

LIVING WITH LEUKEMIA: A PHENOMENOLOGICAL STUDY OF SCHOOL-AGE CHILDREN'S EXPERIENCES DURING CHEMOTHERAPY IN INDONESIA

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ABSTRACT

Introduction

Leukemia is the most prevalent childhood cancer and its primary treatment, chemotherapy imposes profound physical, psychological, social, and spiritual burdens on affected children. Understanding children's own lived experiences of this illness and its treatment is essential to developing person-centered nursing interventions. This study objectives was to explore the lived experiences and health problems of school-age children with leukemia during chemotherapy.

Method

A descriptive qualitative study using phenomenological design was conducted with five school-age children (7–13 years) with acute lymphoblastic leukemia (ALL) in the consolidation phase. Data were collected through semi-structured child interviews, then analysed using qualitative content analysis assisted by NVivo 12.

Result

Four themes emerged from children's narratives: (1) altered physical condition, characterized by fatigue, nausea, and limited mobility; (2) pervasive negative emotions, including procedural fear, anxiety, sadness, and boredom; (3) restricted social and spiritual participation, encompassing loss of schooling, peer separation, and disrupted religious routines; and (4) transformed play experiences, marked by dependence on digital devices and absence of meaningful play in the hospital setting.

Conclusion

Children with leukemia experience multidimensional suffering during chemotherapy that extends well beyond physical symptoms. Integrated nursing interventions addressing physical, psychological, social, and spiritual dimensions simultaneously are urgently needed to improve their quality of life during hospitalization.

INTRODUCTION

Leukemia is the most common childhood malignancy worldwide. According to GLOBOCAN (2020), approximately 80,491 new leukemia cases were diagnosed in children aged 0–19 years globally, representing 28.8% of all childhood cancers. In Indonesia, the burden is particularly significant, with leukemia accounting for 34.3% of all childhood cancers, approximately 3,880 cases annually and a mortality rate of 38.5% (GLOBOCAN, 2020). Acute lymphoblastic leukemia (ALL) is the predominant subtype in the pediatric population, with an incidence approaching 30 cases per million individuals (Kaplan, 2019). Data from the Indonesian Pediatric Cancer Registry (2022) recorded 1,519 cases of lymphoblastic leukemia across 16 pediatric oncology centers between 2020 and 2022, confirming its position as the leading childhood cancer in the country.

Chemotherapy remains the cornerstone of leukemia treatment, typically administered across three phases: induction, consolidation, and maintenance. Despite its therapeutic efficacy, chemotherapy exerts considerable physical side effects including nausea, vomiting, fatigue, stomatitis, hair loss, and sleep disturbances (Wang et al., 2021). Beyond the physical dimension, the literature consistently documents adverse psychological consequences, including anxiety, fear, depression, and mood disturbances (Dupuis et al., 2016; Myers et al., 2014). Socially, prolonged hospitalization and treatment schedules disrupt children's schooling, peer relationships, and daily routines. These cumulative burdens compromise quality of life across all domains — physical, psychological, social, and spiritual (Hertanti et al., 2015; Polańska et al., 2020).

The consolidation phase, during which children receive high-dose chemotherapy on a cyclical basis following initial disease remission, represents a particularly vulnerable period. Children in this phase are relatively medically stable compared to the induction phase yet continue to experience significant treatment-related distress. This phase is also when children and families begin to feel the sustained burden of a chronic illness trajectory, including waning hope and spiritual distress (Martins et al., 2020; Moeini et al., 2014).

Despite this well-documented burden, most existing research has focused on quantitative outcome measurement or parent-proxy reports of children's experiences (Anthony et al., 2014). Children's own subjective accounts, their voices, meanings, and priorities have received comparatively little attention, particularly in the Indonesian cultural context. Understanding children's first-person narratives is not merely a methodological preference; it is ethically necessary for developing truly child-centered interventions (Creswell, 2014). Nursing interventions that are built on children's authentic experiences are more likely to be acceptable, contextually appropriate, and effective.

This qualitative study was conducted as the first stage of a sequential exploratory mixed-methods research programmed aimed at developing an integrated therapeutic intervention for children with leukemia. The specific aim of this stage was to explore and understand the lived experiences of school-age children with ALL during the consolidation phase of chemotherapy, including the health problems they faced. The findings of this study provided the empirical and experiential foundation for the subsequent development of a culturally grounded, integrated board game intervention (Leukofun) that addressed children's holistic needs.

