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FAMILY DECISION-MAKING AND ACTIONS IN CANCER EMERGENCY EVENTS

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ABSTRACT
Emergency deterioration in cancer patients often occurs unexpectedly at home, requiring families to respond rapidly despite limited knowledge and skills. This study explores the experiences of family caregivers in managing home-based cancer emergencies using a descriptive qualitative approach through in-depth semi-structured interviews with 11 (eleven) family caregivers, analyzed manually with thematic analysis. Four themes emerged. The first theme, Emotional and Psychological Experiences of Families, describes distress such as panic, fear, and confusion that hindered effective responses. The second theme, Family Preparedness and Capabilities in Handling Emergencies, highlights limited knowledge, insufficient practical skills, and the lack of basic equipment, which created uncertainty during initial actions. The third theme, Decision-Making and Family Response Strategies, shows that decisions were made under time pressure and often relied on instinct or brief discussions due to limited guidance. The fourth theme, Social Support and the Healthcare System, emphasizes the importance of communication with health workers and support from neighbors or community volunteers, although delays in accessing emergency services remained common. These findings indicate the need for practical educational programs, clear emergency action guidelines, community-based training, and improved telehealth or hotline services to enhance family preparedness in managing cancer emergencies at home.

Keywords: cancer; emergency response; emotional distress; family caregivers; social support

INTRODUCTION
Cancer is one of the leading causes of death worldwide and has a significant impact on the quality of life of patients and their families. The Global Cancer Observatory (GLOBOCAN) report indicates that more than 20 million new cancer cases will occur in 2022, with mortality rates continuing to rise, particularly in middle-income countries like Indonesia (Andinata et al., 2023). In Indonesia, cancer is the second-leading cause of death, and many patients undergo long-term outpatient care (Effendy, Uligraff, et al., 2022). This condition causes most episodes of deterioration, including severe pain, shortness of breath, bleeding, and decreased consciousness, to occur at home. These emergencies can arise suddenly without the presence of healthcare professionals, so families, as the primary caregivers, play a crucial role in responding to critical patient conditions.

Prompt and appropriate treatment of emergency situations in cancer patients is crucial for patient safety and comfort. However, most families lack emergency training and often face limitations in direct access to healthcare facilities, especially in urgent situations or outside of service hours (Dasat & Anggraini, 2023a). Families need to make critical decisions quickly, such as providing first aid, assessing the severity of the condition, or deciding when to refer the patient to a hospital. Therefore, a family's ability to cope with emergencies depends not only on technical knowledge but also on mental preparedness, courage, and the support of their surrounding community. The family's experience in dealing with these conditions is a crucial element to understand more deeply.

Despite the crucial role of the family, various challenges often arise in the process of managing emergencies at home. Families often face fear of making mistakes, anxiety when the patient's condition suddenly deteriorates, and confusion in choosing the most appropriate action. Limited equipment, a lack of basic skills, and emotional distress also hinder optimal initial response (Dasat, Mulyono, Khasanah, & Anggraini, 2024a). In many cases, families feel overwhelmed due to the limited opportunities for training or guidance on emergency procedures. A lack of support from healthcare professionals and a lack of practical information make families feel insecure in dealing with situations that resemble clinical critical conditions.

In addition to technical challenges, some families felt that the information they received about emergency care was unclear, too theoretical, or out of context for their home situation. Difficult-to-understand written guidelines, incomplete instructions, or minimal communication between healthcare providers and families made decision-making more difficult (Dasat, Mulyono, Khasanah, & Anggraini, 2024b). Families hoped for a more practical, case-based educational approach that was relevant to their real-life situations. Furthermore, families desired emotional and psychological support from healthcare providers, as the mental stress they felt was often as great as the physical challenges they faced.

Family reflections on their experiences in emergency care are a crucial aspect in evaluating the preparedness and effectiveness of support provided by healthcare providers. Family perspectives can illustrate the internal and external barriers they face when responding to critically ill cancer patients. Previous studies have focused more on clinical aspects and pain management, while studies that address families' subjective experiences are limited. However, exploring family experiences and emotional dynamics can reveal needs not captured through quantitative approaches, such as fears, risk perceptions, or cultural values that influence family actions (Hermawan et al., 2025).

