International Journal of Contemporary Sciences (IJCS)
Vol. 1, No. 12, 2024: 902-915

# Key Determinants of Family-Centered Care for Children with Leukemia

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ARTICLEINFO

*Keywords:* Family-Centered Care, Health Status, Parental Knowledge, Parental Attitudes, Pediatric Leukemia

*Accepted : 10, August*
*Revised : 22, September*
*Accepted: 29, October*

ABSTRACT

This study examines the relationship between health status, parental knowledge, and parental attitudes with the application of family-centered care (FCC) for children with leukemia at Abdul Moelok Regional Hospital, Lampung Province. Using a quantitative approach with a cross-sectional design, 92 respondents were selected from a population of 1,200 leukemia patients treated between 2021 and 2022. Data were collected through a validated questionnaire that measured parental knowledge, attitudes, and health status, with analysis conducted using the gamma correlation test. The results indicate significant relationships between health status, parental knowledge, and parental attitudes with the implementation of FCC. Factors such as age, education, income, caregiving duration, and disease length influenced the health status and FCC application. The study also reveals that caregivers face challenges in providing care, particularly due to financial burdens and physical strain, impacting their quality of life. Additionally, cultural factors affect how parents communicate the diagnosis to children, with some families delaying disclosure based on cultural norms.

E-ISSN: 3047-4078
DOI: https://doi.org/10.55927/ijcs.v1i12.12039

## INTRODUCTION

Family-centered care (FCC) has become a pivotal approach in pediatric healthcare, particularly for children with chronic illnesses such as leukemia. This model emphasizes collaboration between healthcare providers, patients, and families to ensure that the care delivered aligns with the needs, values, and preferences of both the child and their caregivers. In the context of leukemia, where prolonged treatments and emotional burdens are common, FCC fosters a supportive environment that enhances the well-being of both the patient and their family. Factors influencing the effectiveness of FCC include communication quality, emotional support, cultural sensitivity, and the involvement of families in decision-making processes. Understanding these factors is crucial to improving care outcomes and ensuring that families remain engaged and empowered throughout the treatment journey. FCC emphasizes individualized support, respect, encouragement, and strengthening family competence to promote better health outcomes (Boshagh & Hakim, 2022). This model focuses on partnership-based decision-making between healthcare providers, patients, and their families (Seniwati, Rustina, et al., 2023). As a philosophy embraced by many healthcare professionals and systems, FCC integrates essential principles such as listening and respect, information sharing, participation, and collaboration. These elements benefit not only patients but also their families and healthcare workers across various healthcare settings (Guo et al., 2024; Seniwati, Wanda, et al., 2023).

Children with leukemia require intensive and long-term care, involving multiple parties to ensure an improved quality of life (Wu et al., 2024). Treatment for leukemia includes chemotherapy, radiation, and bone marrow transplants, which are often extended over a lengthy period (Al Omari et al., 2021). Resilience in children with leukemia has been positively correlated with family strength, communication with parents, and social support during cancer care (Son, 2024). Effective FCC, facilitated by a multidisciplinary healthcare team, ensures that parents receive the necessary information and support to care for their child at home through various therapies (Camiré-Bernier et al., 2021).

Health status reflects an individual's level of well-being and is influenced by behavior, environment, heredity, and health services (Allen et al., 2022). Environmental and behavioral factors play a crucial role in achieving optimal health, along with genetics, economic conditions, social structures, and cultural practices (Inhestern et al., 2024). For children with chronic conditions like leukemia, FCC ensures that families receive appropriate guidance and healthcare access, further contributing to better health outcomes. To maintain an optimal health status, it is necessary to promote healthy environments, lifestyles, and effective healthcare services (Marcia & Nancy, 2024).

Knowledge plays a pivotal role in enabling families to manage their child's health effectively. It arises from human sensory perception and includes levels such as understanding, application, analysis, and evaluation. Several factors affect knowledge, including education, media access, socio-economic status, and environmental conditions. Empowering parents with FCC has been shown to enhance their knowledge, attitudes, and self-efficacy, especially in managing chronic illnesses such as asthma (Rajabi et al., 2016). Similarly, parents of children with leukemia benefit from tailored education, empowering them to handle treatment at home confidently.

