Embracing family presence: exploring the reasons for family decision-making dependence on in-hospital palliative care for cancer patients

Boby Febri Krisdianto,[1] Debie Dahlia,[2] Agung Waluyo[2]

[1]Faculty of Nursing, Universitas Andalas, Padang; [2]Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

Abstract

The implementation of home-based palliative care is widely recognized as a commendable and effective model of care provision. However, it is noteworthy that families residing in Indonesia exhibit a propensity to predominantly seek palliative care services within hospital environments for their family members afflicted with palliative-stage cancer. Therefore, the aim of this research was to investigate the perceptions of family members in their decision-making process regarding the care of palliative-stage cancer patients at home. This qualitative study employed a descriptive phenomenological approach. Data were obtained through in-depth interviews with ten Indonesian family members of palliative-stage cancer patients refusing discharge, and were analyzed using the Colaizzi method. Furthermore, the inclusion criteria were that the dominant family member who cares for the patient lives with the patient and is involved in the decision-making process. Two themes emerged from this study: i) a lack of support in decision-making, and ii) pain and chronic sorrow. Home-based palliative care for cancer patients presents significant decision-making challenges and persistent grief for families, necessitating robust support and education from healthcare professionals such as nurses and policymakers. Additionally, a national health insurance system that enables effective palliative care is crucial.

Correspondence: Boby Febri Krisdianto, Faculty of Nursing, Universitas Andalas, Depok, Indonesia.
E-mail: bobbyfk@nrs.unand.ac.id

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Introduction

Cancer is a general term for a large group of diseases characterized by the overgrowth of abnormal cells that invade adjacent parts of the body and spread to other organs.[1] Cancer is the second leading cause of death in the world after cardiovascular disease.[2] The incidence of cancer, in general, is higher in high-income countries.[3] The global cancer burden has been a significant concern, with an increasing number of new cases and deaths projected annually. In 2019, it was estimated that 10 million people died due to cancer worldwide.[4] Based on statistics provided by the World Health Organization (WHO) (2022), roughly 10 million deaths, or nearly one in six deaths, will be caused by cancer in 2020, making it the top cause of death globally.[5] In 2020, there were an estimated 19.3 million new cancer cases and almost 10.0 million cancer deaths worldwide.[6] Indonesia, being the fourth most populous country globally with a population of 270,203,917 as of 2021, faces a significant burden of disease, comprising the highest percentage in non-communicable (58%) ailments. Among these, cancer stands out with an incidence rate of 14 cases per 1,000 individuals. Alarmingly, the number of newly diagnosed cancer cases was projected to escalate to 19.3 million by 2020 in Indonesia, resulting in approximately 10 million deaths directly attributed to cancer.[2] Cancer ranks as the second most prevalent cause of mortality among children aged 1 to 14 years.[7]

The etiology of cancer is still unknown, but according to Ling *et al*. (2018), the cause of cancer is related to smoking, alcohol consumption, and viral infection (Human Papilloma Virus). Other cancer etiologies include accumulating genetic alterations, including mutations, amplifications, or DNA deletions.[8] The majority of cancer patients in Indonesia typically seek healthcare services at an advanced stage of the disease.[4] Among several endeavors, chemotherapy is preferred as part of the primary cancer treatment to induce tumor cell death and reduce tumor mass. Meanwhile, the main treatment for cancer metastasis also uses chemoagent-based therapy.[9] The primary focus of caring for patients in advanced stages of cancer is to provide palliative care, and there is a growing consensus advocating for the delivery of palliative care in home settings.[10] Research findings suggest that home-based palliative care provides several benefits, including improved cost-effectiveness in healthcare, reduced risk of hospital-acquired infections, enhanced quality of life for patients, and increased convenience for both patients and their families.[11]