A qualitative approach allows researchers to understand families' experiences more comprehensively, including the emotional, social, and cognitive aspects of facing an emergency. Family narratives can provide a rich picture of their decision-making processes, coping strategies, and the types of support they need. This in-depth understanding can form the basis for designing more adaptive and contextual educational interventions and support models for families of cancer patients (Hermawan & Wihardja, 2024). This approach is crucial for improving the quality of home care, not only technically but also in terms of the family's psychological preparedness as first responders.

Advances in healthcare technology, innovations such as telehealth, emergency hotlines, and multimedia-based education have demonstrated potential in helping families cope with critical patient situations (Wong, 2024). Healthcare institutions and nursing staff need to consider more responsive, realistic, and accessible support strategies for families of cancer patients. An integrated approach to education and monitoring can boost family confidence and strengthen their ability to handle emergencies at home (Effendy, Kurianto, et al., 2022).

The main research question focuses on how families reflect on their experiences when dealing with cancer emergencies at home. This study aims to explore the challenges families face, how they interpret these experiences, and their expectations for healthcare support. Family reflections are considered an important source of information for evaluating the effectiveness of education, communication, and support provided by healthcare providers. This understanding is expected to form the basis for designing more effective family-based interventions and care strategies. The purpose of this study is to explore in depth the experiences of families in dealing with cancer emergencies at home, including the challenges, meanings, and expectations for better healthcare support.

METHOD

This study used a descriptive qualitative design to explore families' experiences in managing emergency situations in cancer patients at home. This approach allows researchers to describe phenomena in depth as experienced by participants without manipulating variables (Fiantika et al., 2022). The primary focus of this design is to understand the meanings families attach to their experiences when facing emergency situations in patients at home. This design was chosen because it aligns with the research objectives, which emphasize subjective interpretations and lived experiences of families in the context of cancer patient care.

Eleven family members who served as primary caregivers for cancer patients participated in this study. Purposive sampling was used to select participants who met the inclusion criteria: family members who lived in the same household as the patient, had experienced or were directly involved in the emergency management of cancer patients, were at least 18 years old, and were willing to participate voluntarily. Participants who were not directly involved in the emergency or refused to participate in the interview process were excluded from the study.

Data collection was conducted through in-depth interviews using a semi-structured approach. Interviews lasted 30 to 60 minutes face-to-face. Each interview was audio-recorded with the participant's written consent, and field notes were taken to document the context, nonverbal expressions, and situations during the interview. The interview guide was developed based on the research focus, which included families' experiences in dealing with emergencies, decisions made, challenges faced, and expectations for healthcare support.

All interviews were transcribed verbatim by the researcher to maintain the authenticity of the participants' narratives. Member checking was conducted by asking participants to reconfirm the transcripts or summaries of the interviews to ensure data accuracy. Data validity was strengthened through regular reflection by the researcher throughout the data collection and analysis process to minimize bias and maintain the integrity of the qualitative analysis. This effort was made to ensure that the resulting interpretations remained consistent with the meaning conveyed by the participants.

Ethical principles were strictly adhered to throughout the research process. Each participant was given a detailed explanation of the study's purpose, interview procedures, and the right to withdraw at any time without consequence. Participants' identities were disguised in all reports and publications to maintain confidentiality and privacy. Careful data analysis was conducted to avoid interpretive bias and ensure that the meaning conveyed by the families remained intact throughout the analysis.

The data analysis process was conducted using a thematic analysis approach that follows standard steps in qualitative research. The analysis stage began with repeated reading of the transcripts to capture the context and overall content of the data. Next, the researcher identified key sections for initial coding and then grouped these codes into categories with similar meanings. From these categories, the researcher developed key themes that reflected the patterns and meanings emerging in the data. An interpretive narrative was then constructed to explain the overall interrelationships between the themes. The analysis was conducted manually to allow the researcher to remain deeply engaged with the data and have space to explore meanings in greater detail. The credibility of the analysis was strengthened through discussions with colleagues to ensure consistent and accurate interpretations (Nurfajriani et al., 2024).

