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An overview of family management in the care of children with cancer

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***Abstract*:**
Effective family management can enhance a family's ability to cope with illness, maintain psychological stability, and support treatment outcomes. However, this has not yet been explored explicitly among families caring for children with cancer in the Province of Aceh. This study aims to analyze the characteristics of family management in caring for children with cancer, to provide a basis for designing appropriate nursing interventions to enhance family caregiving practices. This quantitative study employed a cross-sectional design, involving a total sample of 62 mothers and 30 fathers. Participants were families of children with cancer residing in various cities across Aceh Province who were receiving treatment in Banda Aceh. Data collection took place from March to April 2025. A non-probability, purposive sampling technique was employed, and quantitative data were collected using the Family Management Measure (FaMM). The results indicated that fathers reported higher scores compared to mothers across nearly all subscales of family management, including Child's Daily Life (3.867), Condition Management Ability (3.455), Condition Management Effort (3.483), Family Life Difficulty (3.576), and View of Condition Impact (4.017). In contrast, mothers demonstrated slightly higher scores on the Parental Mutuality subscale (3.772). The results suggest that fathers tend to have a more positive perception than mothers regarding most dimensions of family management, including the child's daily life, the ability and effort to manage the condition, and the perceived impact of the illness on family life. However, mothers showed a slightly higher perception of parental collaboration.

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INTRODUCTION

Pediatric cancer represents a complex and multifaceted health challenge that necessitates a collaborative approach involving both healthcare professionals and families throughout the care continuum (Volberding et al., 2021). The intricate nature of childhood malignancies, which often require aggressive multimodal treatments such as chemotherapy, radiation, and surgery, places significant physical, emotional, and logistical demands on both the child and their caregivers. Effective management extends beyond clinical interventions to encompass psychosocial support, symptom management, and adaptive care planning, all requiring seamless coordination between medical teams and families to navigate the uncertainties and stressors inherent in the cancer trajectory (Prates et al., 2024). This complexity underscores the importance of a unified care model where healthcare providers actively educate and partner with families to ensure comprehensive, patient-centered treatment strategies that address the disease and the holistic well-being of the child and their support system (Jones et al., 2024).

Children diagnosed with cancer typically face prolonged and intensive treatment regimens that can span months or even years, involving frequent hospital visits, complex medication schedules, and potential complications that disrupt daily life (Tonorezos et al., 2022). During this arduous

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journey, parents serve as indispensable partners in care, assuming critical responsibilities such as administering medications, monitoring side effects, maintaining treatment adherence, and providing unwavering emotional reassurance to their child (Roug et al., 2023). This central role of parents is strongly supported by empirical evidence; Mawarpury et al. (2023) emphasize that successful treatment outcomes and post-therapeutic recovery are not solely determined by medical protocols but are significantly enhanced by the presence of robust familial support systems, particularly from parents who act as primary advocates and caregivers. Without consistent parental engagement, even the most advanced medical interventions may falter, as adherence to treatment plans, timely communication of symptoms, and emotional resilience often hinge on the stability and advocacy provided by family members.

The interdependence of clinical expertise and familial involvement highlights the necessity of integrating family-centered care models into pediatric oncology practice to optimize long-term outcomes. Healthcare systems must prioritize equipping parents with the education, resources, and psychological support needed to navigate the demands of their child's illness, fostering a collaborative environment where families feel empowered rather than overwhelmed (Yuan et al., 2024). The synergy between medical care and parental support creates a foundation for resilience, enabling children to endure treatment challenges better and transition into survivorship with improved physical and psychosocial health. Ultimately, recognizing and strengthening the role of families within the care ecosystem is beneficial and essential for addressing the full spectrum of needs in pediatric cancer care, ensuring that no child faces their journey alone (Huang et al., 2023).

Families, especially parents, as the primary caregivers of children with cancer, are vulnerable to a range of health issues, including physical, social, and psychological challenges, due to the demanding nature of caregiving that requires considerable time, energy, and personal sacrifice. Emotional symptoms such as depression, guilt, anger, and anxiety are commonly reported psychological burdens among parents (Lewandowska, 2022). Changes in family dynamics, such as altered parental roles and responsibilities, are also seen (Lin et al., 2023).

The family as the primary caregiver plays an essential role in caring for children, especially children with chronic health conditions such as cancer. Therefore, effective family management is critical for optimizing the care process. Previous research has shown that effective family management enhances a family's ability to cope with the child's illness. Moreover, family management is a key construct to describe how families integrate chronic condition management into their daily lives and collaborate on caregiving responsibilities (Lin et al., 2023).