Attitudes, including emotional responses, behavioral tendencies, and cognitive processes, influence how families engage with FCC. Najafi and Rabari (n.d.) demonstrated that interventions—such as educational pamphlets and slides—significantly improved knowledge and awareness in families dealing with thalassemia. This highlights the importance of structured interventions in shifting family behaviors and attitudes toward active involvement in care. By fostering positive attitudes and behavioral responses, FCC enables families to participate effectively in their child's healthcare journey, promoting better health outcomes.

Cancer poses a serious threat to children's health worldwide, with the incidence of new cases rising each year. According to the International Agency for Research on Cancer (IARC), it is projected that by 2040, approximately 29.5 million new cancer cases and 16.3 million deaths will occur globally. In Indonesia, childhood cancer is a growing concern, ranking as the 10th leading cause of death among children (World Health Organization, 2022). The incidence of childhood cancer varies by age, with 0.3% occurring in children under 1 year, 0.1% in children aged 1-4 years and 5-14 years, and 0.6% in those aged 5-24 years. Additionally, cancer incidence differs by gender, affecting 0.6% of boys and 2.2% of girls. Unlike adult cancer, childhood cancers are predominantly leukemia, which accounts for one-third of pediatric cases (Kemenkes RI, 2022). This alarming trend highlights the urgent need for effective healthcare strategies, such as family-centered care, to improve treatment outcomes and support the well-being of children with leukemia and their families.

Failure to properly treat children with cancer can lead to severe consequences, including the spread of the disease, worsening of the child's condition, prolonged recovery, and potential drug resistance, although responses to treatment vary among children (Son, 2024). Adherence to treatment has been shown to improve the child's quality of life, but only a limited number of parents actively prioritize strategies to ease their child's burdens (Budiarty & Nafianti, 2020). The concept of family-centered care (FCC) or Patient and Family-Centered Care (PFCC) emphasizes sharing information, respect for differences, cooperation, and care within the family and community context (Allen et al., 2022). Guidance and health education for parents have also been found to enhance the quality of life for children with cancer (Yang et al., 2020). However, various challenges hinder effective family involvement, such as lack of structural and social support, health status limitations, and intrapersonal barriers (Inhestern et al., 2024). Additionally, family functioning, income level, parental education, and geographic location significantly impact family management during the child's treatment process (Y. C. Lin et al., 2023). These challenges create a gap in understanding how family-centered care can be optimized across diverse family structures and socioeconomic backgrounds to improve the well-being of children with leukemia and their families.

This study aims to explore the characteristics of health status, parental knowledge, parental attitudes, and the implementation of family-centered care (FCC) for children with leukemia. It seeks to analyze the relationship between health status and FCC, as well as the influence of parental knowledge and attitudes on the effectiveness of FCC. Additionally, the research will examine how the frequency of FCC practices affects the care provided to children with leukemia. The study will focus on identifying these relationships specifically within the context of patients at Abdul Moeloek Regional Hospital to better understand how family involvement can enhance care outcomes and improve the quality of life for children undergoing leukemia treatment.

## LITERATURE REVIEW

The literature on Family-Centered Care (FCC) highlights its critical role in enhancing healthcare outcomes for children with chronic illnesses, particularly leukemia. FCC prioritizes partnership and collaboration between healthcare providers, patients, and families, aiming to align care with the values, preferences, and needs of the child and their caregivers (Boshagh & Hakim, 2022). Research has shown that factors such as effective communication, cultural sensitivity, and family involvement in decision-making are essential to successful FCC, fostering a supportive environment that bolsters family resilience and child well-being (Camiré-Bernier et al., 2021; Seniwati, Rustina, et al., 2023). Additionally, studies suggest that FCC improves parental knowledge, attitudes, and confidence, enabling families to manage care at home, which is especially valuable for children requiring prolonged treatments like chemotherapy (Rajabi et al., 2016; Guo et al., 2024). However, challenges such as lack of support and socio-economic disparities can hinder family participation, highlighting a need for targeted interventions to ensure FCC's efficacy across diverse family backgrounds (Inhestern et al., 2024; Y.C. Lin et al., 2023).