While there exists a preference among families of palliative cancer patients to administer care at home, the decision to transition patients from the hospital to home care presents considerable challenges.[12] Nurses play an instrumental role in assisting these families, offering vital information to facilitate informed decisions about the most appropriate care setting for palliative cancer patients.[13] It is imperative to equip families with comprehensive information encompassing both the benefits and drawbacks of prolonged hospital stays.[14]

The choice by some families to forego home-based palliative care can adversely affect the patient's quality of life. Hospital policies, though not deliberately restrictive, may curtail the patients' freedom and ability to spend valuable time with their loved ones.[15] Consequently, hospitalized palliative cancer patients often endure distress, loneliness, depression, and acute anxiety as they approach the end of their lives.[16,17] Furthermore, research indicates that nearly half of the families of hospitalized patients experience considerable distress during this period.[17] Hence, it is imperative for nurses to be adequately equipped with the knowledge and skills to guide families in making informed decisions about home-based palliative care.[18]

There is a scarcity of research exploring the perspectives of Indonesian families of palliative cancer patients regarding their decision-making process for home-based care.[19-22] This study aimed to fill this knowledge gap and develop effective interventions to assist families in making decisions about home-based palliative care. Conducting this research is critical to enhancing our understanding and providing insightful guidance to support families in their decision-making processes.

Materials and Methods

Research design

In this qualitative study, we adopted a descriptive phenomenological approach grounded in Van Manen's theory of lived experience, which emphasizes the exploration of personal experiences as central to comprehending the essence of human existence.[23] This methodological approach facilitates an in-depth exploration of families' perspectives and insights concerning their decision-making process in the context of home-based palliative care. Utilizing this design allows for the extraction of valuable insights, thereby enriching our understanding of the familial decision-making dynamics in this specific healthcare setting.

Study participants

This qualitative study comprised family members of palliative cancer patients who had been hospitalized in a national referral hospital and were directly involved in decision-making regarding home-based care. The participant group included both families who chose to continue hospital care and those who opted for home-based care. Using purposive sampling, we selected ten individuals, all of whom had declined home-based palliative care for their gravely ill family members. Detailed characteristics of these participants are provided in Table 1.

Data collection

We recruited ten family members who had refused home-based palliative care. The inclusion criteria specified that participants be immediate family members (such as parents, spouses, or children) who lived with and cared for a palliative cancer patient in a leading referral hospital in Jakarta. Hospital ward nurses assisted in initially identifying potential participants. These individuals were then contacted, informed in detail about the study, and their informed consent was obtained. The first author conducted in-depth interviews, each lasting about 60-70 minutes, at locations chosen by the participants, usually their homes. The interviews were audio-recorded, and data collection continued until saturation was achieved with the 10th participant.

Data analysis

We utilized Colaizzi's phenomenological method to analyze the experiences of these families in making decisions about home-based palliative care. The analysis began with an extensive reading of interview transcripts to grasp the overall context and identify key statements. These statements were categorized and organized into themes, which were then elaborated and integrated to present a comprehensive view of the family decision-making process regarding home-based palliative cancer care. To validate our findings, we contacted participants by phone.

Study trustworthiness

The study's trustworthiness was assured through considerations of credibility, transferability, confirmability, and dependability. The first author, primarily responsible for data analysis, collaborated with the second and third authors - both seasoned in qualitative research - for a thorough review process.

Rigor

To ensure the study's rigor, we focused on credibility, transferability, and confirmability. Credibility was established through meticulous peer debriefing and detailed review by the corresponding author of the transcripts, subthemes, themes, and findings. While direct member-checking with participants was not performed, two research team members with oncology nursing expertise, less involved in data analysis, validated the themes and subthemes as accurately representing the data. Concerns regarding trustworthiness due to translation (the analysis was conducted in Bahasa and presented in English) were addressed through a meticulous forward-backward translation process by an external translator. This ensured accurate translation of themes, subthemes, categories, and quotes into English. Transferability was enhanced by including rich, detailed descriptions, offering a deep understanding of the study's context. Confirmability was maintained through the authors' commitment to reflective honesty. Additionally, all authors had training in qualitative research methods, further reinforcing the study's confirmability.