This methodological approach was chosen to allow the study to deeply explore families' experiences in responding to emergency situations in cancer patients at home. The results are expected to provide a basis for healthcare professionals and service institutions to develop support and education strategies that

are more contextual, realistic, and tailored to family needs. The descriptive qualitative design also provides space for families to share in-depth personal experiences, both technical and emotional, that they face while caring for cancer patients in critical situation (Surayya, 2020).

Table 1.
Interview Guidelines

No.	Interview Questions	Code	Exploration Objectives	Thematic Indicators
1	Can you tell us about your first experience dealing with a cancer patient emergency at home?	Q1	Exploring initial impressions and spontaneous responses of families	Panic, confusion, emotional shock
2	What is the first action you take when the patient's condition starts to deteriorate?	Q2	Identifying the family's initial response	Early action, quick judgment, spontaneous response
3	What are the main challenges you face while handling such emergencies at home?	Q3	Understanding technical and emotional barriers	Limited knowledge, fear, emotional stress
4	How do you determine when to seek medical help or take a patient to the hospital?	Q4	Exploring the decision-making process	Risk assessment, previous experience, level of emergency
5	Have you ever felt doubtful about an action you took? If so, what caused it?	Q5	Assess the level of self-confidence and causes of doubt	Uncertainty, lack of information, psychological burden
6	Who helps you in case of an emergency at home?	Q6	Assess self-confidence and factors causing doubt	Family support, health worker guidance, neighbor assistance
7	How do the limitations of home tools or facilities affect the actions you take?	Q7	Exploring forms of external support	Lack of equipment, access to medicine, housing conditions
8	How do you feel after going through that emergency at home?	Q8	Identifying environmental and resource constraints	Stress, relief, trauma, guilt
9	What knowledge or information do you think is most needed in dealing with this emergency?	Q9	Exploring short-term and long-term emotional impacts	First aid, danger signs, proper steps
10	What are your expectations of health workers in helping families deal with emergencies at home?	Q10	Identifying educational needs	Clear communication, ongoing support, practical education

RESULT AND DISCUSSION

Table 2.
Participant Characteristics

Code	Gender	Age (Years)	Education Stage	Learning Experience Emergency Response	Never Applied to Real Situations
P1	Female	38	Wife	Yes	No
P2	Male	45	Husband	Yes	Yes
P3	Female	52	Children	Yes	No
P4	Female	33	Children	Yes	No
P5	Male	41	Siblings	Yes	No
P6	Female	56	Mother	Yes	Yes
P7	Female	47	Wife	Yes	No
P8	Male	35	Children	Yes	No
P9	Female	60	Mother	Yes	No
P10	Female	30	Children	Yes	No
P11	Male	58	Husband	Yes	No

Based on participant characteristics (Table 2), 11 family members who were primary caregivers for cancer patients participated in this study, ranging in age from 30 to 60 years, with the majority being female. All participants had experienced emergencies at home, although almost none had received formal training or information on emergency response. Most of the actions taken were spontaneous and based

on personal experience, rather than structured skills. These findings indicate that family preparedness for emergency management is still limited, necessitating more effective education and support to improve their ability to respond to critical patient situations at home.

Theme 1. Emotional and Psychological Experiences of Families

Participant responses indicated that cancer emergencies place a strong emotional burden on families. Fear, panic, and uncertainty are common initial reactions when a patient's condition suddenly deteriorates. Many families feel unprepared for critical situations and struggle to control their emotions while still taking swift action. This emotional experience not only impacts their ability to respond to emergencies but also contributes to post-event mental fatigue. Despite this, some participants attempted to calm themselves and focus on the patient's safety as a strategy to remain resilient.

P3: *When my mother suddenly became short of breath, I panicked... my hands were shaking, but I had to do something.*
P7: *I was afraid of making a mistake, but the situation was critical, so I tried to stay calm even though I was very anxious inside.*
P1: *When my husband suddenly became weak and nearly fainted, I was completely at a loss for what to do.*
P9: *I'm used to caring for my child, but when it's this critical, I still feel scared and unprepared.*
P10: *It's a mixture of anxiety and the need to act quickly to avoid being late.*

Theme 2. Family Preparedness and Capabilities in Handling Emergencies

Participants described that their preparedness to handle emergencies is still very limited, both in terms of knowledge and technical skills. Most families lack a basic understanding of emergency response steps, so initial actions tend to be spontaneous and often fraught with doubt. Limited equipment and the absence of practical guidance also pose significant obstacles to determining appropriate action. Meanwhile, participants who have received basic information or training feel more supported, although they still feel that their skills are inadequate to handle critical situations. This situation indicates that family capabilities are strongly influenced by previous experience, access to information, and opportunities for practical learning.