METHOD

This study employed a descriptive qualitative design using a phenomenological approach, consistent with the aim of capturing the subjective lived experiences of children with leukemia (Creswell, 2014). The study was conducted at Al Islam Hospital, Bandung, Indonesia, between April and July 2023.

Participants and Sampling

Purposive sampling was used to recruit five school-age children (7–13 years) diagnosed with ALL who were in the consolidation phase of chemotherapy. Inclusion criteria were confirmed ALL diagnosis, currently undergoing consolidation-phase chemotherapy, aged 7–12 years, and willingness to participate. Children who were unable to communicate verbally or who were acutely unwell on the day of interview were excluded.

Data Collection

Three methods of data collection were employed. First, semi-structured interviews were conducted with children at their bedsides, in a seated face-to-face position with a parent present in a supportive (non-intervening) role. Interview guides covered children's general experiences of illness and treatment, physical and emotional symptoms experienced, coping strategies, and wishes regarding interventions. Interviews lasted 30–40 minutes on average. All interviews were audio-recorded with informed consent.

Data Analysis

Transcripts were analyzed using qualitative content analysis, following the inductive approach described by Creswell (2014). Analysis proceeded through the following stages: (1) organizing and preparing data; (2) reading and immersion in all data; (3) open coding; (4) grouping codes into categories; (5) identifying relationships between categories to construct themes; (6) member checking and verification with participants; and (7) presenting findings. NVivo 12 software was used to support the coding and categorization process. Methodological rigour was ensured through triangulation (member checking with participants, and reflexive journalling by the researcher).

Ethical Considerations

Ethical approval was obtained from the Ethics Committee of the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada (No. KE/FK/0413/EC/2023) and from Al Islam Hospital, Bandung (No. 013/KEPK-RSAI/3/2023). Written informed assent was obtained from children and informed consent from parents prior to participation. Confidentiality was maintained through participant coding; no personally identifiable information appears in this report.

RESULT

The five child participants ranged in age from 7 to 13 years (mean 9.6 years); four were male and one was female. All had ALL; four were on high-risk protocols and one on a standard-risk protocol. They came from five different cities in West Java province.

Qualitative content analysis yielded four overarching themes from children's narratives: (1) altered physical condition; (2) pervasive negative emotions; (3) restricted social and spiritual participation; and (4) transformed play experiences. These themes are described below with supporting excerpts. In the quotations below, participant codes are used: IA (Informan Anak, i.e., child informant).

Theme 1: Altered Physical Condition

All five children described significant physical deterioration attributable to both the disease process and chemotherapy-related side effects. Fatigue emerged as the most pervasive physical complaint, consistently limiting children's capacity for basic activities such as standing, walking, and self-care.

"rasanya lemes sedikit, lemes dan males-males aja dikit [I feel a little weak, weak and just a bit sluggish]"
(IA-1)

"Saya rasa lemes banget, saya sampai ga bisa main [I feel really weak, I can't even play]"
(IA-5)

"kalo jalan itu cape, suka ngantuk dan jatuh, jadi suka istirahat dulu [walking makes me tired, I get sleepy and fall, so I have to rest first]"
(IA-1)

"kalo berdiri dan berjalan ga bisa lama-lama [I can't stand or walk for long]"
(IA-1)

Gastrointestinal disturbances, particularly chemotherapy-induced nausea and vomiting were also widely reported. Children described nausea as a direct consequence of chemotherapy infusion, leading to anorexia and involuntary vomiting:

"kalo masuk obat rasanya mual, jadi ga mau makan...ehmmm kadang muntah juga [when the medicine goes in, I feel

nauseous, I don't want to eat...and sometimes I vomit]"

(IA-2)

These accounts were corroborated by parent observations. Mothers and fathers described witnessing dramatic physical changes in their children across the course of treatment, including profound weakness, reduced oral intake, oral mucositis, hair loss, and bone or joint pain. One parent recounted:

"Iya kan mual, terus ininya makan nggak bener gitu kan...kaki sama ya lemes...[Yes, there's nausea, and eating isn't right...the legs are weak...]"

(IO-1)

Theme 2: Pervasive Negative Emotions

A second prominent theme encompassed a cluster of negative emotional experiences that children reported across the course of their illness and hospitalization. These included procedural fear, anxiety, sadness, disbelief, and persistent boredom.

