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# Parents' Experiences of Caring for Children with Cancer in the Early Diagnosis Phase: A Qualitative Study

**Susi Roida Simanjuntak[a]* | Maria Lupita Nena Meo[a]| Christha Zenithy Tamburian[b]**
[a] Department of Nursing, Faculty of Medicine, Sam Ratulangi University, Indonesia
[b] Department of Surgery, Faculty of Medicine, Sam Ratulangi University, Indonesia
*Corresponding Author: susiroidasimanjuntak@unsrat.ac.id

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**ABSTRACT**

***Background:*** *The diagnosis of childhood cancer imposes a significant emotional and practical burden on parents, particularly during the early diagnosis phase, when they must cope with uncertainty, complex treatment-seeking decisions, and disruptions to daily life within a short period of time.*
***Objective:*** *This study aimed to explore parents' experiences in caring for children with cancer during the early diagnosis phase in North Sulawesi.*
***Methods:*** *This study used a descriptive phenomenological design. Twelve mothers of children diagnosed with cancer were recruited through purposive sampling at a central referral hospital in North Sulawesi. Data were collected through in-depth interviews and analyzed using Colaizzi's method.*
***Results:*** *Three main themes emerged from the data: (1) Health Service Navigation, describing mothers' health-seeking behaviors, including the use of alternative therapies, utilization of health services, and circular treatment-seeking patterns; (2) Dynamics of Psychological Response, encompassing feelings of helplessness, negative emotions, self-blame, and anticipation of the possible diagnosis; and (3) Challenges, including difficulty understanding medical information, caregiving burden, and social stigma. Collectively, these themes illustrate that mothers' experiences during the early diagnosis phase are shaped by an ongoing tension between cultural beliefs and medical care, which intensifies the burden of uncertainty long before a definitive diagnosis is established.*
***Conclusion:*** *The early diagnosis phase was experienced by mothers as a period marked by uncertainty, emotional distress, treatment-seeking complexity, caregiving disruption, and stigma. Early psychosocial support and culturally sensitive health education are needed to help mothers navigate this critical period.*

***Keywords: childhood cancer; early diagnosis; parents' experience; qualitative; psychosocial burden***

## Introduction

Every year, an estimated 400,000 children are diagnosed with cancer worldwide (World Health Organization, 2021).Cancer is the leading cause of death among children and adolescents (Hockenberry et al., 2019). In Indonesia, according to Globocan data from 2020, there are approximately 11,156 new pediatric cancer patients each year (Kemenkes, 2025) . The results of the 2018 Basic Health Research (Riskesdas) report indicated an increasing prevalence of cancer cases in children each year (Badan Penelitian dan Pengembangan Kesehatan RI, 2018).

In North Sulawesi, RSUP Prof. Dr. dr. R. D. Kandou serves as the sole tertiary referral hospital providing comprehensive pediatric cancer care, drawing patients not only from across the province but also from neighboring regions, including North Maluku, Maluku, Central Sulawesi,

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and Papua. Research in North Sulawesi shows that children with cancer treated at RSUP Prof. Dr. dr. R. D. Kandou are diagnosed with various types of cancer, including leukemia, lymphoma, teratoma, Wilms tumor, retinoblastoma, and osteosarcoma, with the majority being aged 7-15 years (Simanjuntak, 2023). Given this wide catchment area and the limited availability of pediatric oncology services across the eastern Indonesian region, families are often required to travel long distances and relocate temporarily to access treatmen.

When a child first develops unexplained symptoms, parents often initially interpret these as signs of a common childhood illness rather than a serious condition, which may lead some families to first seek alternative, spiritual, or local remedies before the child's worsening condition prompts referral to the hospital. Upon arrival at the hospital, parents are confronted with a series of complex diagnostic procedures and unfamiliar medical terminology, and once the diagnosis is confirmed, they experience intense shock, fear, guilt, and uncertainty. The diagnosis and treatment of cancer in children is a traumatic experience that changes parents' lives (Pierce et al., 2017; H. Wang et al., 2021). Parents experience stress, anxiety, and helplessness while accompanying their child through the treatment process (Carlsson et al., 2019; Y. Liu et al., 2023; Pierce et al., 2017). Trauma arises for parents as they witness their child's suffering but feel unable to alleviate it (Schwartz-Attias et al., 2023). Parents also face a series of examinations and chemotherapy that carry risks of side effects such as pain, nausea, and vomiting (Chodidjah et al., 2022; Pierce et al., 2017). During treatment, parents confront emotional changes in their child, such as increased irritability, crying, and decreased appetite (McEvoy & Creaner, 2022; Schwartz-Attias et al., 2023).