P2: *I've attended counseling sessions, so I know a little bit about what to do... but I'm still confused when it's a real emergency.*
P6: *I got some information from the nurse, but when it happened, I still doubted whether I was doing the right thing.*
P4: *I didn't know where to start; I just tried to calm the patient and wait for help.*
P10: *I felt inadequate because I'd never been taught how to handle a situation like this.*
P8: *We didn't have adequate equipment at home, so we just relied on what we had.*

Theme 3. Decision-Making and Family Response Strategies

Participants described how the decision-making process during an emergency situation is heavily influenced by rapid assessment, prior experiences, and communication dynamics within the family. Many families must quickly determine whether to provide first aid, wait for the situation to develop, or immediately transport the patient to the hospital. Hesitation often arises due to the lack of clear guidelines, leading to decisions based on instinct or prior experience. Some participants also explained that brief discussions among family members are key to determining action, while others are forced to make decisions on their own when the situation unfolds rapidly. These findings indicate that family response strategies vary, but most remain reactive and lack clinical judgment due to limited information.

P1: *When my husband's condition worsens, I have to decide quickly whether to take him to the emergency room or treat him at home.*
P5: *I monitor his condition first... if it gets worse, then we agree to take him to the hospital.*
P8: *Sometimes I have to make the decision alone because the other family members are panicked and don't know what to do.*
P3: *We had a brief discussion, but the situation escalated quickly, so I decided to call an ambulance.*
P10: *I was unsure whether my actions were appropriate, but I had to act quickly before it was too late.*

Theme 4. Social Support and the Healthcare System
Participants emphasized the importance of support from healthcare workers, community health workers, and their surrounding community in helping them cope with emergencies at home. Many families felt more reassured when they had access to communication with a nurse or doctor, even if only by phone. However, most participants also experienced barriers, such as difficulty contacting healthcare facilities during emergencies or slow service response times. Emotional support from other family members, neighbors, or relatives also played a role in reducing anxiety and empowering them to take action. These findings indicate that the healthcare system is not yet optimal, and families urgently need structured, accessible, and responsive support to help them make quick and informed decisions.

P6: *I managed to contact a nurse, and it was very helpful, even if it was just a phone call.*
P3: *A neighbor helped calm the situation, because we were really panicking at the time.*
P11: *I tried calling the hospital, but it took a long time to respond, so we decided to go on our own.*
P8: *A cadre came after we asked for help, and that really helped guide us on what to do.*
P9: *Having support from healthcare workers makes me feel calmer and less alone in the face of an emergency.*

The characteristics of the participants, all of whom had experienced emergency situations but most of whom had no prior training or information, suggest that family experiences were heavily influenced by spontaneous responses and real-life situations at home. Unlike simulation-based learning for healthcare professionals, families responded to critical situations in a confined, emotionally stressful environment without direct instruction from medical personnel. This reinforces the finding that family preparedness is largely shaped by empirical experience, which is often inadequate for emergency situations requiring rapid and accurate decisions. Previous research has confirmed that a lack of understanding of warning signs and initial treatment steps can increase the risk of delayed treatment in cancer patients experiencing sudden deterioration (Huang et al., 2022a).

This study shows that families' experiences in dealing with emergency situations in cancer patients are significantly influenced by emotional states, limited knowledge, decision-making processes, and healthcare support. Feelings of panic, fear, and confusion are key barriers to responding to critical situations, leading to psychological distress that can reduce the quality of family decisions (Milberg et al., 2020). A lack of technical understanding also leads to intuitive and undirected family actions, highlighting the importance of accessible, practical education (Huang et al., 2022a). Furthermore, decisions are often made quickly without adequate guidance, necessitating immediate communication from healthcare professionals (Broadhurst et al., 2021). Barriers to accessing services also slow down the process of providing care. Overall, these findings emphasize the need for practical education, psychological empowerment, emergency communication mechanisms, and community-based support to improve family preparedness for handling critical situations at home.

