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Original Article

Information Needs of Parents Caring for Children with Leukemia: A Qualitative Exploration

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Abstract

Background: Parents of children with leukemia experience an intensive and prolonged treatment process that frequently leads to significant psychological distress. As they adapt to their caregiving roles, these parents seek information from various sources; however, their information needs often go unmet, and little research examines how these needs change across the treatment trajectory.

Objective: This study explored the information needs of parents of children with leukemia, focusing on the sources and content of information they use and the barriers they face in meeting these needs.

Method: We used a qualitative approach, conducting semi-structured, in-depth interviews with 13 parents of 12 children diagnosed with leukemia at the Estella Pediatric Oncology Center, Prof. Dr. R. D. Kandou General Hospital, Manado, Indonesia, between September 1 and 30, 2025. We recruited participants through purposive sampling until data saturation was achieved. We analyzed the data using thematic analysis in NVivo 15.

Result: We identified two primary themes. The first theme, information during the care of a child with leukemia, encompassed sources of information (healthcare providers, the internet, and peer parents) and content areas (nutrition, hygiene, and activity restriction). The second theme, barriers to information, included psychological, cognitive, interactional, and family support barriers, which were most prominent early in treatment and diminished as trust with healthcare providers increased.

Conclusion: The findings underscore the importance of healthcare providers pacing and personalizing communication based on parents' readiness, as well as implementing community-based education to address stigma and misconceptions related to childhood cancer.

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Keywords
Access to Information; Child; Information Needs; Leukimia; Parents.

Background

Cancer is a leading cause of death among children, with an estimated 400,000 children diagnosed with cancer worldwide each year (1, 2). The prevalence of childhood cancer in Indonesia has also increased annually (3). A study conducted in North Sulawesi showed that the number of children diagnosed with cancer at Prof. Dr. R. D. Kandou General Hospital has increased year by year, with leukemia accounting for the largest proportion of cases (4).

Parenting a child with leukemia, along with the intensive and prolonged treatment, often leads to stress and anxiety among parents (5–8). To manage these feelings, parents typically seek information about their child's condition (8, 9). This information-seeking also helps them adapt and function effectively in their new role (6, 10).

Several studies report that parents face challenges in obtaining comprehensive information while caring for a child with leukemia (8, 11–13). A systematic review confirms that information needs are among the most frequently unmet needs for these parents (14). Time constraints among healthcare providers, along with parents' lower education and socioeconomic status, often discourage discussions about the child's condition (8). As a result, parents' information needs are not always addressed by healthcare providers. Information needs refer to clients' self-expressed requirements; healthcare providers should meet the information needs individuals articulate rather than what professionals determine (15). Parents may also seek information from other parents, family members, the internet, or personal experience (16–19). However, little is known about how parents select, evaluate, and interpret these sources while supporting their child. This gap matters because information from different sources may vary in accuracy and may differ from what healthcare providers offer.

Information needs of parents of children with leukemia have not yet become a clinical priority, as treatment remains focused on medical management. A recent study at Prof. Dr. R. D. Kandou General Hospital (2024) found that parents struggled to provide optimal care because they had difficulty understanding complex medical terminology, which hindered effective information processing (20). However, this study did not examine parents' information needs in depth. Another study reported that inadequate information standards during cancer treatment increase emotional distress among parents (21). Additionally, healthcare providers in the pediatric oncology ward at Prof. Dr. R. D. Kandou General Hospital currently lack a structured module with comprehensive information on caring for children with leukemia. As a result, they deliver information only verbally and in an unstructured way. This gap may contribute to parental stress, anxiety, and fear, potentially affecting their ability to provide optimal care and support throughout treatment (10, 22, 23).

While the information needs of parents of children with cancer have been widely studied, research focused specifically on parents of children with leukemia is limited. Most existing studies address information needs in general terms or use predetermined

instruments (17, 18, 22, 24–27), so they do not fully capture parents' lived experiences of seeking, obtaining, understanding, and using information during treatment. It remains unclear how these needs develop and change over time, which information is most important in specific situations, which sources parents use, how they interpret them, and what barriers exist. This study aims to explore the information needs of parents caring for a child with leukemia, including the sources and content they rely on and the barriers they face.