As mothers typically assume the role of primary caregiver, they must also manage separation from extended family, financial challenges, and social pressures, alongside fear of potential death and disease recurrence and uncertainty about the future during treatment (Björk et al., 2016; Schwartz-Attias et al., 2023; J. Wang et al., 2017). The uncertainty in treatment burdens parents with the prolonged process of care (Atout et al., 2021; Tan et al., 2020). Even after treatment is complete, parents continue to fear the possibility of cancer recurring (Tan et al., 2020). The pressure on parents puts them at risk for physical and psychological health problems that require intervention from healthcare professionals (Çevik Özdemir & Şenol, 2022).

The early phase of diagnosis represents a critical and turbulent period for parents, as this is when they first confront the reality that their child has cancer, while simultaneously being required to adapt to complex medical decisions, overwhelming information, and drastic changes in family life within a very short time. The shock, denial, and confusion that emerge during this phase can affect parents' ability to comprehend information provided by healthcare professionals and to make decisions regarding their child's treatment, making an in-depth understanding of parents' experiences during this period essential for informing appropriate early intervention.

However, most existing studies have focused on parents' experiences throughout the entire treatment trajectory, while research specifically exploring parents' experiences during the early diagnostic phase, particularly within the cultural context, remains very limited. Therefore, this study is important to conduct in order to gain a deeper understanding of how parents perceive and navigate the experience of caring for a child with cancer from the earliest stage of diagnosis, so that the findings may serve as a foundation for healthcare professionals in developing interventions and psychosocial support that are responsive to parents' needs as early as possible, particularly in the North Sulawesi region.

## Methods

### *Study Design*

This study is a qualitative research using a descriptive phenomenological approach utilizing semi-structured interviews. The descriptive phenomenological approach aims to uncover the meaning of a phenomenon as experienced by an individual or group (Sarosa, 2021).

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***Setting***

The study was conducted at R.D. Kandou Hospital in Manado. Data collection took place from June 3 to August 30, 2024. The study population consisted of all parents of children with cancer who were undergoing treatment at R.D. Kandou Hospital Manado.

***Research Subject***

The sampling technique used was purposive sampling with the following inclusion criteria: parents of children with cancer who had been diagnosed by a pediatric specialist and were currently undergoing or had undergone treatment; parents who served as the primary caregiver of the child; and parents who were able to communicate verbally in a clear and coherent manner. The exclusion criterion was parents of children with cancer who declined to be interviewed. As participants were interviewed after their child had commenced treatment, data regarding the early diagnosis phase were obtained retrospectively, with participants recounting their experiences from the time of symptom recognition through diagnosis confirmation. Data collection was concluded when no new information emerged from the interviews with participants (data saturation).

Although this study was designed to explore the experiences of parents broadly, only mothers met the inclusion criterion of serving as the primary caregiver during the child's treatment process. Fathers were involved in the family's caregiving arrangement, but they generally assumed a supporting role, such as managing employment and financial responsibilities, rather than the primary caregiving role. Therefore, fathers were not represented among the participants of this study.

***Instruments***

Data were collected through semi-structured, in-depth interviews designed to explore parents' experiences comprehensively. Each interview was conducted face-to-face with one parent at a time in a quiet room provided by the hospital. A voice recorder was used to capture the conversations, and the interviewer also took observational notes to document any non-verbal expressions. Each participant took part in a single interview session, lasting approximately 35 to 60 minutes. Afterward, all interviews were transcribed word-for-word for further analysis.