Theme 1. Emotional and Psychological Experiences of Families

Findings from the first theme indicate that families experience strong emotional reactions such as panic, fear, and confusion when faced with a cancer emergency. Participants' accounts of trembling hands, uncertainty in determining initial steps, and fear of making mistakes illustrate the significant psychological distress they experience (Xu et al., 2024). Emotional distress among families of cancer patients increases significantly when the patient's condition suddenly deteriorates, which can hinder their ability to respond appropriately to critical situations.

Many families in this study reported feeling unprepared for an emergency situation, despite having been involved in the patient's daily care. This was evident in participants' statements about shock, confusion, and fear when the patient suddenly experienced severe shortness of breath or near-fainting (Huang et al., 2022b). These emotional reactions are consistent with the fact that first-time experiences with cancer emergencies at home often result in emotional shock, which can impair the family's ability to objectively assess the situation.

Despite facing high emotional stress, some families attempted to control themselves and remain focused on the patient's safety. Families attempted to calm themselves, think quickly, and take action as best they could, despite their mental instability (Hermawan and Wihardja 2024). This adaptive strategy emphasizes that emotional regulation helps families remain (Hermawan & Wihardja, 2024). This adaptive strategy emphasizes that emotional regulation helps families remain resilient in emergency situations. However, the ability to manage emotions varied significantly among participants, influenced by prior experiences and individual levels of psychological preparedness.

In addition to the effects that emerged at the time of the incident, families also described experiencing mental exhaustion after facing the emergency situation. Some participants experienced recurring anxiety, fear of a similar event occurring again, and emotional exhaustion as aftereffects (Goerling et al., 2023). Managing the critical condition of a cancer patient can place a long-term psychological burden on families. Therefore, ongoing psychosocial support is crucial to help families restore emotional balance and prepare for future similar situations.

Theme 2. Family Preparedness and Capabilities in Handling Emergencies

Research findings indicate that family preparedness in handling emergencies in cancer patients remains very limited, particularly regarding basic knowledge and technical skills. Many participants expressed not knowing the appropriate initial steps when a patient's condition suddenly deteriorates, leading to spontaneous actions not based on clear guidelines. This situation illustrates that families lacking basic understanding often rely on intuition, which does not always align with the principles of proper emergency management (Dasat, Mulyono, Khasanah, & Anggraini, 2024a).

Limited access to education and training is also a major obstacle to improving family capacity. Some participants who had received basic information through counseling or explanations from nurses did feel slightly better prepared, but still experienced doubt when an emergency situation actually occurred (Hermawan & Wihardja, 2025). These findings suggest that theoretical information alone is insufficient to develop the practical skills needed in critical situations. Knowledge without practical practice cannot build confidence or an effective response.

In addition to limited knowledge, the availability of equipment and facilities at home also significantly impacts family preparedness (Ris et al., 2022). Several participants reported not having basic equipment such as oxygen or other support devices, severely limiting the actions they can take. Reliance on inadequate equipment can slow the response and increase the risk of worsening the patient's condition.

Limited home facilities are a significant barrier to emergency care for patients with chronic illnesses, including cancer.

Overall, findings from this theme indicate that family capabilities are influenced by previous experiences, opportunities to acquire information, and access to practical learning support (Jacob et al., 2025). To improve family preparedness, more practical interventions are needed, such as demonstration-based training, emergency steps booklets, short educational videos, or accessible telehealth support. Targeted, simple, and practical education can help families act more confidently and appropriately when facing critical situations at home.

Theme 3. Decision-Making and Family Response Strategies

Research findings on this topic indicate that family decision-making in the face of a cancer emergency is rapid and stressful (Jabeen et al., 2024). Many participants described having to assess the patient's condition within minutes to determine whether to initiate immediate action or immediately transport the patient to a health facility. This situation suggests that families are often faced with situations that require rapid decision-making, and the initial response is highly dependent on the family's perception of the severity of the situation.

