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Family Perceptions of Palliative Care for Advanced-Stage Cancer Patients at Home

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Abstract

Family assistance with palliative care for advanced cancer patients is very important in optimizing patients' quality of life. The purpose of this study was to explore family perceptions of palliative service provision to advanced cancer patients at home. The study adopted a qualitative research design with a phenomenological approach based on in-depth interviews with six participants. The main theme that emerged was family perceptions of participation in palliative care programs for cancer patients at home. There were three subthemes: family administering additional treatment, the patient being resigned to and accepting their condition, and the patient being helped by treatment. The families' perceptions of caring for cancer patients at home were positive, and the patients demonstrated adaptive coping in dealing with their diseases. Family assistance to advanced cancer patients requires support from health workers as well as palliative cadres in the form of training on how to treat cancer patients and be good companions, as this can improve patients' quality of life.

Keywords: cancer, family perception, palliative care

Abstrak

Persepsi Keluarga dalam Memberikan Pelayanan Paliatif untuk Pasien Kanker Stadium Lanjut di Rumah. *Pendampingan keluarga pada perawatan paliatif pasien kanker stadium lanjut sangat penting untuk meningkatkan kualitas hidup pasien. Tujuan penelitian ini adalah mengeksplorasi persepsi keluarga dalam memberikan pelayanan paliatif pada pasien kanker di rumah. Penelitian ini mengunakan desain kualitatif dengan model pendekatan fenomenologi. Teknik pengumpulan data dilakukan dengan wawancara mendalam terhadap enam partisipan. Pada penelitian ini ditemukan satu tema yaitu persepsi keluarga yang berpartisipasi dalam program perawatan paliatif bagi pasien kanker di rumah. Terdapat tiga subtema, yaitu keluarga melakukan pengobatan tambahan, pasien pasrah dan ikhlas dengan kondisinya, dan pasien terbantu dengan pengobatan. Hasil penelitian menunjukan bahwa persepsi keluarga dalam merawat pasien kanker di rumah adalah positif dan pasien memiliki koping yang adaptif dalam menghadapi penyakitnya. Pendampingan keluarga kepada pasien kanker stadium lanjut memerlukan dukungan dari tenaga kesehatan dan kader paliatif melalui pelatihan yang berfokus pada cara merawat pasien kanker untuk menjadi pendamping pasien kanker yang baik guna meningkatkan kualitas hidup pasien.*

Kata Kunci: *kanker, pelayanan paliatif, persepsi keluarga*

Introduction

Palliative care is a service provided to improve patients' physical, psychologically, and spiritual quality of life. Care for critically ill patients in the form of specialist palliative care is a crucial part of this provision. However, specialist palliative care is not uniformly available (Koerner et al., 2021). The degree of complexity of the treatment situation is determined by the intensity of the patient's experiences and interactions and the psychosocial or ethical issues that affect their care (Lehmann et al., 2021).

This study was conducted to identify how families perceive care provision for advanced cancer patients at home. This inquiry is important because it could make it easier for health workers to administer treatment. How the family and the patient they are caring for perceive treatment impacts the problems experienced by the patient. Thus, it is important to know the needs of each patient and family to improve the quality of life of, in this case, cancer patients.

Professionals in the field of cancer care must understand global epidemiological differences and their impact on palliative care, integrate palliative care into the cancer care arena, provide cancer-specific palliative education from the beginning to the end of life, advocate for poor and developing countries, which often suffer from a lack of resources and services, and understand relevant cultural and religious differences to provide holistic, sensitive cancer-related palliative care (Brant & Silbermann, 2021). The public has poor knowledge of palliative care focused on terminal illnesses (Mallon et al., 2021). Palliative care is one of the services offered to advanced-stage cancer patients by medical personnel in hospitals, but the COVID-19 pandemic showed that it is important to be able to offer palliative care at home as well.