***Data Collection***

Interviews were conducted by the first author, a pediatric nurse with a Master's degree in Nursing. The interviewer had no prior familial relationship with the participants. Interviews were conducted in Bahasa Indonesia. Interview recordings were transcribed verbatim by a research assistant who was a native resident of North Sulawesi, to ensure accurate transcription of local language nuances. The transcripts were then analyzed collaboratively with the second author, who holds a Master's degree in Nursing, has expertise in qualitative research, and had received formal training in qualitative interviewing and analysis. Following each interview, the transcript was read back to the participant to confirm accuracy and to provide an opportunity for the participant to clarify or revise any part of their responses. No repeat interviews were conducted with participants.

Interviews were conducted in a private room within the pediatric ward, with only the participant and the interviewer present; no other hospital staff were present during the interview, and the child was not present in the room. Privacy and confidentiality were maintained by storing participant data securely and using it solely for the purposes of this research.

***Data Analysis***

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Data were analyzed using conventional qualitative content analysis, following the approach described by Creswell (2018) in which coding categories are derived inductively and directly from the text data rather than from a predetermined coding framework. Two researchers (the first and second authors) independently coded all interview transcripts line by line to develop an initial coding scheme. Coding was performed manually. The two coders then met to compare and discuss their codes; any disagreements in coding were resolved through discussion and consensus, with reference back to the original transcripts until agreement was reached. The agreed codes were subsequently organized into a hierarchical tree diagram consisting of themes, sub-themes, and codes.

To ensure the rigor and quality of the data analysis, several strategies were employed as recommended by Morse (2015), including investigator debriefing and interrater reliability checks. The research team met three times, for two hours each session, to discuss and refine the coding scheme and resulting themes. Member checking was performed at the transcript level, as transcripts were read back to participants to confirm the accuracy of their statements; however, the final themes were not returned to participants for validation. Data saturation was reached at the twelfth interview, when no new codes, categories, or themes emerged from the data.

***Trustworthiness***

Trustworthiness was established according to the criteria of Lincoln and Guba (1985): credibility, dependability, confirmability, and transferability. Credibility was enhanced through member checking, prolonged engagement, and peer debriefing, supported by direct participant quotations in the results. Dependability was established through an audit trail documenting coding decisions and research team discussions, as detailed in the Data Analysis section. Confirmability was addressed through peer review of coding between the two researchers and ongoing reflexive discussion to minimize the influence of their clinical backgrounds on data interpretation. Transferability was supported through thick description of participants' characteristics, the clinical setting, and the sociocultural context of North Sulawesi.

**Ethical Consideration**

This study has fulfilled the ethical review requirements from the Ethics Committee of R.D. Kandou Hospital Manado, with reference number No. 084/EC/KEPK-KANDOU/V/2024 dated May 16, 2024. Written permission was obtained from the relevant institution. Parents were fully informed about the study before participation, and both verbal and written informed consent were obtained from them.

## Results

This study involved 12 participants, whose sociodemographic characteristics are presented in Table 1. All participants were mothers (100%), with a mean age of 37.25 ± 0.85 years. The mean age of the children was 7.04 ± 3.71 years, with the majority being male (66.66%). Regarding diagnosis, the most common type of childhood cancer was Acute Lymphoblastic Leukemia (41.60%), followed by Lymphoma Hodgkin and Brain Cancer (16.66% each), while Ovarian Cancer, Colon Cancer, and Mandibular Tumor each accounted for 8.3% of cases.

Tabel.1 Sociodemographic characteristics of study participants (n=12)

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| Variabel | f (%) | Mean ± SD |
|---|---|---|
| Age of parents | | 37,25 ± 0.85 |
| Age of child | | 7.04 years±3.71 |
| Parent's role | | |
| Mother | 12 (100) | |
| Father | - | |
| Child gender | | |
| Female | 4 (33,33) | |
| Male | 8 (66,66) | |
| Child's Diagnosis | | |
| Acute Lymphoblastic Leukemia | 5 (41,60) | |
| Lymphoma Hodgkin | 2 (16,66) | |
| Ovarium Cancer | 1 (8,3) | |
| Colon Cancer | 1 (8,3) | |
| Brain Cancer | 2 (16,66) | |
| Mandibular Tumor | 1 (8,3) | |

This study identified three main themes: Health Service Navigation, Dynamics of Psychological Response, and Challenges. These themes, along with their corresponding categories, are presented in Table 2.