The following is the framework in this study:

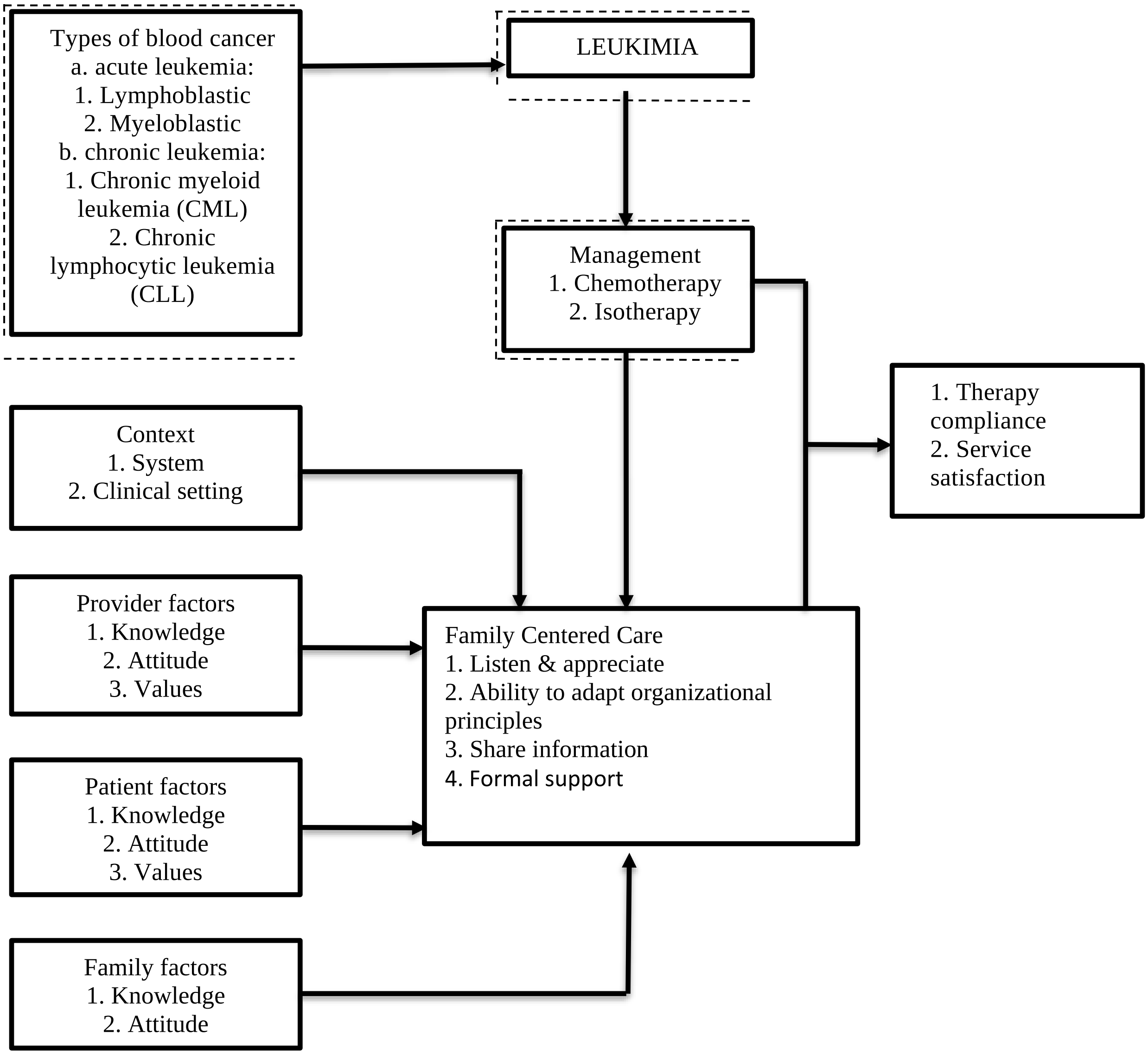

Figure 1. Conceptual Framework

## METHODOLOGY

This research employs a quantitative approach with a cross-sectional design to analyze the relationships between health status, parental knowledge, parental attitudes, and the application of family-centered care (FCC) in children with leukemia. The study population consisted of 1,200 leukemia patients registered at Abdul Moeloek Regional Hospital from 2021 to 2022, with 92 respondents selected as the sample using appropriate sampling techniques.