Procedural fear was particularly salient. All children expressed distress related to needle-based procedures — intravenous cannulation, injections, intrathecal chemotherapy, and blood draws — which they experienced as among the most frightening aspects of hospital care:

"takut jarum...sakit ditusuk jarum...merasa degdegan...ga seneng disuntik [afraid of needles...it hurts to be pricked by a needle...I feel my heart beating fast...I don't like injections]"

(IA-1, IA-3, IA-4)

"takut rumah sakit, ga suka dirawat [afraid of the hospital, don't like being hospitalised]"

(IA-2)

Sadness and a sense of incredulity were also expressed. Several children articulated confusion and distress at having to interrupt normal life — at having become, as they

perceived it, fundamentally different from healthy peers:

"sedih...ga percaya [sad...I can't believe it]"

(IA-3)

Chronic boredom and fatigue with the hospital environment were frequently described. Children expressed strong desires to return home and escape the monotony of ward life:

"males ke RS...bosan di RS...mau minta pulang [I'm tired of going to the hospital...bored of the hospital...I want to go home]"

(IA-1, IA-2, IA-5)

Parents validated these emotional states, noting that their children had become more emotionally reactive since diagnosis. Several parents observed marked changes in temperament — increased irritability, short temper, and emotional unpredictability — which they attributed to the combined stressors of illness, treatment side effects, and confinement:

"jadi adatnya itu lebih apa yaa... meledak-meledak lah...kalo ada maunya itu harus, awalnya adatnya ga kaya gitu [the behaviour has become more, well, explosive...if there's something they want it has to happen immediately; it wasn't like this before]"

(IO-2)

These emotional disruptions anxiety, boredom, sadness, and behavioural changes collectively represent the psychological toll of sustained hospitalization on developing children.

Theme 3: Restricted Social and Spiritual Participation

A third theme reflected the profound social and spiritual losses experienced by children during hospitalization. These losses were multidimensional, encompassing educational disruption, peer isolation, and changes in religious practice.

The inability to attend school represented one of the most emotionally significant losses identified by children. Schooling, for children

aged 7–12 years, is not merely an academic activity — it is the primary social arena through which children construct identity, relationships, and a sense of normalcy:

"kesel ga sekolah...sedih ga bisa sekolah...susah buat sekolah [annoyed that I can't go to school...sad that I can't go to school...it's hard to do school stuff]"

(Composite: IA-1, IA-2, IA-4)

Peer relationships were severely curtailed. Children reported feeling isolated from friends, unable to engage in the casual social interactions that characterised their pre-illness lives:

"ga ketemu temen-temen...bosan ga ada temen...ga ada temen di RS [I don't get to see my friends...bored with no friends...no friends at the hospital]"

(Composite: IA-1, IA-3, IA-5)

Spiritual life was also disrupted. Several children noted that regular prayer — a central practice in the Muslim faith observed by the participants — was difficult or impossible to maintain during hospitalization, particularly given physical weakness and the logistical constraints of an IV-attached bedridden state:

"di RS ga sholat...tidak bisa sholat [at the hospital I don't pray...I can't pray]"

(IA-3, IA-4)

The disruption of spiritual routines was particularly meaningful in the Indonesian cultural context, where religiosity is deeply embedded in family and social life. The loss of the capacity to pray — understood not only as religious obligation but as a source of comfort and connection — compounded children's sense of disorientation and loss. This finding is consistent with earlier research showing that leukemia and its treatment increase children's spiritual needs while simultaneously creating barriers to spiritual practice (Moeini et al., 2014; Reis et al., 2013).

Theme 4: Transformed Play Experiences

The fourth theme concerned the profound transformation of children's play lives during

hospitalization. Play is developmentally essential for school-age children, yet the hospital environment fundamentally constrained the nature, variety, and social character of children's play.

Field observation revealed that virtually all children engaged predominantly with digital devices — smartphones and tablets — as their primary recreational activity, often watching videos or playing mobile games for extended periods. This pattern was corroborated by children's own accounts:

"nonton film di hp...main game di hape...lihat youtube di hp...mainin hape [watching films on the phone...playing games on the phone...watching YouTube on the phone...using the phone]"

(Composite: IA-1, IA-2, IA-3, IA-4, IA-5)

The dominance of screen-based play was largely attributable to the absence of alternative play materials and play partners within the ward environment. Children reported limited access to physical toys at the hospital:

"ga ada mainan...mainan bawa sendiri [there are no toys...I brought my own toys]"

(IA-2, IA-4)

The social dimension of play — interaction with peers, shared games, group activities — was virtually absent from hospital life. Children who had previously engaged in physically active and socially rich play (football, cycling, outdoor games with friends) found themselves confined to solitary, sedentary, screen-based activity. This represented not only a loss of developmentally important play but also a loss of a primary source of social connection and positive emotion.