Table 2. Themes and Categories of Parents' Experiences in Caring for Children with Cancer in the Early Diagnosis Phase

| Themes | Categories |
|---|---|
| Health Service Navigation | 1. Utilization of alternative therapies |
| | 2. Utilization of health services |
| | 3. Circular treatment-seeking pattern |
| Dynamics of Psychological Response | 1. Helplessness |
| | 2. Negative emotions |
| | 3. Self-blame |
| | 4. Anticipation of possible diagnosis |
| Challenges | 1. Medical terminology |
| | 2. Caregiving burden |
| | 3. Stigma |

**Health Service Navigation**

This theme consists of three categories: utilization of alternative therapies, utilization of health services, and circular treatment-seeking patterns. This theme describes the efforts made by mothers upon noticing changes and health complaints in their children. In this study, when mothers first noticed the emergence of clinical symptoms in their children, they initially perceived the problem as a common health issue typically experienced by children. The efforts made by mothers included engaging in local cultural practices, such as administering herbal remedies and taking the child to a massage therapist. In addition, this study also found mothers who chose a spiritual approach, seeking help from religious figures for *ruqyah* therapy (recitation of Qur'anic verses), driven by a belief that the child's condition was influenced by supernatural forces. Nevertheless, all participants who initially opted for alternative treatment eventually returned to seek hospital care due to the worsening condition of their child. This theme is reflected in the following statement:

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*"Some people said it was caused by black magic, so we did ruqyah, did various things, but it still didn't work, so we tried herbal remedies, like honey and other things—I tried everything, but it still didn't work, so finally I took him to Ternate, I admitted him to the hospital."* (P8)

Nevertheless, this study also found mothers who took their child directly to the hospital upon noticing changes in the child's health. An interesting finding in this study was that some mothers who had initially sought medical care at the hospital subsequently switched to alternative treatment. This decision was triggered by fear following the doctor's explanation of the invasive procedures the child would need to undergo, as described in the following statement:

*"With alternative treatment, there are herbal remedies like that—maybe in terms of side effects, compared to hospital treatments or procedures that use needles, I think [the hospital procedures] are more frightening than alternative treatment."* (P6)

**Dynamics of Psychological Response**

This theme consists of four categories: helplessness, negative emotions, self-blame, and anticipation of possible diagnosis. This theme describes the psychological responses experienced by mothers while waiting for and receiving their child's cancer diagnosis. The diagnostic process took approximately 2–4 weeks at the central referral hospital in the provincial capital of North Sulawesi. During this waiting period, mothers reported that their child's condition continued to deteriorate, as treatment could not begin until the diagnosis was confirmed. In this situation, the children became increasingly thin and weak, and complained of more intense pain. While awaiting diagnostic results, the cancer treatment process could not yet be initiated. In this study, mothers also expressed their sense of powerlessness in witnessing their child's suffering throughout the series of invasive procedures. Although mothers made efforts to motivate their children to remain cooperative, they were unable to contain their profound sadness, often crying while their child was in the procedure room, and even expressing a wish that they could take their child's place. The helplessness experienced by mothers is illustrated in the following statement:

*"He could no longer walk, and I cried because by that time he had already been hospitalized for about two weeks and had not received any medication except antibiotics, since at that point there was still no clarity about what illness my child had."* (P6)

Upon receiving the disclosure of their child's cancer diagnosis from the physician, mothers experienced emotional distress, including shock, disbelief, fear, sadness, exhaustion, and anxiety. This shock arose because the symptoms experienced by their child appeared suddenly, coupled with the assumption that cancer could not possibly occur at such a young age. The cancer diagnosis also triggered profound worry that weighed heavily on their minds, particularly concerning the uncertainty of their child's future, the complexity of the treatment to be undergone, and the anticipation of their child's death.

