL) of parents is significantly impaired across multiple domains physical, psychological, social, and financial. Mothers, often the primary caregivers, report higher levels of emotional distress and role strain, while fathers are more affected by economic responsibilities and occupational challenges. Coping mechanisms vary, ranging from problem-solving and spirituality to maladaptive avoidance strategies. Social and cultural factors further shape parental responses, influencing both resilience and vulnerability.

Holistic nursing care plays a critical role in mitigating these challenges. Nurses, by virtue of their close and continuous interaction with families, are uniquely positioned to provide comprehensive support. Evidence-based strategies such as psychosocial assessment, counseling, stress management programs, mindfulness-based interventions, and family-centered care are effective in reducing distress and enhancing QoL. Additionally, culturally sensitive approaches that integrate family beliefs and spiritual practices are essential in diverse contexts like India.

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• Childhood Cancer • Psychological Distress • Quality of Life • Caregivers • Holistic Nursing • Parents

INTRODUCTION

Cancer in childhood represents a life-threatening illness that not only disrupts the life of the affected child but also reverberates across the entire family system. Globally, an estimated 400,000 children and adolescents are diagnosed with cancer annually, with leukemia, brain tumors, and lymphomas being the most common types (WHO, 2022). In India, approximately 50,000 new cases are reported every year, contributing to a significant disease burden (Gupta *et al.,* 2021).

Medical advances have improved the survival rates of childhood cancers, with cure rates approaching 80% in high-income countries. However, in low and middle-income countries (LMICs), survival rates remain significantly lower due to limited resources, delayed diagnosis, and inadequate treatment facilities. Beyond survival, the diagnosis and treatment of childhood cancer impose immense psychosocial challenges on families, particularly parents.

Parents are central figures in caregiving, responsible for managing hospital visits, adhering to treatment regimens, and providing emotional support. The stress of caregiving often results in psychological distress, defined as emotional suffering characterized by depression, anxiety, and fear (Kwak *et al.,* 2020). Furthermore, quality of life (QoL) a multidimensional construct encompassing physical, emotional, social, and financial well-being is significantly impaired (WHOQOL Group, 1998).

Understanding the psychological distress and QoL of parents is critical for holistic nursing practice. Nurses, as frontline healthcare providers, can assess caregiver well-being, provide psychosocial support, and design interventions that enhance resilience and coping. This article synthesizes existing literature on parental distress and QoL, focusing on implications for holistic nursing care.

REVIEW OF LITERATURE

Psychological Distress in Parents of Children with Cancer

Parental psychological distress is well-documented in pediatric oncology. Distress peaks at the time of diagnosis and during active treatment but can persist for years even after remission. Van Warmerdam *et al.* (2019) reported that nearly 60% of parents experience clinically significant anxiety and depression within the first year of diagnosis. Additionally, 25–35% continue to show post-traumatic stress symptoms long after treatment ends (Patino-Fernandez *et al.,* 2020).

The emotional burden stems from uncertainty about the child's prognosis, painful treatment procedures, and fear of relapse. Parents often oscillate between hope and despair, leading to chronic psychological strain (Maurice-Stam *et al.,* 2021).

Quality of Life Among Parents

QoL among parents is negatively affected across multiple domains:

- **Physical QoL:** Fatigue, insomnia, somatic symptoms, and neglect of self-care are common (Sloper, 2020).
- **Psychological QoL:** Persistent anxiety, depression, and emotional exhaustion reduce overall well-being (Mishra *et al.,* 2021).
- **Social QoL:** Parents experience social withdrawal, marital conflicts, and role disruptions within the family (Ozdemir & Akdemir, 2020).
- **Financial QoL:** Treatment-related expenses, travel costs, and loss of income exacerbate economic hardship (Gupta *et al.,* 2021).
- Mishra *et al.* (2021) found that in India, low socioeconomic status and lack of psychosocial support were key predictors of poor QoL among caregivers.