Parents were keenly aware of the importance of play to their children's wellbeing and uniformly expressed a desire for more structured, meaningful play opportunities during hospitalisation:

"Iya pasti bermain itu bermanfaat, biar anak gak jenuh...biar pikirannya ga fokus ke penyakitnya [Yes,

playing is definitely beneficial, so the child doesn't get bored...so their mind isn't only focused on the illness]"

(IO-3)

"daripada maen hape terus...kalau ada permainan mah kan jadi kana bacaan atau kana permainan [rather than always playing with the phone...if there's a game they will engage with reading or the game]"

(IO-3)

Nurses similarly affirmed that play was both beneficial and insufficiently utilized in the ward, noting that its implementation was constrained by time pressures, limited materials, and the need for specialized skills, a finding that directly informed the development of a facilitated, structured play intervention.

DISCUSSION

This phenomenological study illuminates the multidimensional experience of school-age children with ALL during chemotherapy consolidation, yielding four interconnected themes that together paint a portrait of pervasive, multi-system suffering that extends far beyond the physical domain. The findings offer both empirical grounding and a compelling imperative for holistic, integrated nursing care.

The first theme: altered physical condition aligns closely with the established literature on chemotherapy side effects in pediatric oncology. Fatigue is recognized as one of the most debilitating and prevalent symptoms in children with cancer, with estimates suggesting its prevalence in those undergoing active chemotherapy may exceed 70% (Hendrawati et al., 2021; Nunes et al., 2015). Fatigue in this population is multifactorial, arising from direct tumor effects, hematological compromise, corticosteroid use, disrupted sleep, and the systemic toxicity of cytotoxic agents (Daniel et al., 2016). The intensity of fatigue reported by our participants, children who described themselves as unable to play, stand for extended periods, or walk without collapsing underscores

the degree to which physical function is compromised even in the consolidation phase, when children are considered more medically stable than during induction. Similarly, chemotherapy-induced nausea and vomiting (CINV) are among the most distressing treatment-related symptoms. Despite advances in antiemetic pharmacology, a subset of children continues to experience breakthrough nausea and vomiting that significantly impairs oral intake and contributes to nutritional deterioration (Dupuis et al., 2016). The malnutrition and weight loss described by parents in this study reflect the downstream consequences of uncontrolled CINV and align with findings from Indonesian pediatric oncology settings (Hertanti et al., 2015).

The second theme, pervasive negative emotions extend findings from quantitative studies by providing rich phenomenological texture to the psychological burden of pediatric ALL. Procedural fear, particularly needle phobia, has been consistently documented as one of the most distressing aspects of cancer treatment for children (Dupuis et al., 2016; Myers et al., 2014). What emerges distinctively from our participants' narratives is the way in which procedural fear bleeds into generalized health anxiety and a pervasive sense of threat, children did not merely dread individual procedures but experienced the hospital itself as a frightening environment. This has important implications for nursing practice, as reducing procedural distress requires not only targeted interventions at the point of care (such as distraction or topical anesthesia) but also broader efforts to make the hospital a psychologically safer, more normalizing space for children. The chronic boredom and confinement reported by children is equally clinically significant. Extended hospitalization during development disrupts the acquisition of self-regulatory, social, and cognitive competencies that depend on active engagement with varied environments and peers (Elkind, 2009). Emotional dysregulation, manifesting as irritability and explosive behavior as described by parents is a well-documented consequence of both the illness itself and its psychosocial sequelae in children with cancer (Vasquez et al., 2022; Heo et al., 2022).

The third theme, restricted social and spiritual participation reflects dimensions of suffering that are frequently underappreciated in biomedically-oriented cancer care. The loss of schooling is, for school-age children, a profound disruption not only of education but of identity, belonging, and daily purpose. School represents the central social institution of middle childhood; its loss removes children from their primary developmental context, severing peer relationships and interrupting the developmental tasks of this stage (Elkind, 2009). The sense of grief at school loss expressed by our participants words like 'annoyed', 'sad', and 'hard'. It suggests that educational continuity should be treated as a priority health concern in pediatric oncology, not merely an administrative matter. Hospital school programmed and structured educational activities during chemotherapy admission deserve greater investment in the Indonesian context.