*"I was afraid my child would be taken by God. If my child died, what would happen to me?."* (P3)

After the cancer diagnosis was confirmed, mothers were often overwhelmed by profound feelings of guilt, viewing themselves as the trigger for their child's condition. Mothers blamed themselves for not caring for their child properly, for overly strict parenting practices, for giving their child instant complementary foods, and for not bringing their child to the hospital sooner. In addition, this study also found a mother who felt she was being punished by God for having once intended to terminate her pregnancy. This experience is illustrated in the following statement:

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*"I wasn't angry at God. I was angry at myself. Maybe I failed, or wasn't careful enough as a parent."* (P1)

This study also identified a participant (mother) who did not show a shock reaction upon confirmation of her child's diagnosis. This was because, during the one-month waiting period, she had actively searched for information online regarding her child's clinical symptoms, and the results of her search consistently pointed toward indications of leukemia. As a result, when the official diagnosis was delivered by the physician, this mother tended to be more psychologically prepared to accept the reality, having already anticipated it based on the digital health literacy she had gained beforehand, as reflected in the following statement:

*"So when I got here, [after] the BMP, and received the results and the doctor said leukemia, I honestly wasn't shocked anymore (laughs softly). Because, so to speak, I had already known from the very beginning."* (P5)

**CHALLENGES**

This theme consists of three categories: difficulty understanding information, caregiving burden, and stigma. This theme describes the challenges and difficulties experienced by mothers from the diagnostic process through to the moment of receiving their child's cancer diagnosis. Participants in this study reported significant difficulty in understanding medical information and terminology used by healthcare providers. This difficulty included understanding laboratory results, interpreting the child's critical condition that necessitated referral to a provincial-level hospital, and comprehending the series of medical examinations such as Bone Marrow Aspiration (BMP), biopsy, and surgical procedures. These health literacy barriers led mothers to delay providing consent for further procedures. This delay in consent was driven by fear of the invasive procedures and the perceived risk of complications, such as paralysis or death. Mothers also experienced difficulty understanding chemotherapy treatment procedures, as they received a great deal of negative information from their social environment. This is illustrated in the following statement:

*"People said chemotherapy is deadly, so I was afraid. They said that once my child had chemotherapy, it would be the same as dialysis that he wouldn't survive."* (P3)

The caregiving burden experienced by participants in this study stemmed from the prolonged treatment process, which was centered at the referral hospital in the provincial capital, requiring mothers to relocate and leave other family members behind. Participants in this study came not only from North Sulawesi but also from surrounding provinces such as North Maluku, Maluku, Central Sulawesi, and Papua. This demographic condition meant that mothers had to leave their other children at home, leave their jobs (thereby disrupting family finances), and be separated from their extended family. During the diagnostic process and early stages of treatment, mothers stayed with their child at a temporary shelter house (rumah singgah) located near the hospital. During their stay at the shelter house, family visits were highly restricted. This also contributed to mothers feeling lonely and exhausted from their sole role as caregiver for their sick child. Mothers also felt guilty for being unable to care for their other, healthy children at home. This is reflected in the following participant statement:

*"What hurt me most was that I have 4 children, but I had to leave 3 of them far away from me just to take care of this one."* (P6)

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Another challenge faced by participants was the emergence of social stigma related to childhood cancer. Mothers reported that after their child was diagnosed with cancer, family members and the surrounding community blamed them as the cause of the cancer, viewing them as failing to care for their child properly. Mothers also interpreted their child's cancer diagnosis as a form of punishment or consequence for sins the parents had committed in the past. This experience is reflected in the following statement:

*"Other people gave negative comments. They said things like, 'the mother and father are like this or like that, that's why the child has cancer."* (P12)

## Discussion

This study found that mothers' experiences during the early diagnosis phase were shaped by several factors working together, including cultural beliefs, the distance and difficulty of accessing referral hospitals, financial pressure, and the expectation that mothers serve as the primary caregiver. These factors did not act separately; instead, they combined to delay the diagnosis process and increase the emotional burden mothers carried, even before treatment began.