Ethical clearance

The ethical approval for this research was granted by the Ethical Committee of the Faculty of Nursing at Universitas Indonesia, under the reference number 99/UN2.F12.D/HKP.02.04/2017. Participation in this study was entirely voluntary, with all participants providing their informed consent. We ensured strict confidentiality throughout the research process, which included the anonymization of participant data. Additionally, the authors declare no competing interests related to this study.

Results

Demographic characteristics of participants

Table 1 presents the demographic characteristics of the study participants. Among the 10 patient participants, the majority were female (60%), over 40 years of age (50%), college graduates (60%), daughters of the patients (40%), and housewives (40%). Although most patients had been diagnosed with cancer two years ago, the majority of them had advanced stage IV cancer (70%).

Themes

The data analysis revealed the following themes (Table 2).

Lack of support of family in the decision making

The data analysis identified a primary theme: the lack of family support in decision-making regarding home-based palliative cancer care. Participants commonly expressed feeling unsupported in deciding to care for palliative cancer patients at home. This lack of support manifested in several dimensions.

Firstly, a significant number of participants disclosed a lack of understanding regarding the palliative condition and goals of care. This gap in knowledge largely stemmed from insufficient communication from healthcare providers, with many families unaware of these critical aspects until participating in this study. Such a lack of information led to confusion in both decision-making and subsequent patient care at home. Participants reported that healthcare professionals had not adequately explained the palliative diagnosis and its home management, leaving them ill-prepared for potential worst-case scenarios. The families often found themselves receiving only basic information about patient care at home, and this typically occurred just before the patient's discharge. For instance, Participant 2 highlighted the absence of preparatory information prior to discharge: "We expected some information to prepare us to take care of mother before she got discharged, so we knew what to do at home, whether we needed follow-up visits to the hospital clinic or not. Such information should have been provided by the nurse. They should not have just sent the patient home like that. That's all I expected" (P2)

This sentiment was echoed by Participant 3, who encountered the concept of palliative care for the first time during the study: "When I received the initial call from you, that's when I received information about it. You explained to me what palliative care entailed. That was the first time I became aware of such a service. Prior to that, it was completely unfamiliar to us, and, of course, I really wanted my mother to recover as before" (P3)

These expressions represent the overarching theme of inadequate support in the decision-making process for home-based care versus hospitalization. Furthermore, families expressed a desire for more active support from physicians in making these decisions. They anticipated more frequent home visits from doctors and a continuous supply of medications for the patient. Another salient issue was the lack of resources to support home-based care. Families yearned for better access to appropriate facilities and resources to adequately care for palliative cancer patients at home. This need for a more robust support infrastructure is illustrated by Participant 1's experience: "In an unexpected turn of events, my father experienced a significant complaint, and we rushed him to the hospital. However, the process of seeking medical attention was protracted. Upon our arrival at the hospital, they had to conduct the analysis again, a time-consuming process. If my father had already been admitted to the hospital, the entire process would have been much quicker and more streamlined" (P1)

These findings underscore the crucial need for enhanced support and resources for families making decisions about home-based palliative care.

Discussion

In this qualitative research grounded in phenomenology, the discussion is organized around two central themes informed by Van Manen's lived experience theory. The first theme, "lack of support in decision-making," delves into the pivotal role of family readiness and capability in the decision-making processes related to home-based palliative care, as underscored by previous research.[24-26] The complexities in these decisions arise from healthcare providers' assessment of whether family caregivers are sufficiently prepared for the responsibilities of such care. Studies from the UK and Australia[27] highlight that not all palliative cancer patients are candidates for home treatment due to challenges in managing pain and symptoms, the need for continuous care, and progressive patient deterioration, often necessitating hospitalization. Family preferences, limited access to palliative care services, and the family's inability to provide sufficient home-based care significantly influence these decisions.