Family decision-making appears to be heavily influenced by previous experiences, both personal and similar events the family has faced. However, these experiences do not always translate to more complex emergency situations, often leading to doubts in decisions (Hermawan & Wihardja, 2025). Family decision-making appears to be heavily influenced by previous experiences, both personal and similar events the family has faced. However, these experiences do not always translate to more complex emergency situations, often leading to doubts in decisions.

Communication dynamics within the family also play a crucial role in determining the response. Several participants explained that they held brief discussions with other family members before deciding on a course of action. However, this communication process often subsided due to panic and limited time (Torres-Marrero et al., 2025). In some situations, participants even had to make decisions alone because other family members were unable to think clearly or provide input. Emotional instability and unstructured communication were major obstacles to quick and accurate decision-making in emergency situations.

Overall, family responses to emergencies are reactive and not based on informed clinical considerations. The lack of emergency guidelines leads to a wide variety of decisions, ranging from calming the patient and waiting for the condition to improve, to immediately calling an ambulance or taking the patient to the emergency room (Huang et al., 2022b). These findings highlight the importance of simple, easy-to-understand, and accessible guidelines for families facing critical situations. Therefore, families need practical education and standardized instructions to help them make more informed and safe decisions when facing cancer emergencies at home.

Theme 4. Social Support and the Healthcare System

Research findings on this theme indicate that social support and easy access to healthcare professionals are important factors influencing families' ability to respond to cancer emergencies at home. Many participants expressed that communicating with a nurse or doctor, even by telephone, provided a sense of reassurance and helped them determine initial actions (Guo et al., 2024). These findings confirm that rapid access to healthcare professionals can improve the accuracy of a family's response in critical situations. This verbal support not only provides guidance but also acts as emotional support, especially when families are in a state of panic.

In addition to healthcare workers, support from the surrounding community, such as neighbors, relatives, and health workers, also plays a crucial role in helping families cope with critical situations. Several participants reported that the presence of others can calm the situation, reduce fear, and encourage families to act more quickly (Dasat, Mulyono, Khasanah, & Hermawan, 2024). These findings suggest that social support can strengthen families' capacity to handle emergencies by reducing anxiety levels and providing practical assistance during the incident.

However, this study also found that not all health services were easily accessible in emergencies. Some participants experienced difficulty contacting hospitals or getting a quick response from medical services. This situation forced families to make their own decisions, including transporting patients to health facilities without professional assistance (Barlund et al., 2021). These barriers indicate that the emergency services system is not optimally supporting families of cancer patients at home. This finding suggests that delays in health service response can reduce the chances of survival in critical situations.
Overall, this theme emphasizes the importance of a more structured, accessible, and responsive support system for families of cancer patients. Some interventions that could be developed include emergency hotlines, strengthening the role of cadres, increasing telehealth access, and more systematic family support mechanisms (Dasat & Anggraini, 2023b). Integration between professional healthcare services and community-based support is necessary to improve families' ability to make quick and appropriate decisions when facing emergencies at home. Such comprehensive support not only helps reduce family anxiety but also improves overall patient safety.

CONCLUSIONS

The results of this study indicate that families' experiences in dealing with cancer emergencies at home are influenced by four main aspects: emotional state, level of knowledge and skills, decision-making processes, and social support and healthcare services. Families experience psychological stress such as panic, fear, confusion, and uncertainty when the patient's condition suddenly deteriorates, often hampering their ability to assess the situation. Limited knowledge and a lack of technical skills make initial actions more spontaneous and intuitive without clear direction. Furthermore, the lack of tools and facilities at home limits the range of responses available. Decision-making is rapid and often fraught with uncertainty due to the lack of standard guidelines, so decisions are often based on instinct, previous experience, or brief discussions among family members.

Overall, this study underscores the need for more structured support to improve families' ability to respond to emergencies at home. While social support from healthcare workers, community health workers, neighbors, or relatives helps reduce family anxiety, barriers to accessing emergency healthcare services indicate that the existing system is suboptimal. Therefore, interventions such as practical education on emergency steps, practical community-based training, the provision of simple, easily accessible guidelines, and an increased role in telehealth or telenursing and emergency hotlines are urgently needed. These measures are expected to strengthen family preparedness, improve decision-making accuracy, and ultimately enhance the safety of cancer patients being treated at home.

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