

# Navigating Motherhood: Life Experiences and Challenges of Mothers of Leukemic Children on Parenting

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## ABSTRACT

Leukemia is the most common cancer in children, accounting for 101% of all children with cancer. Due to the improvement in the treatment and management of childhood acute lymphoblastic leukaemia, it was shifted from being a life-threatening disease to a chronic disease. this studied aimed to explore the life experiences and challenges faced by the mothers of children with leukemia. using a qualitative phenomenological research design and purposive sampling technique 10 mothers were evaluated with socio demographic data, and thematic content analysis. results revealed that three main themes: family impact post-diagnosis, mental and emotional health impact, and day-to-day challenges in managing the child's disease. Under family impact post-diagnosis, sub-themes include social life impacted, the child's school experiences, and family dynamics and unaffected siblings. The theme of mental and emotional health impact encompasses sub-themes of affected child's mental and emotional health, unaffected children's mental and emotional health, and impact on parents' mental and emotional health. Finally, the day-to-day challenge's theme covers dietary restrictions and management, travelling and mobility challenges, and monitoring the child's condition. These themes and sub-themes underscore the profound challenges faced by mothers of leukemic children.

**Keywords:** Life experiences, challenges, mothers, Leukemic children.

## Introduction:

Leukemia is a cancer of the blood-forming tissues. White blood cells may be produced in uncontrollable excessive amounts and are unable to work properly which weakens the immune system. Blood cells are formed in the bone marrow and the spongy tissues found inside the bones. Blood-forming stem cells divide

to produce either more stem cells or immature cells that become mature blood cells over time. A blood stem cell may enhance a myeloid stem cell or a lymphoid stem cell.

Chemotherapy is the primary treatment modality for leukaemia in children. The standard treatment protocol for children with leukaemia consists of five phases of treatment which are induction of remission, consolidation and CNS prophylaxis, interim maintenance, delayed intensification of re-induction, and maintenance. Play therapy is the set of interventions to promote children's well-being during the hospitalization or the play activities structured depending on the child's health condition, age, and development.

### Background of the Study:

**Global scenario:** As on 2023, the **American Cancer Society** in the U.S. reported that there will be an estimated 1,9108,310 new cancer cases and 609,820 cancer deaths.

According to the WHO, leukaemia accounts for 33% of all new cancer cases and 31% of all cancer deaths in children aged 0-14 years. The American Cancer Society reports that leukaemia is the most common cancer diagnosed in children and adolescents under 20 years old, making up 25.1% of all cancer cases in this age group.

**National scenario:** In India, one in nine people is likely to develop cancer in his/her lifetime. Among the childhood (0-14 yr.) cancers, lymphoid Leukaemia (boys: 29.2% and girls: 24.2%) was the leading site. The incidence of cancer cases is estimated to increase by 12.8 per cent in 20210 as compared to 2020.

**State scenario:** A total of 610,1090 cancer cases were diagnosed in 2016 in Tamil Nadu and the estimated cancer burden in 2020 was 78,641. Of this, the highest CIR of cancers was observed in Chennai (140.8) and the least in Krishnagiri (48.10) as per Antony A. et al. (2020). There are many treatments done in Chennai for each type of leukaemia according to specific and accurate diagnosis.

### Need for the study

Leukemia is the most common type of cancer among children under 110 years of age worldwide. The incidence rate of leukaemia varies across regions, ranging from 17.94 per 100,000 in Asia and Oceania to 37.74 per 100,000 in America, Canada, and Europe. In the United States, leukaemia is the most common cancer in children, and in Thailand, cancer has been typically ranked as the third leading cause of death among children after accidents and infectious diseases.

**Statement of the problem:** *“Life experiences and challenges of mothers of leukemic children on parenting at Institute of Child Health and hospital for children, Egmore, Chennai”.*

**Objectives:** Explore the life experiences and challenges of mothers of leukemic children on parenting in the Institute of Child Health and hospital for children, Egmore, Chennai.