In Indonesia, the accessibility of palliative care services is a major hurdle.[28] With over half of its 265 million population residing in rural areas, accessible care is a pressing concern.[6] Palliative care is mainly available in urban centers, and despite its introduction as a national program in 1989, access remains limited.[27] Currently, only ten government-designated hospitals across seven cities provide such care, a stark contrast to Indonesia's vast archipelago of over 17,000 islands.[28,29] This study's participants, nine out of ten, voiced a need for more accessible palliative cancer care. The study further reveals that families often opt for hospital care due to their lack of ability and proficiency in managing palliative cancer patients at home. Concerns regarding inadequate home-based treatment and its inability to address cancer-related physical symptoms and side effects were common. Caregivers who found themselves unable to provide home care experienced significant stress, impacting their well-being.[30]

A considerable proportion of participants (six out of ten) admitted their incapacity to care for palliative cancer patients at home, advocating for comprehensive hospital care.[28] The challenges faced by palliative cancer patients in Indonesia include inadequate facilities, scarcity of skilled healthcare professionals, and limited access to palliative care services, especially for home-based care. The introduction of universal health coverage in Indonesia in 2014 by the Healthcare and Social Security Agency (BPJS)[2,31] has influenced patient care decisions. Five study participants cited their reliance on hospital care due to the comprehensive services covered by BPJS insurance. However, this reliance might strain the healthcare system's efficiency. In contrast, systems like Medicaid in the United States have shown cost savings by prioritizing home-based care.[12]

Cultural factors also play a significant role in decision-making processes. Most study participants entrusted decision-making to extended family members, a practice rooted in cultural norms and the value placed on familial bonds and communication. This aligns with other studies[28,32] highlighting the active involvement of families in patient care and decision-making within Indonesian hospitals. Additionally, the study uncovers the varied decision-making patterns across Indonesian ethnic communities. While most communities follow a patriarchal system some, like the Minang tribe, adhere to a matrilineal pattern. Cultural values heavily influence perceptions and behaviors in areas like family care.[33] Similarly, the ethnic Lampung, Indonesia community reflects cultural diversity, comprising various ethnic groups, each upholding distinct cultural values that inform perceptions, attitudes, and behaviors in daily life, both individually and collectively. Notably, Lampung women exhibit profound respect towards men, often refraining from contradicting their husbands' words and diligently attending to childcare and household chores. Fear of being perceived as disobedient if they deviate from their husbands' instructions is deeply ingrained within these women. In the public sphere, decision-making is predominantly dominated by men, and women seldom participate in public affairs. This observation is a consequence of the interplay between the kinship system and the prevalence of patriarchal ideology within Lampung society.[29]

The second theme, "pain and chronic sorrow," delves into the profound and enduring hardships faced by families providing home-based palliative care. Chronic pain presents a formidable challenge, encompassing not only the fear of potential complications or emergencies that may arise without immediate professional help but also the relentless impact on daily life. Participants reported unpreparedness and negative emotional responses when faced with the prospect of home care, highlighting the necessity of adequate discharge planning and preparation. Another study[11] indicates that the main causes of family unreadiness for home-based care include difficulties in hospital readmission for patients in deteriorating conditions, exhaustion from providing daily care at home, and concerns about the well-being of other family members, particularly children, as the majority of energy is directed towards the severely ill patient. Additionally, caregiver burden within the family is identified as a major reason why families are reluctant to provide care at home.[34]

According to a study,[35] when families are unprepared to serve as caregivers, they may experience fear and a sense of incompetence in providing palliative care for cancer patients at home.

Table 1. Demographic characteristics of the participants.

