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RESEARCH ARTICLE

Assess the Psychosocial Problems Among Parents of Leukaemia Child in Selected Hospitals.

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Abstract: Leukemia is the most common childhood cancer in India, comprising 25–40% of pediatric malignancies, with acute lymphoblastic leukemia (ALL) accounting for 60–85% of cases. Compared to developed countries, Indian ALL shows a higher prevalence of T-cell subtype (20–50% vs. 10–20%) and adverse cytogenetic features such as hypodiploidy and translocations t (1;19), t(9;22), and t (4;11), contributing to poorer prognosis. T-cell ALL is more frequent in socioeconomically disadvantaged groups, while with urbanization and affluence, common ALL—peaking at ages 2–5 years—becomes more predominant.1 The present study aimed to identify the psychosocial problems among parents of children with leukemia. A quantitative research approach was adopted, and the study was conducted among 88 parents of children diagnosed with leukemia, selected through non-probability purposive sampling. Ethical clearance was obtained from the institutional ethical committee. Data were analyzed using descriptive and inferential statistics, with frequency, percentage, and item analysis applied to assess psychosocial problems. Results revealed that nearly half of the affected children (48.87%) were in the 3–7 years' age group. Fathers constituted 51.13% of the respondents, with most fathers employed in service or jobs, while mothers were primarily housewives. A majority of families (79.55%) had a monthly income below Rs. 20,000, and more than half (56.84%) lived in joint families. Most children had been undergoing treatment for 1–3 years (61.36%), and 9.09% reported a family history of leukemia. The findings highlight that most parents experienced considerable emotional and financial stress, including fear of further health complications in their child, anxiety about the illness affecting other family members, and distress related to prolonged treatment routines and expenses. Parents also reported feelings of guilt, social withdrawal, and isolation; however, family, friends, and community groups provided significant support. Importantly, parents expressed that discussing their concerns with health professionals alleviated some of their stress. In conclusion, parents of children with leukemia face multidimensional psychosocial challenges, underscoring the need for targeted psychosocial interventions and professional support systems to improve their coping and overall well-being.

Keywords: Psychosocial Problems, Parents, leukemia child.

INTRODUCTION

Leukemia is a major health problem in India, especially among children. Acute lymphoblastic leukemia is the most common diagnostic group of childhood cancers. Leukemia is a cancer of the body's blood-forming tissues, including bone marrow and lymphoid tissue. Leukemia affects the psychosocial problem not only for children but also for their caregivers. Acute Lymphoblastic leukemia (ALL) constitutes 20% to 30% of pediatric cancers. Acute Lymphoblastic leukemia was the most common 78.6%, followed by Acute myelogenous leukemia 15.6%. The prevalence rate in India serves as a summary and overview of the incidence of childhood cancer across 25 Indian population-based cancer registries. Cancer For boys and girls, the incidence rates varied from 18.6 to 159.6 per million and 11.3 to 112.4 per million, respectively. The prevalence was lowest in the northeast for both boys (18.6) and girls (11.3), and it was highest for males (159.6) in the southern part of the country. The most prevalent cancers in boys were leukaemia and lymphoma, whereas the most common cancers in girls were leukaemia and brain tumors.[2]

In India, among children aged 5 to 14, cancer ranks as the ninth most common cause of death. According to Indian cancer registers, the percentage of paediatric cancers compared to all cancers ranged from 0.8% to 5.8% for boys and from 0.5% to 3.4% for girls.[1]

While advances in treatment have significantly improved survival rates in children with ALL, the illness continues to place a heavy psychosocial burden on families. Parents often experience intense emotional strain, including anxiety, guilt, and fatigue, as they manage prolonged hospital stays, unpredictable treatment outcomes, and financial hardships. These challenges are further compounded by the stigma associated with childhood cancer, which can isolate families socially and hinder open communication within both family and community settings. Such factors collectively increase psychological distress and reduce coping capacity (Monteverde, 2023). Given that parents serve as the primary caregivers, addressing their psychosocial difficulties is essential not only for the child's recovery but also for ensuring the overall well-being of the family.[3]

Numerous studies have highlighted the significant emotional distress, including anxiety, depression, and grief, that parents experience following their child's leukemia diagnosis. A study published in the (2020) reported that parents often undergo intense emotional struggles, especially during treatment, leading to long-term psychological effects. Indian studies have focused on the emotional toll within the context of familial and cultural expectations. Research from the Indian Journal of Psychiatry (2019) indicates that parents often experience feelings of helplessness and guilt, compounded by societal pressures and lack of support. Research published in Supportive Care in Cancer (2020) has shown that parents adopt various coping strategies, such as seeking social support, relying on religion, or using distraction techniques. Studies have also noted the critical role of peer support groups in improving the psychological well-being of these parents.[4]