The spiritual dimension identified in this study is particularly significant given the Indonesian cultural context. Indonesia has the world's largest Muslim population, and religious practice, particularly the five daily prayers (*salat*) is a central organizing feature of daily life for most families. The children's distress at being unable to pray during hospitalization reflects not merely the loss of a ritual but the severing of a primary source of meaning, comfort, and connection. This finding resonates with the international literature on childhood cancer and spirituality, which has consistently shown that spiritual well-being moderates the psychological impact of serious illness in children and that spiritual distress is associated with poorer quality of life outcomes (Moeini et al., 2014; Reis et al., 2013). Children and families in the Indonesian context may derive particular benefit from spiritual care interventions that support the maintenance of religious routines within the ward environment.

The fourth theme; transformed play experiences speaks directly to a fundamental developmental need that is inadequately met in most pediatric oncology settings. Play is not a luxury for hospitalized children; it is a therapeutic necessity. The American Academy of Pediatrics (2012) and the nursing literature consistently affirm that play reduces anxiety, promotes coping, fosters social development,

and improves cooperation with medical procedures in hospitalized children (Bulechek et al., 2013). Yet the almost universal reliance on digital devices observed in this study and described by children themselves as their predominant activity suggests that, in the absence of structured, social play alternatives, children default to passive, solitary screen-based engagement. While digital engagement has some benefits (entertainment, connection with family at home), it does not fulfil the developmental functions of active, social, and imaginative play and may exacerbate rather than alleviate social isolation.

The near absence of physical toys in the ward and the lack of organized play activities reflect a systemic gap in the provision of developmentally appropriate hospital environments in Indonesian pediatric oncology settings. Nurses in this study acknowledged the importance of play but identified time constraints, lack of materials, and limited training as barriers to implementation, findings consistent with those reported in Brazil (Falke et al., 2018; Claus et al., 2021) and Portugal (Ribeiro et al., 2020). This systemic gap represents a modifiable target for quality improvement in pediatric cancer nursing.

Taken together, the four themes reveal the inadequacy of single-domain interventions in addressing the holistic burden of leukemia in school-age children. Physical symptoms, psychological distress, social disruption, spiritual loss, and play deprivation co-occur and interact. Fatigue limits the capacity for social and play engagement; fear and anxiety compound the distress of physical symptoms; spiritual disruption undermines the coping resources that support psychological resilience. An intervention that addresses only one of these dimensions, however rigorously designed will inevitably leave much of children's suffering unaddressed. This analysis provided the empirical foundation for the integrated board game intervention (*Leukofun*) developed in the subsequent stages of this research programmed, which sought to simultaneously address play, spiritual care, acupuncture for physical symptom management, and educational continuity within a single, child-friendly, family-engaged format.

Several limitations of this study should be acknowledged. The sample was small ($n = 5$

children), consistent with phenomenological methodology but not intended to support transferability claims. All participants were recruited from a single hospital in Bandung, limiting geographic and institutional diversity. Children aged 7–8 years provided shorter, less elaborated responses than older participants; future studies might employ adapted participatory methods (drawing, photograph elicitation) to facilitate expression in younger children. The study did not include children in other chemotherapy phases, and experiences may differ across induction, consolidation, and maintenance.

CONCLUSION

This phenomenological study reveals that school-age children with leukemia undergoing chemotherapy experience profound multidimensional suffering encompassing altered physical function, pervasive psychological distress, restricted social and spiritual participation, and impoverished play experiences. These dimensions are interconnected and mutually reinforcing, arguing strongly for integrated, holistic nursing interventions that address children's physical, psychological, social, and spiritual needs simultaneously. In the Indonesian cultural context, particular attention should be paid to the spiritual dimension of care and to the restoration of meaningful, structured play within pediatric oncology settings. The lived experiences documented in this study were integral to the development of a novel integrated board game intervention (Leukofun), which subsequently demonstrated efficacy in improving quality of life and reducing anxiety in this population. These findings contribute to the international evidence base for person-centered pediatric oncology nursing and provide a replicable framework for qualitative needs assessment prior to intervention development.

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