Knafl's Family Management Style Framework (FMSF) outlines three core components of family management: (1) the family's perception and interpretation of the child's health condition; (2) their ability to manage medical care while balancing daily life; and (3) the family's adaptability and restructuring in response to the challenges imposed by the child's illness. The FMSF facilitates understanding how families respond to complex health conditions and offers valuable insights for healthcare professionals in designing appropriate supportive interventions (Knafl et al., 2021).

Meanwhile, in Aceh Province, families of affected children have not received much support, even though the cases have increased significantly. Families have only received support from external stakeholders, such as shelters or independent nonprofit communities. This lack of structured support highlights the urgent need for evidence-based, targeted intervention programs. There is a critical need to explore and assess the current state of family management in caring for children with cancer in Aceh Province, as a step toward the development of appropriate and context-specific support interventions.

METHOD

Based on the data obtained in the Pediatric Chemotherapy Inpatient Unit, Thursina 1 at RSUDZA between 2024 and early 2025, 66 children were diagnosed with cancer and are still undergoing chemotherapy from various areas in Aceh Province. Accordingly, the population for this study comprised all families with children diagnosed with cancer who were receiving chemotherapy during the study period. This quantitative study employed a cross-sectional design, involving a total sample of 62 mothers and 30 fathers.

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The first step is to determine the eligible respondents in the study. Once the participants were identified, the researchers comprehensively explained the study, including its objectives, procedures, and potential benefits. Informed consent forms were then distributed to participants to indicate their voluntary agreement to participate in the study. The data collection was facilitated by a research team that included two trained nurses who served as enumerators. Before data collection, these enumerators received a detailed briefing on the study protocol and data collection procedures. The researchers and enumerators coordinated the data collection schedule with each participant and distributed the self-administered questionnaires. Participants were provided clear instructions on completing the questionnaire, which took approximately 20 minutes.

Upon completion, the research team collected the questionnaires. As a token of appreciation, each participant received a small gift for their time and effort participating in the study.

The research design employed is a cross-sectional study, conducted at a children's cancer shelter in Banda Aceh. This study was conducted after an ethical review process and was approved by the Research Ethics Committee of the Faculty of Nursing, Syiah Kuala University, with approval number 112026140225. All respondents have provided consent to participate in this study.

RESULT

Based on the research that has been conducted, the following results were obtained:

Table 1. Demographic Characteristics of Family with Cancer Pediatric (n=66)

Demographic Characteristics	Frequency (f)	Percentage (%)
Gender of Children with Cancer		
Boys	36	54.5
Girls	30	45.5
Age Group		
Toddler	8	12.1
Preschoolers	23	34.8
School children	23	34.8
Adolescent	12	18.2
Birth Order		
First Born	47	71.2
Second Born	7	10.6
Third Born	7	10.6
Fourth Born	5	7.6
Number of children in the Family		
1 child	18	27.3
2 children	20	30.3
>2 children	28	42.4
Region of Origin		
Urban	9	13.6
Rural	57	86.4
Type of Family		
Nuclear Family	52	78.8
Extended family	10	15.2
Single Parent Family	4	6.1
Age at Initial Diagnosis		
≤2 Years	5	7.6
25 years	27	40.9
5 - 10 Years	22	33.3
>10 Years	12	18.2
Types of Cancer Diagnosed		
ALL	39	59.1
AML	2	3.0
CML+ALL	1	1.5
Rhabdomiosarcoma	6	9.1
Willm's Tumor	2	1.5

Demographic Characteristics	Frequency (f)	Percentage (%)
Types of Cancer Diagnosed (cont...)		
Retinoblastoma	3	4.5
Osteosarcoma	3	4.5
Fibrosarcoma	1	1.5
Adenocarsinoma Ovarium	2	3.0
Ca. Nasopharing	1	1.5
Lymphoma Hodgkin	1	1.5
Limphoma non-Hodgkin	1	1.5
Hepatocellular Carcinoma	1	1.5
Epithelioid Sarcoma	1	1.5
Lymphoma Burkitt	1	1.5
Disgerminoma	1	1.5
Current Treatment		
Chemotherapy	64	97.0
Traditional/ Alternative Medicine	1	1.5
Combination of Chemotherapy and Traditional Medicine	1	1.5

Based on Table 1, most of the 66 child respondents were within the preschool and school-age groups (4–12 years), each accounting for 34.8% of the sample. Most children had more than two siblings (42.4%) and originated from regions outside Banda Aceh City (86.4%). The most common cancer diagnosis among the children was Acute Lymphoblastic Leukemia (ALL), accounting for 59.1% of cases.