During the symptom recognition phase, mothers typically normalized their child's early symptoms as a common childhood illness, delaying the perception that anything serious was occurring. When parents did seek treatment, several variations were found in their choices. Some parents chose to directly access healthcare facility services, while others opted to use herbal remedies, and several mothers initially attributed their child's symptoms to supernatural causes, seeking help from religious figures for ruqyah before considering biomedical care. This pattern reflects the strong influence of cultural values on health behavior in Indonesian society, where the use of alternative medicine remains a common option when health problems arise (Susilawati et al., 2016). This response cannot be understood merely as delay or misinformation. Within the sociocultural context of North Sulawesi, illness, particularly one as frightening and poorly understood as childhood cancer, is often first interpreted through a spiritual rather than biomedical lens, consistent with findings that perceptions of supernatural causation shape early treatment decisions in cancer-affected families (Nurhidayah et al., 2025). Family members, including extended kin, frequently reinforced this interpretation and the accompanying recommendation for alternative or spiritual treatment, echoing evidence that family suggestions are a key factor influencing the use of alternative medicine among parents of children with cancer (Faruqui et al., 2019). This suggests that in North Sulawesi, the decision to seek treatment is rarely made by mothers alone. It is a negotiated, family-embedded process in which extended family members hold considerable authority over how a child's illness is defined and addressed, at least until the child's deteriorating condition overrides this consensus.

This was followed by an alternative treatment-seeking phase in which some mothers who had already initiated medical consultation withdrew and reverted to alternative treatment, believing that medical procedures would cause pain to their child and that alternative treatment would provide greater comfort by comparison (Njuguna et al., 2016). Feelings of pessimism and skepticism toward medical services were among the factors contributing to this delayed treatment (Faruqui et al., 2019), illustrating that treatment-seeking during this period was not linear but circular, consistent with the "*pengobatan sirkular*" pattern identified in this study. This reliance on alternative medicine caused several families to delay seeking care at healthcare facilities altogether (Kumar et al., 2022), a delay further compounded by parents' limited

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knowledge in recognizing cancer symptoms and their child's condition (Nurhidayah et al., 2025). This study found that after avoiding medical treatment and trying alternative therapies, children's conditions did not improve but instead continued to deteriorate, underscoring that delayed cancer treatment can affect a child's quality of life.

This cultural pathway intersected directly with the region's geographic and health-system context. RSUP Prof. Dr. R. D. Kandou functions as the only tertiary referral hospital for pediatric cancer across not only North Sulawesi but also several neighboring provinces, including Central Sulawesi, North Maluku, Maluku, Central Sulawesi, and Papua. For families residing far from this single referral center, the decision to pursue alternative treatment first may also reflect a rational response to geographic and logistical inaccessibility, not merely cultural belief. By the time symptoms failed to resolve and families finally sought hospital care, children were often already required to undergo referral processes and travel substantial distances, compounding the delay already introduced by earlier alternative treatment-seeking. This referral geography appears to be a distinguishing feature of the North Sulawesi context and a structural amplifier of the emotional burden mothers described, consistent with evidence that the diagnostic process becomes especially difficult and confusing for parents when children must be referred from one hospital to another (Faruqui et al., 2019).

Only once the child's condition deteriorated further did families enter the referral and diagnostic waiting phase, during which the child was transferred to RSUP Prof. Dr. R. D. Kandou and underwent a diagnostic process lasting approximately one month. During this period, the child's condition continued to deteriorate, yet without receiving meaningful treatment, as this had to wait until the diagnosis was confirmed. This situation became an extremely difficult and confusing moment for mothers, who faced their child's declining health while the treatment plan remained uncertain. This phase was characterized less by fear of the unknown diagnosis itself and more by a specific, concrete form of helplessness: witnessing the child's suffering while being unable to do anything to protect them (Schwartz-Attias et al., 2023a). The difficult situations and conditions faced by mothers during this waiting period left them feeling unable to act to ease their child's suffering (Kirakosyan et al., 2025). This distinguishes the diagnostic waiting phase from the disclosure phase that follows it, as the emotional burden here stemmed from clinical limbo rather than from the diagnosis itself.