Participant	Gender	Age (years old	Length of time suffering cancer	Education	Relation to patient	Occupation	Patient's diagnosis
P1	Female	36	1 year	University	Daughter	Housewife	Stage IV liver cancer
P2	Male	30	2 year	University	Son	College Student	Stage IV skin cancer
P3	Female	42	2 year	High school	Daughter	Housewife	Stage IV breast cancer
P4	Male	54	1 year	Primary school	Husband	Cleaner	Stage IV breast cancer
P5	Female	32	2 year	University	Daughter	Employee	Stage IV lung cancer
P6	Male	46	2 year	University	Husband	Online Driver	Stage IV breast cancer
P7	Female	57	1 year	Primary school	Wife	Housewife	SOL (Space of Lesion) stage III
P8	Male	25	2 tahun	University	Son	IT Operator	Pancreatic cancer stage III
P9	Female	48	1 tahun	High school	Wife	Housewife	Bone cancer stage III
P10	Female	25	2 tahun	University	Daughter	Voluntary worker	Stage IV lung cancer

Table 2. (Sub)themes emerging from the analyzes regarding family perceived in depending on a caring patient with palliative cancer in a hospital.

No	Themes	Sub-themes	Elements
1	Lack of support in the decision-making	Lack of understanding in the palliative condition Provide information earlier	Limited time
		Lack of understanding in the goal of care Misinterpretation of the purpose of palliative care	Forming unreadiness for the worst
		Lack of knowledge of caring patient in home Need for ongoing education and support Inadequate communication	Lack of skills
		Lack of resources to support home-based care Opioid needs for patient	Health facilitation
2	Pain and chronic sorrow	Chronic pain Impact on daily life Long-term pain Difficulty in managing	Fear of potential complications or emergencies
		Chronic sorrow Emotional distress and sadness	Risks or uncertainties

Additionally, another study[36] suggests that a family's lack of readiness can lead to negative emotions and attitudes towards home-based palliative care, resulting in resistance to bringing the patient home. Families who are unprepared and still choose home treatment are at a higher risk of experiencing traumatic situations during the care process. Some families may make uninformed decisions about home-based palliative care without fully understanding the implications involved.

However, the findings of this study shed light on the fact that several families exhibited reluctance to have their severely ill family members discharged from the hospital. This resistance stemmed from their significant reliance on the hospital, as they perceived it to possess the capability to cure their loved ones' illnesses. This aligns with the research,[34] which elucidated that the primary reason for patients and families heavily depending on hospital care, even in cases where palliative care had been recommended for terminal patients, was the family's inability to cope with the patient's complaints and distress at home due to the debilitating nature of their condition. Consequently, when health insurance coverage is available to facilitate the ongoing treatment of sick family members in the hospital until recovery, families or caregivers tend to develop a dependency on these health insurance facilities in Indonesia (BPJS), which only cover caring for patients in the hospital, not in patients' houses.

The findings of this study emphasize the importance of providing early education and discharge planning to the families of palliative cancer patients, as stated by six out of ten participants. Early education plays a crucial role in decision-making and preparation for home-based patient care.[37] One participant mentioned that education and discharge planning should ideally occur at least two weeks prior to discharge. Insufficient time for preparation and a lack of resources at home were identified as major concerns influencing the family's decision to opt for home-based palliative cancer care. It is essential to provide early education and discharge planning to both patients and their families. Involving patients in decision-making and treatment planning has positive effects on their well-being, aligning with the concept of a peaceful end of life where dignity and respect are attained through the active involvement of patients and families in decision-making processes.[16,17,35]

In developed countries, the challenge of limited access to palliative care at home for families is effectively addressed through the establishment of Specialist Palliative Care (SPC) services, which are strongly supported by the World Health Organization. SPC consists of a multidisciplinary team of healthcare providers, including physicians, experienced nurses, psychologists, and social workers, who work both within hospitals as a consulting team and in the community to deliver home care, nursing home support, and hospice services.[36] The implementation of SPC in the United States over the past decade has led to a significant increase in the demand for palliative care, with a fivefold rise from 15% to 75%. As a result, families are more inclined to choose home-based palliative care instead of prolonged hospitalization, and SPC plays a pivotal role in facilitating such decision-making processes. The primary focus of SPC is to enhance the quality of life for patients, with a particular emphasis on alleviating pain in individuals with life-threatening cancer.[38,39]