Table 2. Distribution of Family Management Subscales (Mother and Father)

Family Management Subscale	Mother (n=62)		Father (n=32)	
	Mean	SD	Mean	SD
Child's Daily Life (CDL)	3.768	0.584	3.867	0.554
Condition Management Ability (CMA)	3.336	0.467	3.455	0.508
Parental Mutuality (PM)	3.772	0.451	3.732	0.499
Condition Management Effort (CME)	3.210	0.791	3.483	0.719
Family Life Difficulty (FLD)	3.543	0.443	3.576	0.503
View of Condition Impact (VCI)	3.876	0.926	4.017	0.878

Based on Table 4, fathers rated the child's daily life (CDL) slightly more positively (3.867) compared to mothers (3.768), indicating a perception that the child's daily routines are still functioning relatively well. The average score for Condition Management Ability (CMA) suggests that both mothers (3.336) and fathers (3.455) believe they are capable of independently managing their child's condition. Although the father's score is marginally higher, the difference is minimal. For the Parental Mutuality (PM) subscale, fathers scored slightly lower (3.732) than mothers (3.772), though both are within a similar range. Fathers reported a higher score (3.483) than mothers (3.210) in Condition Management Effort (CME), indicating a greater perceived involvement or effort in managing the condition. Perceptions of Family Life Difficulty (FLD) due to the child's condition were relatively balanced between mothers (3.543) and fathers (3.576), suggesting that both parents experience similar levels of strain in daily family life. Finally, the View of Condition Impact (VCI) score indicates that fathers (4.017) perceive the child's illness as having a greater impact on family life than mothers (3.876), potentially reflecting a higher level of concern or psychological burden among fathers.

DISCUSSION

Based on Child and Parent Demographic Data

The distribution of children's gender in this study indicates that most children diagnosed with cancer were male (54.5%), while females accounted for 45.5%. This finding aligns with previous studies, which reported that boys are more frequently diagnosed with leukemia than girls (Daltveit et al., 2025).

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The most significant proportion came from the preschool and school-age groups (34.8% each), followed by adolescents (18.2%), and toddlers (12.1%). The results indicate that most children undergoing cancer treatment are in preschool and school age. These periods are crucial for emotional and psychological growth, making continuous, compassionate support essential for their development. Additionally, external support, such as that of a school psychologist, is highly recommended to assist students and their families throughout the treatment process. (Alexandra & Denise, 2023).

Most respondents (71.4%) reported that the ill child was the firstborn in the family. Meanwhile, 10.6% were second- and third-born children, and only 7.6% were the fourth child. The most prevalent type of cancer was Acute Lymphoblastic Leukemia (ALL), comprising 59.1% of cases. Other types included Acute Myeloid Leukemia (AML) (3.0%), Rhabdomyosarcoma (9.1%), and other forms of cancer in smaller proportions (1.5%). ALL is the most common type of cancer among children aged 1–14 years globally, affecting the blood and bone marrow, and its incidence continues to rise in several countries (Namayandeh et al., 2020).

The results of the demographic analysis showed that most respondents in this study were mothers (54.5%), fathers (6.1%), and both parents. (39.4%). This reflects a general pattern in caregiving roles, where mothers often take primary responsibility for household duties and caring for a sick child. (Sandra et al., 2025). Other studies have shown that women often assume the leading role in daily household routines, including managing schedules and maintaining home order. (Ciciolla & Luthar, 2019). Consequently, mothers tend to be more intensively involved in the care of children with cancer, which can directly impact their psychosocial well-being. These findings are consistent with studies that show mothers often feel caregiving burdens (Koyu & Arslan, 2021).

Most respondents live outside Banda Aceh (86.4%), whereas health services and chemotherapy facilities in the province are only available in Banda Aceh. Previous studies have found that living in rural areas or small towns is associated with an increased risk of cancer in children. (Dąbrowska & Malicka, 2022). Other studies have also linked the location of residence to cancer survival rates, which tend to be lower in families living in remote areas. (Delavar et al., 2019). Additionally, families residing in areas distant from Banda Aceh City may have limited access to tertiary healthcare facilities, information sources, and psychosocial support.

Most respondents had between three and five children (42.4%), followed by those with two children (30.3%), and then those with one child (27.3%). This suggests that most families have more than one dependent. The number of children in a family can influence the dynamics of managing a child with cancer. Larger families may face more complex challenges in dividing attention, time, and resources. According to Knafl's Family Management Style Framework (FMSF), the number of children is a factor that can affect family management strategies, particularly in daily functioning and parental burden. (Knafl et al., 2021).

An only child tends to get undivided attention from their parents; however, families can be more emotionally and socially vulnerable because the burden of care is only focused on one child. Families with multiple children often face dual caregiving responsibilities and time management pressures, which can impact the overall effectiveness of family management. However, other children in the family can also provide emotional support for both parents and the ill child, depending on the family's internal support structure. In some studies, siblings of children with cancer reported that although the experience was difficult and stressful, they felt closeness between family members (Dąbrowska & Malicka, 2022).