Methods

Research Design

This qualitative study uses a descriptive phenomenological approach and semi-structured interviews. The descriptive phenomenological method seeks to uncover the meaning of a phenomenon as experienced by individuals or groups [27]. The study adhered to the comprehensive criteria outlined in the Checklist for Reporting Qualitative Research (COREQ) (28).

Sample and Participants

The study was conducted from September 1 to September 30, 2025, and included 13 parents of 12 children diagnosed with cancer at the Estella Pediatric Oncology Center, Prof. Dr. R. D. Kandou General Hospital, Manado. The study population comprised all parents of children with leukemia undergoing treatment at Kandou General Hospital. Purposive sampling was employed. Inclusion criteria required that participants be parents of a child diagnosed with leukemia, serve as the primary caregiver, and be able to communicate verbally clearly and effectively. Data collection ceased when no new information emerged from participants (29).

Instruments

Data were collected through semi-structured, in-depth interviews to explore parents' lived experiences comprehensively. The interview framework was developed based on a review of relevant literature and included the following guiding questions: (1) "What information have you come to know so far while accompanying your child through cancer treatment?"; (2) "What sources of information have you used to obtain this information?"; and (3) "Could you describe the challenges or barriers you have experienced when information was conveyed to you by healthcare providers?" Interviews were conducted individually in a quiet, private space provided by the hospital. All sessions were audio-recorded, and the interviewer also took field notes to capture relevant non-verbal cues. Each parent participated in a single interview session lasting approximately 35 to 60 minutes. All recordings were transcribed verbatim to support analysis.

Data Collection

The first author, a pediatric nurse with a master's degree in Nursing, conducted all interviews and had no prior personal relationship with any participant. Attending nurses at the Estella Pediatric Oncology Center initially identified potential participants

according to the inclusion criteria. The study team introduced eligible parents to the study. The first author explained the study's purpose and invitestudy's d participation. We obtained written consent from all participants before the interviews. Recruitment proceeded sequentially throughout the study period (September 1–30, 2025) until data saturation, as indicated by the absence of new information in subsequent interviews. Interviews were conducted in Bahasa Indonesia and lasted 40 to 60 minutes in a private space within the pediatric ward. Each participant was interviewed only once. A research assistant native to North Sulawesi performed verbatim transcription to preserve the nuances of local language use. The second and third authors, nursing lecturers with Master's degrees in Pediatric Nursing and Palliative Care Nursing, respectively, conducted the data analysis collaboratively. After each interview, the first author reviewed the transcript with the participant to verify accuracy and clarify or amend responses as necessary.

Data Analysis

The data analysis process began with transcription of the first participant's interview. The first author coded transcripts line by line using NVivo 15 software (QSR International) to organize and manage the coding process. The team grouped codes into categories and then synthesized them into themes through investigator debriefing sessions with the second and third authors. The team reviewed, challenged, and refined coding decisions, resolving disagreements through discussion and repeated reference to the original transcripts until consensus was reached. The researchers then developed a comprehensive and systematic description (thick description) of the findings. Data collection concluded after the thirteenth interview, when the research team determined that the interviews had reached sufficient depth and richness to develop meaningful themes. Member checking was conducted at the transcript stage, allowing participants to review and confirm the accuracy of their statements; however, final themes were not returned to participants for further validation. Data saturation was considered achieved after the thirteenth interview, as no new codes, categories, or themes emerged. Reflexivity was maintained through the recording of field notes and memos during interviews and analysis. The research process adhered to the ethical principles of autonomy, beneficence, and justice.