Acute lymphoblastic leukemia (ALL) is the most common childhood cancer, accounting for nearly 25% of all pediatric malignancies in the United States and representing a significant health concern in India (Margolin, Steuber, & Poplack, 2006). The disease primarily affects children between the ages of 1 and 4 years and is characterized by the overproduction of immature lymphoblasts in the bone marrow. These abnormal cells fail to mature into functional B or T lymphocytes, which are essential for immune defense, and instead accumulate in the bone marrow and peripheral blood. As a consequence, healthy blood cell production is suppressed, leading to anemia, frequent infections, and bleeding tendencies due to pancytopenia (Pearce & Sills, 2005).

High-risk ALL presents additional clinical challenges, particularly in children who show resistance to initial treatment or have unfavorable genetic features such as high white blood cell count, T-cell lineage, or chromosomal abnormalities like t (9;22) and t (4;11).[5]

Mothers of children with leukemia often experience significant emotional challenges alongside social difficulties, particularly in relation to their child's treatment, parenting responsibilities, and the struggle to maintain a sense of normalcy for both their child and themselves. Consequently, the present study aimed to gain a deeper understanding of the emotional and social experiences of parents raising children with leukemia. To achieve this objective, the research sought to explore the psychosocial problems faced by these parents, with the intention of constructing a comprehensive portrayal of their lived experiences and providing greater insight into their perceptions and coping mechanisms.

Research Methodology: This study adopted a **quantitative descriptive research approach** to assess psychosocial problems among parents of children with leukemia. A total of **88 parents** were selected using **non-probability purposive sampling**. **Inclusion criteria** included parents (either mother or father) whose child was diagnosed with leukemia, hospitalized for at least six months, and who could understand Marathi or English and provided written consent. Exclusion criteria included parents of children with other chronic or neuropsychiatric illnesses and those unable to understand the study language. Data were collected using a self-structured questionnaire with demographic items and a 25-item Likert scale assessing psychosocial challenges. The tool underwent expert validation and demonstrated reliability with a test-retest correlation coefficient of 0.81. A pilot study on 10 participants confirmed feasibility. Ethical approval was obtained, informed consent was secured, and data were analyzed using descriptive and inferential statistics.

RESULTS

The demographic data of 88 parents of children with leukemia. Most children (48.87%) were aged 3–7 years. Nearly equal numbers of fathers (51.13%) and mothers (48.87%) participated. Many fathers were graduates (33.33%) or postgraduates (26.67%), while mothers had mostly completed higher secondary (34.88%) or secondary education (20.93%). Over half of the fathers (53.49%) were employed in service, and most mothers (77.78%) were homemakers. A majority of families (79.55%) had a monthly income below ₹20,000. Most participants (62.5%) lived in rural areas, and 56.84% belonged to joint families. Only 4.54% reported other health issues in the child, and 9.09% had a family history of leukemia. Most children (61.36%) had been under treatment for 1–3 years.

Item analysis of Psychosocial Problems Among Parents of Children with Leukemia
The findings revealed a high prevalence of psychosocial distress among parents. A statistically significant majority (98.86%) expressed intense fear of their child developing additional health complications, reflecting widespread psychological vulnerability. Likewise, 97.72% reported feeling emotionally overwhelmed, indicating high emotional distress during the treatment journey.

Parental anxiety and misconceptions were notable, with 92.04% believing leukemia may be transmissible—suggesting the need for targeted education and counseling. Social stigma was also a significant concern; 90.90% of parents feared blame or judgment from others. Nearly all parents (97.72%) reported that hospital routines contributed significantly to their stress, highlighting the importance of improving the hospital environment and communication with healthcare staff.
Emotional and social impact was severe—98.86% reported emotional pain, 92.04% experienced social

withdrawal, and 94.31% reported guilt over seeking financial help. Moreover, 98.86% expressed feelings of guilt and self-blame related to their child's illness, underlining the need for accessible psychological interventions.

Financial burden emerged as a dominant theme. 96.59% of parents were concerned about treatment expenses, 93.18% said medical bills affected other family needs, and 98.86% reported working extra hours to manage costs. Additionally, 97.72% worried about long-term financial sustainability, further emphasizing the urgency for financial counseling and support systems.

Support mechanisms showed mixed outcomes. While 97.72% found speaking with health professionals helpful, and 98.86% relied on friends for emotional and practical support, only 17.04% gained strength from prior hospitalization experiences. This points to limited internal coping resources and a high need for external support.