Basic health research has shown that cancer kills more people than all but six other diseases (Ministry of Health, Republic of Indonesia, 2018). Cervical, breast, lung, and liver cancer are the most common types of cancer (Ministry of health, Republic of Indonesia, 2018). Indonesia has a high prevalence of cancer, increasing from 1.4 per 1,000 people in 2008–2013 to 1.79 per 1,000 in 2013–2018 (Ministry of health, Republic of Indonesia, 2018). Amid the increasing number of cancer patients and the budget deficits faced by the Social Security Health Agency (*Badan Penyelenggara Jaminan Sosial Kesehatan*) in recent years, palliative care provision for cancer patients at home is a model worth considering to complement hospital care (Ministry of health, Republic of Indonesia, 2018). One important step in this direction is to educate the community about how important caring for cancer patients at home is and to prepare facilities and medical personnel to support this care.

According to Schoenmaekers et al. (2020), the COVID-19 pandemic caused a massive shift in healthcare distribution. The high number of patients requiring hospitalization and intensive care unit treatment meant that nurses were often transferred to COVID-19 treatment rooms, which had the potential to endanger the care of other patients, such as oncology patients. Cancer patients and those with comorbidities are at high risk of developing COVID-19-related morbidity and mortality. A lung cancer survivor—Megawati Tanto, who is 74 years old—articulated the psychological struggles of cancer patients during the COVID-19 pandemic, including denial or disregarding their disease, being a shut-in, withdrawal, anger, depression, and fear of cancer, plus fear of being infected with COVID-19; patients were also sad, worried, and afraid of death (Al Ansori, 2020).

The data collection for this research was carried out during COVID-19. The researchers wanted to know how families felt about caring for family members who had advanced cancer because, during the pandemic, there were many obstacles to such care. Families who took patients to the hospital were often afraid of being infected with COVID-19, and economic problems were another tough challenge (Dasat et al., 2022), especially when the patient was referred out of town. Incomes decrease when patients cannot work. Cancer patients are often stigmatized negatively by society, as if they were cursed; this can make patients feel inferior and make others unwilling to associate with them. Another stigma is that cancer invariably leads to death.

The purpose of this study was to explore family perceptions of participation in palliative care programs for cancer patients at home. In January 2021, we conducted interviews with the manager of the Indonesian Cancer Foundation (ICF) in the Jakarta area, Stefanus Maman Hermawan. He said that cancer patients during the COVID-19 pandemic were still being cared for through palliative cadres that worked in subdistrict health centers spread throughout Jakarta.

Assistance for patients and families was mostly delivered online due to the fear of transmitting COVID-19. During further interviews with four families that included cancer patients in the Kedoya and Kembangan areas of West Jakarta in January 2021, they said that, during the COVID-19 pandemic, the ICF in the Jakarta area provided support, especially through palliative cadres.

A common problem faced by families was the fear of patients and families being infected with COVID-19, both when visiting the hospital and at home. Thus, if it was not too much of a burden, they provided their own care for patients in accordance with what they had learned from palliative cadres and health workers.

Methods

This study adopted a qualitative research design with a phenomenological approach based on in-depth interviews. The sample for data collection was selected through snowball sampling. Interviews were held with six participants who met the criteria, which included being willing to be a respondent, having a family member with cancer who was undergoing outpatient treatment, being involved in at least two years of treatment, and having lived in DKI Jakarta for at least two years. The researcher conducted home visits to conduct the interviews. The researcher used only six respondents because the data reached saturation at this point.

The data were analyzed using the application NVivo 11 Plus. The thematic categories that researchers analyze during the coding process are stored in nodes, so nodes play a very important role in qualitative data management and analysis when NVivo is used.

According to Jackson and Bazeley (2019), nodes are “containers” in which researchers store themes, participant information, research settings, and relevant research organization data. By examining nodes created based on categories and subcategories of analysis units, researchers can understand the relationships between each theme and/or the concepts generated based on the data. Node creation can be carried out deductively or inductively. Deductive nodes are created based on literature reviews or theoretical concepts, while inductive nodes are createed based on field data without being tied to themes resulting from literature studies.

This research was conducted in May 2021 in the Jakarta area of Indonesia—specifically, in the Cengkareng area of West Jakarta. The study received approval from the relevant ethics committee of the University of Muhammadiyah Jakarta under number 0859/F.9-UMJ/VII/2021.