Data collection was conducted using a structured questionnaire that assessed parental knowledge, attitudes toward FCC, and the health status of children. The instruments used in the questionnaire were subjected to validity and reliability testing to ensure the accuracy and consistency of the data. The questionnaires measured key variables, including the health status of children, parental knowledge and attitudes, and the frequency and quality of family-centered care practices.

The study's data analysis utilized the gamma correlation test, which is suitable for determining the strength and direction of associations between ordinal variables. This statistical method was chosen to evaluate the relationships between health status, parental knowledge, and parental attitudes with the application of FCC. By using a cross-sectional approach, the study captures data at a specific point in time, providing insights into how these variables interact in the current context of care for children with leukemia.

This methodology offers a comprehensive framework for identifying key factors influencing the success of FCC in managing pediatric leukemia. It also provides valuable evidence on how family involvement and parental capabilities impact the child's health outcomes, contributing to the improvement of family-centered care practices in the healthcare setting.

## RESULT AND DISCUSSION

Table 1. Age, gender, education and employment in the families of leukemia patients at Abdul Moeloek Hospital, Lampung Province

| Responden Characteristic | Frequecy (N) | Persentase (%) |
|---|---|---|
| **Age** | | |
| > 30 years | 36 | 39,1 |
| 31-50 years | 38 | 41,3 |
| >50 years | 18 | 19,6 |
| Total | 92 | 100 |
| Gender | | |
| Man | 47 | 51,5 |
| Female | 45 | 48,9 |
| **Total** | 92 | 100 |
| **Education** | | |
| Elementary school | 18 | 19,6 |
| Junior High School | 33 | 35,9 |
| Senior High School | 30 | 32,6 |
| Bachelor | 11 | 12,0 |
| **Total** | 92 | 100 |
| **Work** | | |
| Farmer | 54 | 58,7 |
| Self Employed | 31 | 33,7 |
| Civil Servants | 7 | 7,6 |
| **Total** | 92 | 100 |

The characteristics of parents of children with leukemia in this study indicate that most are aged 38-50 years (41.3%) and predominantly male (51.5%), with junior high school education and occupations as farmers (58.7%), reflecting a population from rural areas. In contrast, caregivers are often 31-40 years old, predominantly female, with a bachelor's degree and no formal employment (Guo et al., 2024). Research also shows that children whose fathers work as freelancers or have higher education levels are at a greater risk of developing acute lymphoblastic leukemia (ALL), with the odds increased by 0.2 to 2.67 times ($p < 0.001$ and $p < 0.02$, respectively). In this study, 58.4% of children with leukemia were boys, while 41.6% were girls, highlighting a slightly higher prevalence among male children (Rafieemehr et al., 2019).

Tabel 2. Age, gender in leukemia patients at Abdul Moeloek Hospital, Lampung Province

| Responden Characteristic | Frequecy (N) | Persentase (%) |
|---|---|---|
| Child Age | | |
| 0 – 5 year | 31 | 33,6 |
| 6 - 10 years | 36 | 39,1 |
| > 11 years | 25 | 27,1 |
| Total | 92 | 100 |
| Child Gender | | |
| Man | 45 | 49,0 |
| Female | 47 | 51,0 |
| Total | 92 | 100 |

The data shows that children with leukemia being treated in the hospital are predominantly aged 6-10 years (39.1%), aligning with the school-age range, with 51% of the cases involving girls (Guo et al., 2024). While most respondents are female and aged 4-7 years, univariable analysis indicates that boys have a higher likelihood of developing acute lymphoblastic leukemia (ALL), though no definitive difference between cases and controls explains this tendency (Rafieemehr et al., 2019). Age is a crucial factor in ALL prognosis, with younger patients generally experiencing better outcomes; for example, a 10-year-old has half the probability of therapeutic failure compared to a 20-year-old (Woods et al., 1981). Older patients often face challenges, such as comorbidities and organ dysfunction, limiting their eligibility for intensive chemotherapy, which negatively affects treatment outcomes (Tebbi, 2021). The role of gender in ALL development remains uncertain due to the limited research available on this topic (Rafieemehr et al., 2019).