Finally, 92.24% reported that the illness had brought their family closer together, and 93.18% were still able to find moments of joy with their families, showing resilience amidst adversity. However, 90.90% struggled to give attention to their other children, indicating emotional and logistical strain on family dynamics.

DISCUSSION

Section I: Demographic Variables

The study included 88 parents of children with leukemia. Most children (48.87%) were in the 3–7 year age group. Fathers (51.13%) slightly outnumbered mothers (48.87%). In terms of education, 33.33% of fathers were graduates, while 34.88% of mothers had completed higher secondary education. Occupationally, over half of the fathers (53.49%) were in service, and the majority of mothers (77.78%) were housewives. Financial strain was evident, as nearly 80% of families earned less than ₹20,000 monthly, with 62.5% living in rural areas. Family structures showed 56.84% belonged to joint families. Most families (90.91%) reported no history of leukemia, and the majority (61.36%) had been dealing with treatment for 1–3 years.

A similarly study was conducted by Tomizawa et al. (2023) examined risk-stratified therapy for pediatric acute myeloid leukemia (AML), which is the second most common childhood leukemia. Their review showed that survival rates in developed countries have increased to 70–80% over the last four decades, largely due to intensive chemotherapy, improved detection of minimal residual disease, better cytogenetic and molecular profiling, and advances in supportive care. However, the study emphasized that treatment-related toxicity, prolonged hospital stays, and the need for allogeneic hematopoietic stem cell transplantation still impose substantial psychosocial and financial burdens on families. This aligns with the present study's findings that hospital routines and long-term treatment contribute heavily to parental stress, while financial strain remains a central issue for families of children with leukemia.

Section II: To identify psychosocial Problems

Parents reported multiple psychosocial difficulties. A vast majority (98.86%) expressed fear of additional health issues for their child, while 92.04% showed high levels of anxiety and misconceptions about the disease. Stigma was a significant concern for 90.90% of parents, and emotional distress was severe, with 97.72% feeling overwhelmed and 98.86% experiencing guilt or self-blame. Financial strain was among the most prominent issues: 96.59% worried about the treatment burden, and 98.86% reported working extra hours, which disrupted family life. Hospital routines were identified as a major stressor by 97.72% of parents, while 92.04% reported social withdrawal and isolation. Despite these hardships, resilience emerged, as over 92% reported that the illness strengthened family bonds, and 93.18% found ways to spend quality time together.

Similarly, Van Oers et al. (2018) conducted a longitudinal study assessing parental distress six months after a pediatric cancer diagnosis. Using the Psychosocial Assessment Tool (PAT), they reported that parents of children with cancer experienced significantly greater psychosocial difficulties than parents of healthy children, across almost all domains, including emotional functioning, social isolation, and family communication. Importantly, the study demonstrated that higher PAT scores at diagnosis predicted higher distress at six months, suggesting that early psychosocial risk screening could help identify families needing targeted interventions. This finding directly supports the present results, where parents consistently reported high levels of anxiety, guilt, and emotional distress, highlighting the urgent need for early psychological support.

Both studies converge on the critical importance of psychosocial care alongside medical treatment. While Tomizawa et al. highlighted improvements in survival and biomedical outcomes, they acknowledged that families still shoulder a major psychosocial burden. Van Oers et al. reinforced that parental distress is not transient but persists over time unless systematically addressed. Taken together, these findings suggest that healthcare teams should integrate structured psychosocial risk assessments and provide ongoing counseling, peer support, and financial guidance, ensuring a more holistic approach to childhood leukemia management.

Implications for Nursing

Nursing Practice: Nurses should identify psychosocial problems early and provide counseling and supportive care to parents. Both bedside and community nurses can help families cope and promote holistic well-being.

Nursing Education: Nurse educators should train students and staff on recognizing and managing psychosocial issues, using methods such as role play, case studies, and counseling sessions.

Nursing Administration: Nurse administrators should organize in-service education, workshops, and programs to enhance staff competence in psychosocial care, ensuring effective and family-centered services.

Nursing Research: Further research is needed to develop and evaluate interventions for parental psychosocial support in both hospital and community settings, with findings shared to guide policy and practice.

CONCLUSION:

This study explored the experiences and strategies of parents caring for children with leukemia, highlighting the profound impact of the illness on family life. Participants described challenges related to hospitalization, treatment demands, caregiver burden, and the need to adapt through various coping methods. The findings indicate that caring for a child with leukemia significantly affects parents' emotional well-being, independence, and social engagement. Many parents reported pressures and inadequacies, including restricted social interactions and limited personal opportunities. These constraints were often linked to emotional struggles such as despair, guilt, and stigma, in addition to the extensive responsibilities of caregiving.

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