### OPERATIONAL DEFINITION:

**Explore:** This study aims to thoroughly explore and discuss the aspects of maternal experience regarding challenges to the care of leukemic children

**Life experiences:** The life experiences of mothers of leukemic children encompass the multifaceted emotional, social, and practical challenges they face while caring for their children.

**Challenges:** A condition of suffering or distress due to ill health, harm, or hurt among mothers of leukemic children

**Mothers:** A mother is the female parent of a child. A woman may be considered a mother having given birth, by raising a child who may or may not be her biological offspring.

**Leukemic children:** In this study, it is referred to as the most common form of blood cancer in childhood.

### **ASSUMPTION**

Mothers of leukemic children underwent a lot of health challenges related to the illness of their children.

### **RESEARCH QUESTION**

What are the health challenges faced by the mothers of leukemic children while caring for the child?

### **DELIMITATION:**

- Limited to mothers of leukemic children only.
- The study period is limited to 4 weeks
- Limited size sample.

### **RESEARCH METHODOLOGY:**

#### **Research Approach & Design:**

Qualitative, phenomenological design.

#### **Research setting:**

**ICH, Egmore, Chennai-08.**

**Study population:** Mothers of leukemic children in hematology ward at selected pediatric tertiary care Centre in Chennai.

**Sample Size:** In this study sample size consists of 10 mothers of leukemic children in a pediatric hematology ward.

**Sampling Technique:** Non-probability Purposive sampling technique was selected based on the objectives of the research.

### **CRITERIA FOR SAMPLE SELECTION:**

#### **Inclusion criteria:**

- Mothers of leukemic children aged between 2- 12 years.
- Mothers of leukemic children who are undergoing treatment in the Paediatric haematology ward.
- Mothers who are willing to participate.
- Mothers who can able to understand Tamil and English.

#### **Exclusion criteria:**

Mothers of leukemic children with diagnosis other than leukemic disease.

Mothers who are not willing to participate.

#### **Validity of the tool:**

The validity of the tool was assessed using content validity. Content validity was determined by experts from Nursing and paediatricians. They suggested certain modifications to the tool. After the modifications, they agreed on this tool for assessment.

#### **Reliability of the tool:**

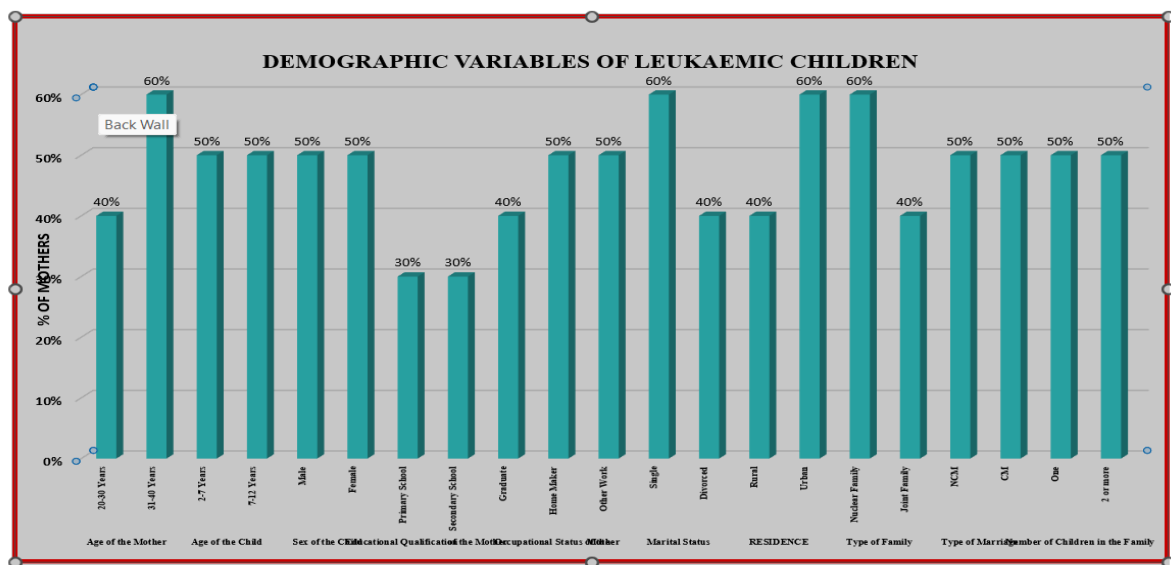
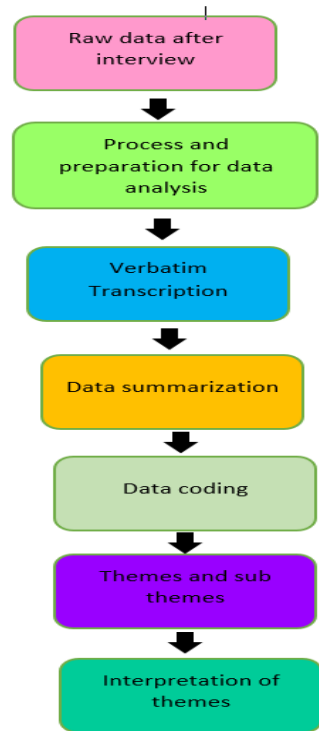
The reliability of the tool was assessed by using the **inter-rater reliability** method.