Table 3. Health Status, Parent Knowledge and Family centered care in the families of leukemia patients at Abdul Moeloek Hospital, Lampung Province

| Family centered care | Frequency (N) | Persentase (%) |
|---|---|---|
| Good | 39 | 42,4 |
| Enough | 42 | 45,7 |
| Not Enough | 11 | 12 |
| **Helath Status** | | |
| Good | 51 | 55,4 |
| Enough | 27 | 29,3 |
| Not Enough | 14 | 15,2 |
| **Parents Knowledge** | | |
| Good | 38 | 41,3 |
| Enough | 45 | 48,9 |
| Not Enough | 9 | 9,8 |
| **Parents attitude** | | |
| Good | 38 | 41,3 |
| Enough | 45 | 48,9 |
| Bad | 9 | 9,8 |

The data indicates that family-centered care (FCC) was categorized as sufficient for 45.7% of participants, with 55.4% reporting good health status, 48.9% demonstrating sufficient parental knowledge, and 48.9% showing good parental attitudes. Families play a crucial role in providing independent care to children with leukemia, contributing to optimal health outcomes. A key factor influencing self-care abilities is the parents' education level, which directly impacts their knowledge and ability to care for their child (N. Lin et al., 2023). However, a lack of knowledge about cancer, its treatment, and possible complications presents significant challenges, particularly for mothers, often leading to psychological stress, social communication barriers, and reduced trust in the medical team (LoCastro et al., 2023). A positive parental attitude, on the other hand, can boost a child’s confidence in managing their illness (Lösemi et al., 2023). Additionally, essential information for children with leukemia includes managing their illness, shielding them from distressing details, and providing emotional support (Yamaji et al., 2022).

Health status is not only influenced by the disease stage but also by economic factors, treatment duration, the child's age, and gender, all of which impact how well a child follows therapy and manages side effects (N. Lin et al., 2023). Family empowerment programs are recognized as crucial interventions to enhance family functioning, especially for families with children suffering from chronic diseases (Punaglom, 2022). Access to informative materials improves communication between families and healthcare teams, fostering parental knowledge and hope for recovery (dos Santos & Mandetta, 2024). Research also highlights that family beliefs in health are shaped by external factors, such as faith in God and healthcare providers, and internal factors, including individual beliefs (Tremolada et al., 2020).

Table 4. The relationship between family centered care, health status, parents knowledge, parents attitude in children suffering from leukemia at Abdul Moeloek Regional Hospital

| **Health Status** | **Family Centered Care** | | | | | | | | ***P-value*** |
|---|---|---|---|---|---|---|---|---|---|
| | **Good** | | **Enough** | | **Not** | | **Total** | | |
| | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | |
| Bad | 3 | 21,4 | 3 | 21,4 | 8 | 57,1 | 14 | 100 | 0,004 |
| Enough | 10 | 37,0 | 16 | 59,3 | 1 | 3,7 | 27 | 100 | |
| Good | 26 | 51,0 | 23 | 45,1 | 2 | 3,9 | 51 | 100 | |
| **Parents** | | | | | | | | | |
| Good | 38 | 100 | 0 | 0 | 0 | 0 | 38 | 100 | 0,000 |
| Enough | 1 | 2,2 | 42 | 93,3 | 2 | 4,4 | 45 | 100 | |
| Not Enough | 0 | 0 | 0 | 0 | 9 | 100 | 9 | 100 | |
| **Parents Attitude** | | | | | | | | | |
| Good | 34 | 89,5 | 4 | 10,5 | 0 | 0 | 38 | 100 | 0,000 |
| Enough | 5 | 11,1 | 38 | 84,4 | 2 | 4,4 | 45 | 100 | |
| Bad | 0 | 0 | 0 | 0 | 9 | 100 | 9 | 100 | |

The study results reveal significant relationships between health status, parental knowledge, and parental attitudes with the application of family-centered care (FCC) for children with leukemia at Abdul Moelok Hospital, Lampung Province. Previous research highlights a similar connection between FCC and reduced anxiety in preschool-aged children during hospitalization (Nopitasari et al., 2024). Enhancing parental knowledge, such as through educational videos, enables caregivers to better understand the illness and treatment process (LoCastro et al., 2023). Providing educational information using technology increases parental knowledge and improves their participation in care, compared to parents who do not receive such information (Hodgson et al., 2024).