Gender Differences in Distress and QoL

Gender differences are consistently highlighted in caregiving research. Mothers often experience higher levels of psychological distress due to their roles as primary caregivers, while fathers are more affected by financial pressures and work-related challenges (Liu *et al.,* 2022). Mothers report more anxiety and depression, whereas fathers frequently experience stress associated with maintaining income and supporting the family economically (Ozdemir & Akdemir, 2020).

Coping Mechanisms

Parents employ diverse coping strategies to manage stress:

- **Problem-focused coping:** Gathering medical information, organizing treatment schedules.
- **Emotion-focused coping:** Spirituality, prayer, acceptance, and mindfulness.
- Social support: Seeking help from extended family, peers, and healthcare teams.
- **Avoidance coping:** Avoiding discussion or denial, which is associated with poorer outcomes (Geng *et al.,* 2021).

Interventions from Literature

Evidence suggests several effective interventions:

- **Psychoeducation programs** reduce uncertainty and promote informed caregiving.
- **Cognitive-behavioral therapy (CBT)** alleviates symptoms of anxiety and depression.
- **Mindfulness-based interventions** enhance emotional regulation and coping.
- **Nurse-led support groups** offer peer connection, emotional validation, and guidance (Kwak *et al.,* 2020).

DISCUSSION

Multidimensional Nature of Distress

Parental distress is influenced by multiple interrelated factors—medical, financial, social, and cultural. The child's disease severity, hospitalization length, and prognosis directly affect parental anxiety. Financial constraints and limited social support worsen distress, particularly in LMICs like India, where health insurance coverage is inadequate.

Holistic Nursing Role

Nurses play a pivotal role in mitigating parental distress. Their consistent presence throughout diagnosis, treatment, and follow-up allows them to build trusting relationships with families. A holistic nursing approach integrates physical, psychological, social, and spiritual care, emphasizing family-centered practices.

1. **Routine Assessment:** Regular screening for psychological distress and QoL using validated tools (HADS, WHOQOL-BREF).
2. **Counseling:** Providing emotional support, grief counseling, and coping strategies.
3. **Stress Management Programs:** Teaching relaxation techniques, mindfulness, and stress reduction methods.
4. **Family-Centered Care:** Involving both parents in care planning and decision-making.
5. **Culturally Sensitive Interventions:** Recognizing the role of spirituality, traditional beliefs, and cultural coping strategies.
6. **Policy Advocacy:** Nurses should advocate for caregiver support policies, financial assistance, and integration of psychosocial care in oncology settings.

Implications for Nursing Practice

Holistic interventions for parents are essential not only for caregiver well-being but also for the child's treatment outcomes. Parental distress negatively impacts treatment adherence, as overwhelmed caregivers may struggle to follow medical advice consistently. By addressing caregiver well-being, nurses indirectly improve the child's recovery trajectory.

Research Gaps

- Few longitudinal studies examining long-term caregiver QoL.
- Lack of culturally tailored interventions in LMICs.

- Need for intervention-based RCTs testing nurse-led psychosocial support.

CONCLUSION

Parents of children with cancer face extraordinary psychological, social, and financial challenges that significantly impair their quality of life. Psychological distress manifesting as anxiety, depression, post-traumatic stress, and anticipatory grief remains a persistent concern. QoL is affected across physical, emotional, social, and financial domains, with mothers disproportionately affected compared to fathers.

Holistic nursing care, grounded in routine psychosocial assessment, counseling, stress management, and culturally sensitive interventions, offers a comprehensive framework for supporting parents. Nurses are uniquely positioned to implement family-centered care models that not only improve parental well-being but also enhance child treatment adherence and long-term resilience.

Future directions should include large-scale, culturally adapted, nurse-led intervention trials, as well as integration of caregiver support programs into national pediatric oncology policies. By addressing parental well-being, holistic nursing care has the potential to transform pediatric oncology practice and promote sustainable family health.

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