### ETHICAL CONSIDERATION

The study was carried out after obtaining an ethical clearance from the ethical committee and the Director of the Institute of Child Health.

### THEMATIC CONTENT ANALYSIS

**FIG.3.1. THEMATIC CONTENT ANALYSIS PRESENTATION**



**FIG.4.1. DEMOGRAPHIC VARIABLES OF THE PARTICIPANTS**

**Results:**

The findings reveal three main themes: family impact post-diagnosis, mental and emotional health impact, and day-to-day challenges in managing the child's disease. Under family impact post-diagnosis, sub-themes include social life impacted, the child's school experiences, and family dynamics and unaffected siblings. The theme of mental and emotional health impact encompasses sub-themes of affected child's mental and emotional health, unaffected children's mental and emotional health, and impact on parents' mental and emotional health. Finally, the day-to-day challenge's theme covers dietary restrictions and management, travelling and mobility challenges, and monitoring the child's condition. These themes and sub-themes underscore the profound challenges faced by mothers of leukemic children.

**Implications of the study:**

Nursing Implications Involve Emotional Support, Communication, And Addressing Psychological Needs to Enhance Mothers Care.

**Nursing Education:**

- Integrate emotional and psychological support training
- Develop practical caregiving skills.
- Foster resilience-building practices.
- Encourage empathy and compassion in care.
- Offer simulation experiences with leukemic child care.

**Nursing Administration**

- Develop policies to support family-centred care.
- Implement stress management programs for nursing staff.
- Ensure adequate staffing levels for paediatric oncology units.
- Provide ongoing training on leukaemia care.

**Nursing Research**

- Explore the psychological impact on mothers of leukemic children.
- Investigate effective coping strategies for families.
- Assess the long-term effects of childhood leukaemia on families.
- Examine the role of support systems in managing stress

**LIMITATIONS**

- Sample Size: Limited to 10 participants, not fully representative.
- Geographic Scope: Specific region, limiting generalizability.
- Qualitative Design: Lacks statistical rigor.
- Interviewer Bias: Potential influence on responses.
- Time Constraints: Short period, missing long-term experiences.
- Self-reporting: Influenced by memory recall and perception.

## RECOMMENDATIONS

- Conduct longitudinal studies to track changes in emotional and psychological well-being over time.
- Include diverse demographic groups to understand cultural differences in coping and support mechanisms.
- Evaluate overall quality of life and satisfaction with healthcare services.
- Develop and assess educational programs aimed at helping mothers manage caregiving responsibilities.

## CONCLUSION:

The study highlights the critical need for comprehensive support systems that address emotional, educational, and financial aspects of caregiving. Such systems can significantly ease the multifaceted burdens faced by these mothers, helping to improve the quality of life for both the child and the family. The insights gained emphasize the necessity for tailored interventions and resources to support mothers in their caregiving roles. By understanding and addressing these challenges, healthcare providers can offer more effective and compassionate care, ultimately fostering better outcomes for families navigating the complexities of childhood leukemia.

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