Trustworthiness and Rigor

This study's trustworthiness was established according to Lincoln and Guba's (1985) criteria: credibility, dependability, confirmability, transferability, and authenticity. Credibility was enhanced through member checking at the transcript stage, investigator debriefing, consensus discussions among the three researchers during three two-hour meetings, and the inclusion of direct participant quotations in the Results. Dependability was supported by maintaining an audit trail documenting the coding process in NVivo 15, conducting debriefing sessions, and resolving disagreements through discussion and reference to original transcripts. Confirmability was addressed through collaborative coding review among the three authors, whose clinical backgrounds include pediatric and palliative care nursing, as well as reflexive dialogue to minimize the influence of professional perspectives on interpretation. Transferability was strengthened through thick description of participant characteristics, the clinical setting, and the sociocultural

context of North Sulawesi. Authenticity was pursued by representing participants' perspectives through direct quotations and participant-verified transcripts, ensuring that the themes accurately reflect parents' lived experiences.

To strengthen the rigor of the analytic process, the study implemented several strategies recommended by Morse (2015), including investigator debriefing and consensus discussions among the research team. The team held three separate two-hour meetings to review and refine the emerging coding structure and themes.

Ethical Clearance

The Ethics Committee of R.D. Kandou Hospital granted ethical approval for this study (Approval No. 123/EC/KEPK-KANDOU/VI/2025, dated June 23, 2025), and the team secured formal institutional permission before data collection. All parents received a comprehensive explanation of the study's aims and procedures before participation, and each participant provided informed consent verbally and in writing.

Result and Discussion

Demographic Characteristic of Participant

The study included parents of children with cancer who attended the Estella Outpatient Clinic at Prof. Dr. R. D. Kandou General Hospital, Manado. A summary of parent demographics is provided in the table below. (Table 1)

Table 1. Demographic Characteristics of Parents of Children with Leukemia

Variable	f (%)	Mean ± SD
Parent Age		
Child Age		7.04 years±3.71
Duration Since Diagnosis		
Parental Role		
Mother	10 (76,92)	
Father	3 (23,07)	
Child's Sex		
Female	5 (41,66)	
Male	7 (58,33)	
Parents' Highest Education		
Elementary School	0	
Junior High Scholl	3 (23,07)	
Senior High School	9 (69,23)	
Higher Education	1 (7,69)	
Child's Diagnosis		
Acute Lymphoblastic Leukemia	11 (91,66)	
Chronic Mieloid Leukemia	1 (8,33)	
Cancer Treatment Phase		
Induction Phase	6 (50)	
Consolidation Phase	1 (8,33)	
Maintenance Phase	5 (41,66)	

Data analysis yielded two overarching themes: (1) *information during the care of a child with leukemia*, and (2) *barriers to information*. The first theme comprised two categories: sources of information and content of information, reflecting where parents obtained information and what they needed or received throughout their child's treatment. The second theme, barriers to information, comprised four categories: psychological, cognitive, interactional, and family-support barriers. These categories represent the various obstacles that prevented parents from having their information needs fully met. The following sections elaborate on each theme and its associated categories, illustrated with representative quotations from participants.

Table 2. Themes and Categories of Parents' Information Needs while Caring for a Child with Leukemia

Theme	Category	Code	Selected Participant Quotes
Information during the care of a child with leukemia	Sources of information	Actively questioning healthcare providers	Yes, and don't be passive. Don't just accept things without asking, for example, if the child is given medication, the parent should ask the doctor, 'What is this for? What is this medicine called?' Or ask the nurse, whoever the medical staff is, ask what it's for
	Content of information	Need for information on nutrition during chemotherapy	"Well, we have to take care of this child, making sure he/she eats nutritious food. And while going through chemo, there are also a lot of side effects. So as parents, we look for foods that won't trigger nausea or vomiting."
Barriers to information	Psychological barriers	Emotional conflict in deciding to continue treatment.	I was also torn between refusing the chemotherapy and continuing with it... I wanted to take him home, I really wanted to take him home and not continue with the chemo... I was torn about whether to go through with the chemo or not, because I'd heard from other parents' experiences that chemo has a lot of side effects, sometimes children even decline to the point of passing away. That was what confused me the most. At that moment, when the results came out, deciding whether to continue or not, I was the most confused I've ever been
	Cognitive barriers	Confusion due to limited knowledge and complex medical terms.	Yes, usually because of a lack of experience or knowledge about medicine, we still don't fully understand, so we keep asking the nurses and doctors. The terms used