Parental age, education level, income, time spent caring for the child, the child's age at diagnosis, and disease duration are internal and external factors influencing health status (Han et al., 2024). Caregivers who spend more time providing care often experience a decline in their physical quality of life, leading to potential difficulties in caregiving. Additionally, financial hardship resulting from caregiving is associated with deteriorating physical health, immune function decline, and psychological issues (Yu et al., 2017). Such caregiving challenges emphasize the need for effective FCC to support both children and their caregivers during treatment.

Access to quality information influences parental knowledge and attitudes, which are essential for effective care at home (Camiré-Bernier et al., 2021). Studies in China show that increased access to information improves public knowledge, attitudes, and personal practices related to leukemia (Jin et al., 2024). However, young children, such as those in Tunisia, may not understand environmental risk factors like smoking and pollution that contribute to leukemia (Maaoui et al., 2022). Ensuring parents receive comprehensive information about the disease can enhance their ability to provide care and make informed decisions.

Cultural differences shape how parents communicate with their children about illness. For instance, Turkish families often prefer not to inform their young children about a leukemia diagnosis, relying on protective attitudes and deferring disclosure until the child is older (Ekman et al., 2011). Similarly, healthcare providers may honor parental requests to withhold certain information from children, emphasizing the importance of aligning care with cultural norms and family dynamics (Camiré-Bernier et al., 2021).

The Institute for Patient- and Family-Centered Care (IPFCC) defines FCC based on four core principles: information sharing, collaboration, respect and dignity, and participation in care and decision-making (Hill et al., 2018). These principles emphasize personalized care that respects the unique roles of parents and integrates their input in healthcare decisions. Parents recognize their distinct roles and draw on different information sources when caring for their children (Sonkola et al., 2021). Effective FCC acknowledges the individuality of patients and families, promotes shared decision-making, and balances relationships with care tasks (Ekman et al., 2011). This approach ensures that children with leukemia and their families receive comprehensive and supportive care throughout treatment.

## CONCLUSION AND RECOMMENDATION

This study highlights the advantage of utilizing 92 respondents from one of the most comprehensive hospitals in Lampung Province, providing valuable insights into family-centered care (FCC) for children with leukemia. Expanding the research to include additional hospitals across different regions in Indonesia could enhance the generalizability of the findings. A limitation of the study is the reliance on direct interviews, which restricts data collection to a specific area; however, future studies could use online forms or links to reach broader populations. Incorporating more diverse variables, along with educational interventions on FCC, would provide a more comprehensive understanding of its application across different age levels and healthcare settings. To improve parental knowledge, attitudes, and health status, educational tools such as videos, leaflets, and other media can be utilized. Additionally, hospitals are encouraged to enhance the attitudes and practices of healthcare workers toward FCC, with patient satisfaction being a potential variable to explore in future research.

## ADVANCED RESEARCH

Further research could explore tailored interventions that address the specific challenges caregivers face, particularly focusing on mitigating financial strain and physical exhaustion to improve their quality of life. Investigating the role of culturally-sensitive communication strategies may also offer valuable insights, especially in understanding how and when parents disclose a child’s diagnosis based on cultural norms. Future studies might assess the effectiveness of educational tools—such as videos, pamphlets, and other media—in enhancing parental knowledge and engagement, potentially leading to improved FCC practices. Additionally, examining healthcare workers' attitudes toward FCC and including patient and family satisfaction as research variables could provide a more comprehensive understanding of FCC’s impact on treatment experiences. This research could guide hospitals in implementing strategies that strengthen FCC and parental involvement, ultimately improving care for children with leukemia.

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