Most respondents come from nuclear family types (78.8%), while others are from extended families (15.2%) or single-parent families (6.1%). The results showed that most children with cancer were raised in complete families. Complete families offer advantages because they enable a more flexible division of roles. For example, one parent focuses on caring for the child while the other continues to work. An intact family structure also strengthens emotional support and coordination in decision-making, so it can help families survive psychologically and economically during times of crisis (Dąbrowska & Malicka, 2022).

Extended families, on the other hand, may provide additional emotional and practical support. Previous studies have noted that extended families can contribute supplementary resources such as childcare for other siblings, financial assistance, or logistical support during treatment. However,

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the dynamics within extended families can also lead to role conflicts or differing opinions in medical decision-making (Kelada et al., 2019).

Almost all respondents reported using chemotherapy as the primary treatment (nearly 100%). A small portion (1.5%) chose to combine chemotherapy with traditional treatment, and one respondent decided not to continue chemotherapy and undergo traditional treatment (1.5%). This shows that chemotherapy is the main therapeutic approach in treating pediatric cancer for families. Previous studies have found that chemotherapy contributes significantly to cancer treatment with increasingly diverse drug preparations and supports increased survival of children with cancer (Bo et al., 2023).

Although the number of respondents who chose traditional medicine was relatively small (3.0%), this is important to note because it reflects the existence of alternative beliefs and practices among families caring for children with cancer. Traditional medicine plays a significant role in the healthcare system in developing countries. Several cancer patients use conventional medicine as primary therapy or complementary treatment (Matowa et al., 2020). In addition, this decision reflects the family's active efforts to seek control over an uncertain situation, as a response to the emotional and psychological stress felt by the family during the long process of caring for a child with cancer (Motlagh et al., 2023).

Based on Descriptive Data of the Family Management Subscale

A descriptive analysis of the family management subscales reveals that fathers tend to perceive their child's daily life (CDL) as proceeding relatively well (mean = 3.867), which is slightly higher than that of mothers (mean = 3.768). Although the difference is not substantial, it reflects a variation in perceptions between fathers and mothers regarding the child's daily routine. Fathers appeared to view the child's life as relatively stable, while mothers perceived more disruptions or impacts on the child's routine. This finding is consistent with Cardinali's study, which found that fathers often maintain the perception that family life, including the child's, remains "normal" compared to mothers. In that study, fathers focused more on the social and economic functions of the family and tended to assess the child's daily life from a practical and functional standpoint. Conversely, mothers were more emotionally attuned and sensitive to subtle changes in the child's condition due to their more intensive involvement in daily caregiving and direct interaction with the child (Cardinali et al., 2019).

The average Condition Management Ability (CMA) score shows that both mothers (3.336) and fathers (3.455) feel quite capable of managing their child's condition independently. Fathers scored slightly higher, but the difference is relatively small. This may suggest that fathers were more frequently responsible for physical caregiving during treatment, such as accompanying the child to chemotherapy, administering medication, or taking the child to the hospital. However, this involvement might not be accompanied by intensive coordination with mothers. In other words, while fathers may be physically involved in care activities, they may not always participate in shared decision-making, scheduling, or aligning caregiving strategies with their partners. Ultimately, this could lower Parental Mutuality (PM) subscale scores.

Interestingly, the PM score for fathers (3.732) was slightly lower than for mothers (3.772), though both remained in the moderate category. This supports the finding of low parental cooperation scores in several cases, as explained above, indicating potential disagreement or lack of effective communication between fathers and mothers in decision-making.

Fathers also reported higher scores (mean = 3.483) in the Child's Daily Management Effort (CME) subscale compared to mothers (mean = 3.210). This could reflect the father's perception of having made significant efforts in caring for the child, although such perceptions may not always align with the mother's perspective. Meanwhile, perceptions of family life difficulties due to the child's condition were nearly equal between mothers (mean = 3.543) and fathers (mean = 3.576), indicating that both parents experienced the pressures of daily life equally. The View of Condition Impact (VCI) subscale, which assesses the perceived impact of the child's illness on family life, showed that fathers (mean = 4.017) rated the impact higher than mothers (mean = 3.876).

High VCI scores in fathers do not necessarily mean that they are emotionally stronger but may reflect a form of hidden stress that can not be expressed. This finding is in line with Lin's research,

which found that fathers often view themselves as the primary supporters both physically and financially, which causes fathers to frequently suppress their feelings and try to appear strong, even when experiencing significant stress or uncertainty regarding the condition of a sick child (Lin et al., 2021).

CONCLUSION

Based on the study's results, the conclusion is that fathers generally hold more favorable perceptions than mothers across several domains of family management, including the child's daily life, their perceived ability and effort in managing the condition, and the overall impact on the family. However, mothers showed slightly higher scores regarding cooperation between parents.

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CONFLICT OF INTEREST

All authors declare that there is no conflict of interest in this research.

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