		are sometimes too complex, so parents don't really understand, parents get confused too
Interactional barriers	Embarrassment as a barrier to communicating with healthcare providers.	Before, because I was still confused at the early stage, I was embarrassed to ask about the medications being given. Eventually I was advised that I had to ask — if I didn't know, I shouldn't just assume
Family support barriers	Family beliefs conflicting with medical recommendations.	When we heard about BMP, we honestly didn't understand what it was, what effects it could have. But family from the village said, 'Don't let them do it, don't let them puncture the hip bone, because once the hip bone is punctured the child could die.' So I was confused because there were two choices

Health Information during the Care of a Child with Leukemia

Caring for a child with leukemia constitutes a novel and challenging experience for parents. The intensive treatment process requires parents to understand relevant procedures and protocols to support treatment adherence. Consequently, parents actively seek and engage with information from diverse sources. This theme includes two categories: information sources and information content.

Sources of information

Parents identified several sources they relied on to obtain information while caring for their child with cancer, namely healthcare providers, the internet (including social media), and fellow parents of children with cancer. Most participants reported healthcare providers as the primary and most trusted source, and they actively questioned healthcare staff before turning to additional sources such as the internet. One participant explained:

> *"Yes, and don't be passive. Don't just accept things without asking — for example, if the child is given medication, the parent should ask the doctor, 'What is this for? What is this medicine called?' Or ask the nurse, whoever the medical staff is, what it's for."* (Participant 10)

The internet also served as an important source of information, particularly to reinforce parents' understanding of explanations previously given by healthcare providers. While waiting with their child in the ward, parents often searched online to revisit information they found difficult to understand or had forgotten from conversations with doctors or nurses. Some parents also used internet searches to verify the accuracy of information they had received from healthcare providers, as described below:

> *"Nowadays, parents already have the internet and a phone. Besides listening here, we also search on Google to find out more. Especially if the child is given a certain*

medicine, we look up what it's for, what its side effects are — that's how resourceful we have to be." (Participant 8)

Another source of information that parents found especially meaningful was other parents who had already gone through cancer treatment with their own children. Kandou General Hospital, Manado, operates a shelter house, Rumah Singgah Estella, located within the hospital grounds and intended for parents of children with cancer in the early stages of treatment. At the time of diagnosis, oncology ward healthcare providers would direct parents to the shelter house to discuss treatment from the perspective of fellow parents. This information was highly meaningful, as the accounts shared by other parents fostered motivation and optimism, giving parents the courage to proceed with chemotherapy. In addition, while staying at the shelter house, parents exchanged information about caregiving strategies during treatment, as one participant described:

"I still ask a lot of questions to friends, to patients who have already recovered. Like just now, with someone whose child has recovered — I still ask them a lot: what they ate, what they weren't allowed to eat, how long they had to rest completely, things like that." (Participant 4)

Content of information

As parents continued to adapt to and learn from the information they received, they reported that understanding it helped them fulfill their caregiving role more effectively throughout treatment. Nutritional management was one aspect that all parents agreed was essential in supporting treatment, as illustrated below:

"We have to make sure the child eats nutritious food. Meanwhile, during chemo there are also many side effects. So as parents we look for foods that won't trigger nausea and vomiting." (Participant 1)

During chemotherapy, parents were informed that their child's immune system was compromised, requiring them to maintain the child's hygiene through daily bathing, limiting visitors at the shelter house, and keeping the child away from crowds by using a mask to reduce the risk of infection. This proved particularly challenging once the child entered the maintenance phase, returned home, and resumed school activities, as one participant explained:

"My child has started school but not full-time. I usually ask the school first about which children are sick. If many children are sick, sometimes he can't go to school for one to two months. At most, he attends twice a week." (Participant 9)