SPC starts working early, as a patient is admitted to the hospital. Cancer patients with palliative conditions will be referred to the SPC. SPC will carry out discussions with the family about the palliative treatment plan. Following the patient's readiness and autonomy, palliative cancer patient care will be moved from the hospital to the community, as chosen by the patients. SPC has shown impacts on improving the patient's quality of life, reducing the stress of the patient and family, lowering aggressive medical treatment, and hence hospital costs, and even increasing patient life expectancy.[40] The United Kingdom (UK) serves as a successful example of the well-developed Specialist Palliative Care (SPC) system that has significantly improved access to high-quality palliative care services. By 2005, the UK had established 361 hospitals offering SPC, along with 277 community palliative care nurses. Additionally, they implemented 263 hospice day care units and provided 24-hour hospice home care for cancer patients. The UK's National Health Service (NHS) plays a crucial role in policy-making, coordination, and providing opioids for palliative cancer patients. Furthermore, the NHS subsidizes 32% of the operational costs for palliative care provided by private healthcare providers.[41] These services demonstrate the effectiveness of early involvement in palliative care planning and the benefits of home-based care options.

The Indonesian government has the opportunity to learn from and adopt the integrated palliative care service model implemented in developed countries. By implementing integrated palliative care, the identified issues highlighted in this study can be effectively addressed. It is crucial to ensure access to opioid medications for palliative cancer patients. Within the integrated palliative care system, nurses play a vital role as coordinators of services such as home care, nursing home, and hospice, involving a multidisciplinary team of healthcare providers including physicians, pharmacists, mental health workers, and therapists. One important aspect that nurses must assess is the family's capacity and preparedness to provide daily palliative care at home.[42] However, the national healthcare insurance (BPJS) does not currently cover home care or visits, an area ripe for improvement.[34] Finally, the study resonates with findings[25] on the psychological and social impact of cancer diagnoses, emphasizing the need for holistic care that addresses not only the physical but also emotional and social needs of patients and their families. The psychological burden, in turn, influenced various aspects of patients' social lives. The participants' expressions regarding the second theme are consistent with the observations of others,[43] who emphasized that rapid changes occur in patients with chronic diseases, including cancer, which subsequently impact their social dynamics. This study is subject to several limitations. Firstly, participant recruitment was confined to three cancer hospitals in Jakarta, Indonesia. While the research methodology was thorough and well-documented, the extent to which these findings can be extrapolated to the broader Indonesian context remains uncertain. Additionally, the absence of internal mentors in the participant pool is notable; their inclusion might have offered diverse insights into the subject matter. Future research should, therefore, consider broadening the participant base to enhance the robustness and applicability of the findings. Lastly, it is important to acknowledge that during the data collection phase, some of the interviewers had professional relationships with a few of the participants. This could potentially have influenced the communication dynamics and affected the interpretation of the data.

Conclusions

The experience of family decision-making for home-based palliative cancer care can be described in two themes: i) lack of support in decision-making, and ii) pain and chronic sorrow. The decision-making process regarding palliative care is a significant and meaningful experience for the family members involved, particularly when caring for patients with palliative cancer towards the end of life. To facilitate effective decision-making and the provision of care at home, families need comprehensive support from both healthcare professionals and government policymakers. It is imperative to deliver early education and detailed information to empower families, enabling them to make well-informed choices and adequately prepare for the complexities of home-based palliative care. Moreover, the Indonesian national health insurance system must be structured to offer inclusive support for home-based palliative cancer care, with a focus on optimizing the efficiency and effectiveness of care for patients requiring such services.

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