The diagnosis disclosure phase brought a distinct and more acute set of emotional responses, including shock, disbelief, sadness, fear, confusion, self-blame, despair, and refusal to accept the diagnosis. This finding is consistent with previous studies reporting that parents felt sad, frustrated, hopeless, disbelieving, shocked, devastated, and experienced feelings of guilt (Alghamdi et al., 2023; BEKAR et al., 2024; Phiri et al., 2024). Notably, mothers who had independently sought health information online prior to disclosure experienced this phase differently, describing psychological preparedness rather than shock, suggesting that anticipatory information-seeking may functionally shorten or soften this sub-phase for some mothers. Having a child with cancer represents one of the major challenges giving rise to psychological problems in parents (Ghaljeh et al., 2024; Shaygani et al., 2024), and in this study, mothers frequently blamed themselves as the cause of their child's cancer, linking their parenting practices to their child's illness or feeling guilty for having recognized symptoms too late. The guilt experienced by mothers appears to be a determining variable shaping their capacity to care for a child with cancer. Kestler –Peleg et al (2025) reported that low self-efficacy, that is, mothers' perceived ability to care for their child, was associated with an increased sense of guilt among parents. This guilt, in turn, led mothers to make continuous efforts to remain present at their child's side, out of concern that something bad might happen if they were not (Kirakosyan et al., 2025).

Finally, in the early treatment decision-making phase, mothers were confronted with unfamiliar medical terminology and invasive procedures at a moment when they were still

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psychologically destabilized by the disclosure itself, a combination that impaired their ability to process information and made informed decision-making considerably more difficult. This is consistent with previous findings that limited access to information is among the key challenges faced by parents of children with cancer (Hashimoto et al., 2023) and that difficulty understanding information leaves parents without a clear picture of their child's condition (Phiri et al., 2024). Parents' psychological state, still shaken by the diagnosis, further prevented them from processing information effectively, consistent with evidence that fear can cause parents to avoid seeking further information about their child's condition altogether (Shaygani et al., 2024). Difficulty understanding information is therefore one of the key sources of stress for parents caring for a child with cancer (Deribe et al., 2023).

Financial pressure further entangled with these cultural, geographic, and informational burdens. Because families came from areas far from the referral hospital, mothers were required to stay at a shelter house or rent accommodation during treatment, a relocation that meant taking on the role of primary caregiver while separated from extended family. Within Indonesian family structures, where mothers are culturally expected to be the primary, if not sole, caregiver for a sick child, this relocation was rarely shared or distributed among family members; fathers typically remained behind to preserve household income, leaving mothers to bear the caregiving burden in physical isolation from their usual support network. This maternal role expectation, rather than being incidental, appears to be a key mechanism by which the broader structural burdens of geography and cost became concentrated onto mothers specifically, intensifying the helplessness, exhaustion, and guilt they described. Without the presence of extended family, mothers struggled alone with the psychological and physical demands of caregiving, spending most of their time at the hospital in ways that led to physical and emotional exhaustion and heightened psychological problems (Marrakchi et al., 2024a). This is consistent with findings that a child's cancer diagnosis brings significant changes to daily life, as parents separate from family to focus on the child's treatment and often feel unable to be optimal parents to their other, healthy children (Phiri et al., 2024; Schwartz-Attias et al., 2023a).

Social stigma compounded these dynamics by adding a moral dimension to what was already a logistically and emotionally difficult experience. Mothers viewed cancer as a frightening and incurable disease, and beyond navigating their child's uncertain diagnosis, they were simultaneously judged by neighbors and community members as the cause of the child's illness. This moral attribution is consistent with stigma patterns reported elsewhere (Graetz et al., 2024), and some mothers internalized it as divine punishment for past actions. This stigma did not operate independently of the cultural belief system described earlier; the same worldview that framed illness as potentially supernatural in origin also provided a ready framework for assigning moral blame to mothers once the diagnosis was confirmed. In response, several mothers withdrew from their social environment altogether, a protective strategy that, while reducing immediate social stress, also removed them from potential sources of practical and emotional support at the moment they may have needed it most (Deribe et al., 2023; Q. Liu et al., 2021). This stigma further affected mothers' ability to make decisions and contributed to delayed treatment (Graetz et al., 2024). Increasing public education on childhood cancer awareness is therefore one important strategy for reducing cancer-related stigma (Q. Liu et al., 2021) and healthcare professionals have a role to play in helping mothers cope with this burden.