Leukemia treatment spans a lengthy period determined by the prescribed protocol. From the outset of treatment, parents received information about regulating their child's daily activities. All participants in this study reported consistently trying to protect their child from physical impact during treatment, given the child's heightened vulnerability to bleeding and injury. This was reflected in the following account:

"After chemotherapy, my child couldn't fall down, so we had to stop his hobby, sports, for a while. The doctor once said the same thing, 'if you want to be active, go for a morning walk, wash your own dishes' — meaning light activities. The doctor often said that: let him wash dishes; if he likes drawing, let him draw; if he likes singing, let him sing, whatever he enjoys, that's fine, but it has to be limited. The main thing is just making sure he doesn't fall, that's it." (Participant 4)

The intensity of the treatment process, coupled with the child's fluctuating condition, required parents to comprehend various types of information appropriate to the child's condition and treatment phase. Throughout this process, parents reported encountering several barriers that hindered their ability to fully understand this information. They categorized these barriers as psychological, cognitive, interactional, and family support barriers.

Barriers to Information

Psychological Barriers

At the start of treatment, many parents experienced emotional instability after learning of their child's leukemia diagnosis. This shock made it difficult for them to process information from healthcare providers, even as they needed to make quick decisions and provide consent. Several participants described struggling to choose between refusing or proceeding with chemotherapy:

"I was also torn between refusing the chemotherapy and continuing with it... I wanted to take him home, I really wanted to take him home and not continue with the chemo... I was torn about whether to go through with the chemo or not, because I'd heard from other parents' experiences that chemo has a lot of side effects; sometimes children even decline to the point of passing away. That confused me most. At that moment, when the results came out, deciding whether to continue or not, I was the most confused I've ever been." (Participant 13)

Cognitive Barriers

When communicating with doctors and nurses about their child's condition, parents encountered unfamiliar terminology that was often hard to understand, prompting them to ask for clarification or look up the terms online. However, as treatment progressed, parents gradually became more familiar with the medical terminology used and were even able to share this understanding with other parents who had recently received a leukemia diagnosis for their own child:

"Yes, usually because of a lack of experience or knowledge about medicine, we still don't fully understand, so we keep asking the nurses and doctors. The terms used are sometimes too complex, so parents don't really understand; parents get confused too." (Participant 5)

Interactional Barriers

Parents who found information difficult to understand reported hesitancy in approaching doctors and nurses for clarification. During the initial stages of treatment, some parents experienced embarrassment when asking repeated questions, especially while adapting to the treatment process. As treatment progressed and familiarity with medical staff increased, this embarrassment lessened. In addition to embarrassment, parents expressed reluctance to ask questions when observing doctors and nurses engaged in discussions or attending to other patients. Consequently, parents often refrained from seeking clarification even when further explanation was necessary:

"Before, because I was still confused at the early stage, I was embarrassed to ask about the medications being given. Eventually I was advised that I had to ask; if I did not know, I should not just assume." (Participant 8)

Family Support Barriers

The information parents obtained often conflicted with stigma circulating among extended family and the community. When discussing the planned Bone Marrow Puncture (BMP) for diagnostic confirmation, parents faced a belief that the procedure could cause death, causing confusion and hesitation in their decisions. Besides stigma around BMP, parents also encountered misconceptions equating chemotherapy with dialysis, along with doubts about whether a young child could endure its side effects when even adults struggled. These stigmas further affected parents' ability to decide on their child's treatment plan:

> *"When we heard about BMP, we honestly didn't understand what it was, what effects it could have. But family from the village said, 'Don't let them do it, don't let them puncture the hip bone, because once the hip bone is punctured the child could die.' So I was confused because there were two choices."* (Participant 2)
> *"The family said, ' The child is still young; just take him home. Chemotherapy is the same as dialysis (blood cleansing)."*(Participant 7)

Discussion

Parents' information needs depend on the type of diagnosis, disease stage, treatment phase, and the child's prognosis (18). The extended duration of leukemia treatment, characterized by numerous procedures and side effects, increases parents' reliance on diverse information sources (17). In this study, parents obtained information from healthcare providers (physicians and nurses), the internet, and other parents who had previously navigated leukemia treatment with their children. These sources were central in supporting parents as they adapted to and managed a challenging and unfamiliar situation (19). Participants represented a range of social, economic, and educational backgrounds, which likely contributed to differences in their information-seeking behaviors. This observation aligns with previous research indicating that personal factors

shape the sources pareParents' engagement with multiple information sources reflects an ongoing process of learning (9). In this study, all parents reported being encouraged from the beginning of treatment to ask questions when they needed verification, with information from physicians and nurses serving as their primary source. Physicians and nurworthy sources due to their use of accessible language and their willingness to address parents' concerns about treatment options (16). This finding aligns with previous research showing that parents rely heavily on nurses because of the significant time they spend together (9). Over time, the relationship between parents and nurses deepened, with some parents describing nurses as akin to family members. This trust appeared to be a key factor in healthcare providers' effective delivery of information. However, trust should not be viewed as a static achievement. As treatment progresses and the child's condition changes, information needs also evolve (30). Healthcare providers must therefore continually reassess these needs and adapt their communication strategies, rather than assuming that initial trust and understanding will suffice throughout the treatment process (17).

Parents also reported turning to the internet, particularly when they didParents also reported using the internet, particularly when they did not fully understand explanations provided by physicians or nurses. During rest periods in the ward or at the shelter house, parents used mobile phones to search online for information related to questions previously discussed with healthcare staff. These searches aimed to reinforce understanding rather than seek entirely new information. This behavior contrasts with earlier evidence: a systematic review found that most parents distrust cancer-related information found online, describing it as frightening and likely to provoke overthinking (16, 18). Other studies have shown that parents of children with cancer generally prefer information delivered verbally by healthcare providers and are less inclined to search the internet or social media (31). In the present study, however, internet use did not indicate distrust of healthcare providers or a preference for alternative sources. Instead, it served as a supplementary strategy to consolidate understanding of information already discussed with physicians and nurses. Hospital-based peer group of parents of children with cancer. Parents frequently discussed their children's conditions with one another, with more experienced parents guiding those who were new to treatment. Notably, physicians and nurses in this setting actively encouraged parents to discuss their children's care with fellow parents undergoing leukemia treatment, suggesting that peer support was not simply an informal coping strategy parents developed on their own, but a channel deliberately integrated into the broader care pathway. Parents with prior caregiving experience were able to help re-explain physicians' explanations to newly admitted parents and to share practical strategies for managing pain or other symptoms experienced by their children (21), drawing primarily on personal experience and practices developed while caring for their own child rather than on formal medical training. This clinically endorsed integration may explain why peer support felt like more than practical information. This exchange took place within a relationship actively encouraged by the healthcare team, rather than being sought out informally as a last

resort, and it appeared to provide parents with emotional reassurance, strength, hope, and optimism as well (16).

At the outset of treatment, parents in this study encountered psychological barriers resulting from emotional distress and the shock of their child's leukemia diagnosis. This burden left most parents unable to process information effectively when they first heard the diagnosis, leading to predominantly one-way communication from healthcare providers (9). As a result, parents were often uncertain about which questions to ask during consultations. This challenge was intensified by the rapid delivery of a large volume of unfamiliar information at the start of treatment, as healthcare providers sought to obtain parental consent without delay. Parents reported that these difficulties were largely limited to the early treatment period and gradually diminished as treatment progressed. This pattern aligns with previous findings that parents struggle most to absorb information during the initial stages of the cancer journey (190. The early difficulty appears to be closely linked to acute psychological distress at diagnosis, rather than to any enduring deficit in parents' ability to process information, as their capacity to adapt increased over time (17).