Distinguishing these sub-phases clarifies that interventions cannot be applied uniformly across the early diagnosis phase as a single block of time. Rather, each sub-phase presents a different point of psychological vulnerability requiring a differently timed and targeted form of support. Taken together, these findings suggest that in North Sulawesi, the early diagnosis phase is not simply a medical waiting period but a socially and culturally negotiated process, in which local beliefs about illness causation, the region's centralized referral system, the financial cost of

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relocation, and rigid maternal caregiving expectations combine to shape both how quickly families reach a diagnosis and how heavily mothers alone absorb the resulting burden.

This study has several limitations. First, only mothers participated as primary caregivers, and fathers' experiences and perspectives were not represented, limiting the study's ability to capture the full family experience of early diagnosis. Second, data were collected at a single tertiary referral hospital, and although participants originated from diverse regions across North Sulawesi and neighboring provinces, this single-site design and the diversity of participants' regional backgrounds may affect the transferability of findings to other healthcare settings and cultural contexts. Third, because interviews were conducted after treatment had already commenced, mothers' accounts of the early diagnosis phase were obtained retrospectively, introducing the possibility of recall bias in the accuracy or emotional framing of their narratives. Fourth, as with all interview-based qualitative research, social desirability bias may have influenced participants' responses, particularly regarding sensitive topics such as guilt, stigma, or delayed treatment-seeking. Fifth, data were collected at a single point in time without longitudinal follow-up, precluding observation of how mothers' experiences and coping strategies evolved across subsequent phases of treatment. Sixth, this study did not incorporate the perspectives of healthcare professionals or other family members, which could have offered a more complete, multi-informant understanding of the early diagnosis phase. Finally, although this study focused on the early diagnosis phase, this phase was not operationalized with a fixed time boundary prior to data collection, which may limit precision in comparing findings across studies; future research should establish a clearer operational definition demarcating the boundaries of this phase.

The findings of this study point to several concrete implications for nursing and healthcare practice. Nurses should implement early psychosocial screening for mothers at the point of diagnosis, rather than waiting until treatment is underway, to identify those at heightened risk of guilt, helplessness, or social withdrawal. Given the difficulty mothers experienced in understanding medical terminology, nurse-led explanations using simple, non-technical language, supported by visual aids or illustrated booklets describing diagnostic procedures and chemotherapy, may help reduce fear and improve informed decision-making during this vulnerable period. Structured counseling addressing parental guilt and self-blame should be integrated into early nursing care, alongside family-centered communication approaches that engage extended family members who often influence treatment-seeking decisions. Community-level education is needed to reduce stigma toward mothers of children with cancer, and healthcare professionals should approach discussions of alternative treatment and spiritual beliefs with cultural sensitivity, engaging rather than dismissing these beliefs, in order to build trust and support timely transitions to biomedical care.

## Conclusion

In North Sulawesi, the early diagnosis phase is not simply a medical waiting period but a socially and culturally negotiated process, shaped by the interaction of local beliefs about illness causation, a centralized referral system, financial pressure from relocation, and rigid maternal caregiving expectations. These findings highlight the urgent need for early, culturally sensitive psychosocial support and clear health education from healthcare professionals, beginning at the point of first symptom recognition rather than only after diagnosis is confirmed. Nurses and other healthcare providers play a vital role in helping mothers navigate this critical period and in reducing delays in treatment-seeking that may affect children's health outcomes. Future research should test culturally responsive psychosocial interventions targeting this early phase and explore the perspectives of fathers and extended family members, who were not represented in this study

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