Parents also faced cognitive barriers, which may have been influenced by their level of health literacy. Those with lower health literacy had greater difficulty recalling and understanding treatment plan details provided by healthcare providers (26). Health literacy is critical for supporting parents' treatment-related decision-making and their ability to adopt health behaviors that benefit their child's treatment (25). To address this barrier, it has been suggested that nurses deliver information gradually, in smaller segments and at different times, allowing parents time to process and reflect on the information provided.

Interactional barriers were also reported, with parents expressing embarrassment and reluctance to ask physicians and nurses questions, especially during the early stages of treatment. This hesitancy may indicate that a trusting relationship with healthcare providers had not yet been fully established. Nurses play a central role in building this trust by demonstrating empathy and maintaining a consistent physical and emotional presence with both the child and the parent (19). In addition to fostering trust, nurses are essential in recognizing when parents become overwhelmed by information. When this occurs, the education session can be paused and rescheduled for a time when the parent can better focus and participate in the discussion (9).

Cancer-related stigma remains prevalent in the community, including among parents of children diagnosed with cancer (32), and manifests in various forms across different settings. For example, in Oman, cancer is associated with death, fear, and misfortune, prompting parents to withdraw from their social environment (16). IIn the present study, however, parents reported more specific stigma, focusing on the Bone Marrow Puncture procedure and treatment choices. Parents noted that information from healthcare providers often conflicted with beliefs held by extended family and the broader community, creating dilemmas during treatment decision-making. Such stigma is frequently rooted in limited community understanding of cancer (25), and if unaddressed by healthcare providers, can become a significant barrier to childhood cancer care (24).

Community-based education programs that address misconceptions about childhood cancer may help raise awareness and prevent this form of stigma from developing (32).The psychological, cognitive, interactional, and family-related barriers identified in this study did not operate independently; instead, they compounded one another throughout the treatment journey. Emotional shock at diagnosis limited parents' ability to absorb complex medical information, low health literacy hindered information retention, reluctance to ask questions left gaps in understanding, and family stigma introduced conflicting beliefs that undermined confidence in decisions made with healthcare providers. As trust and familiarity with the care team increased, many of these barriers diminished, suggesting they are dynamic and responsive to consistent, empathetic communication. This underscores the shared responsibility of healthcare providers, who must pace and tailor communication as parents' readiness evolves, and the broader community, whose understanding of childhood cancer influences the beliefs parents must navigate alongside clinical guidance.

This study was conducted at a single site, the Estella Pediatric Oncology Center in Manado, which may limit the transferability of findings to parents in other healthcare or sociocultural contexts. Future research should develop and evaluate strategies to reduce information-related barriers among parents of children with cancer, including community-based stigma reduction programs, to determine whether such interventions can meaningfully improve parents' access to and understanding of information throughout the treatment journey.

Conclusion

This study examines the barriers parents face in accessing and using information while caring for a child with leukemia. Psychological, cognitive, interactional, and family-related barriers often compounded each other throughout treatment. For example, emotional shock at diagnosis reduced parents' ability to absorb information, low health literacy made retention difficult, hesitancy to ask questions left gaps in understanding, and family stigma introduced beliefs that conflicted with clinical guidance. These barriers were most significant early in treatment but lessened as trust and familiarity with the care team grew, suggesting they can change based on how information is delivered. The findings highlight the need for healthcare providers to tailor communication to parents' readiness, not just clinical urgency, and to support community education to address misconceptions about childhood cancer before they affect treatment decisions.

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Declaration of Conflict of Interest
None.

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Author Contributions
SRS: Conceptualization, methodology, investigation, data collection, formal analysis, writing-original draft preparation. SRS, KN, F: Conceptualization, methodology, formal analysis, writing-review and editing, supervision, Methodology, writing-review and editing, supervision. All authors have read and agreed to the published version of the manuscript.

Data Availability Statement
The dataset generated and analysed during the current study is available from the corresponding author upon reasonable request.

Declaration of the Use of AI in Scientific Writing
The authors declare that artificial intelligence (AI) tools were used solely to assist in language refinement and improving the clarity of the manuscript. The AI did not contribute to the study design, data analysis, or interpretation of results.

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