Results

The research was carried out using interview guideline instruments prepared by the researcher. The participants were family members of patients with advanced cancer, namely husbands, biological mothers, and siblings, with an age range of 35–60 years (Table 1).

The results showed that the four families coping with cancer, including six facing advanced cancer and one family with an early-stage cancer patient, had different experiences with palliative care administration. Among those with cancer patients in the advanced stages, the situation was very emotional, while the families who had a member with early-stage cancer felt calmer. The main theme that emerged was the perception of participating in a palliative care program for a cancer patient at home. Three subthemes emerged: the family providing additional treatment, the patient being resigned to and honest about their condition, and the patient being helped by the treatment (Figure 1).

Subtheme 1: Providing Additional Treatment. Some patients’ families were trying to find alternative treatments other than what they had received in the hospital to improve the patient’s health and even help them recover. On the theme of administering additional treatment, Mr. C revealed the following:

Table 1. Characteristics of the Participants and The Patients They were Treating

Participants					Patients			Participant–patient relationship
Name	Gender	Age	Job	Education	Gender	Age	Disease	
Mrs. A	Female	35 years	Housewife	High school	Female	40 years	Breast cancer	Younger Sibling
Mrs. B	Female	38 years	Housewife	High school	Male	18 years	Leukimia	Biological Mother
Mr. C	Male	56 years	Private Employee	High school	Female	52 years	Breast cancer	Husband
Mr. D	Male	60 years	Laborer	Junior high school	Female	55 years	Breast cancer	Husband
Mr. E	Male	57 years	Merchant	High school	Female	41 years	Cervical cancer	Husband
Mr. F	Male	56 years	Laborer	Junior high school	Female	46 years	Cervical cancer	Husband

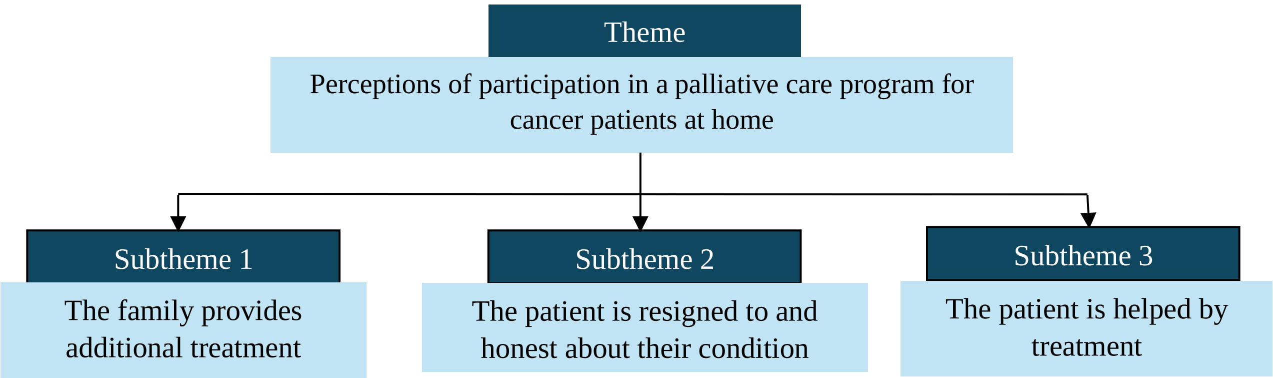

Figure 1. Themes and Subthemes Discovered in This Study

> *"This cancer, in my opinion, must not only be treated medically but also very well through herbal treatment, so that, in addition to the management in the hospital that has been used as a reference, I routinely do alternative medicine in the Kembangan area. And she thinks this is very good, because after doing alternative medicine and following the advice of her father when going to the hospital, the doctor said that the mother's condition is getting better."* (Mr. C)

Subtheme 2: The Patient is Resigned to and Honest About Their Condition. Terminal-stage illness is a condition in which a person has an illness with no hope of recovery or is very close to death. In this condition, the best thing a patient can do is to be honest about their condition. On the theme of patients surrendering to and being honest about their condition, participants (Mr. C, Mr. E, and Mr. F) offered the following reflections:

> *"My experience when treating patients is that we must be patient and resigned to leaving everything to Allah SWT. The important thing is that we have tried to treat them and treat them well. I often attend recitations with patients with a cleric in the Kembangan area. Usually, the recitation is done together with others, and we pray for each other, and this is routinely done every week."* (Mr. C)

> *"The family itself has surrendered and is honest about the condition of his wife. The family can only try and be patient—to treat*

> *patients according to their abilities."* (Mr. E)

> *"My wife has resigned herself to her condition. My wife has been ill for seven years and has had surgery. My wife is treated by several doctors and has received treatment in two hospitals, first in the regional general hospital and second in a specialty cancer hospital. I have resigned and am honest that, indeed, my wife can no longer be cured, even if she must be called by the creator, because my wife has suffered for a long time. And the family is also sorry to see my wife suffering from the pain that never heals."* (Mr. F)

Subtheme 3: Patients Are Helped by Treatment. Palliative care benefits patients because it uses an approach that improves the quality of life of patients (both adults and children) and their families, who are facing life-threatening-illness-related problems. On the theme of patients being helped by treatment, three participants, namely Mr. E, Mrs. A, and Mrs. B, offered feedback.

In an interview with Mr. E, he said, "I really feel sorry for my wife." According to him, his wife was suffering greatly, and her hair was falling out. The patient's physical condition was very bad, and she had to be careful not to get too tired. If she was tired, she would faint and suffer heavy bleeding, as happened when she attended her child's wedding. During the pandemic, the family was also afraid of being infected, both his family and his wife, but because of his desire for his wife to recover, Mr. E continued to administer care and treatment as recommended and tried not being afraid of COVID-19. The family itself was resigned and honest about his wife's condition. The family could only try to be patient enough to care for the patient.

> *"The treatment here actually helps patients. But I feel sorry for the patient because she is also a single parent, and her child is still in school. Her ex-husband also helps financially, but the amount is small. For costs, they rely on rent, the proceeds of which are used for daily living expenses, school fees, and medical expenses. But transportation and food need to be provided so that patients do not starve. On homework, when the patient relapsed, I was helped by myself and other families who lived with the patient, namely, her mother and her grown child."* (Mrs. A)

> *"I am sad because my child has suffered from cancer since childhood. My child is active even though she is sick, as if it is not even felt. She is silent a lot when she is sick, not fussy. In the past, when she was in school, she was often sick and relapsed, and then would rest at home healed. Later, when she relapsed at school and was finally taken home by her teacher, the teacher fully understood my child's condition. The important thing is that my child is always healthy, because according to the doctor, her illness will not be cured. At her age, her is not likely to live very long. That makes me very sad, and if I remember what the health workers said, she will definitely get through this."* (Mrs. B)

Discussion

The goal of this study was to make it easier for health workers to provide assistance to families that treat patients with cancer. We also hope to make it easier for families to treat patients and minimize levels of family stress from caring for patients, as well as the patients' stress levels. This could help patients be more accepting of their condition while still complying with treatment. The current section will illuminate the results of the study in accordance with these research objectives and the diagram in Figure 1. We identified three subthemes in the families' experiences with caring for cancer patients undergoing palliative care programs.

Subtheme 1: Providing Additional Treatment. One family member interviewed was trying to find alternative treatments other than what they had been recommended in the hospital for the sake of the health and even recovery of the sick patient. The interview with Mr. C indicated that the patient's companion routinely administered alternative medicine to complement the medical treatment provided by the hospital. The combination of these two treatments can be very helpful for families in caring for patients, as alternative medicine emphasizes herbal medicine and getting closer to Allah SWT.

The patient's family experienced uncertainty, lost, and setbacks when caring for the patient, causing suffering for the family caregiver. This condition makes families desire help and look for alternative solutions to the problem, one of which is alternative treatments (Nemati et al., 2018).

The result of the present research is in line with those of a study conducted by Kurniawan et al. (2021), which also found that families use alternative medicine. On the subject of medical treatment administered by family clients, participants revealed that they were confident in using traditional medicine because of the expensive medical costs and difficult-to-cure patient conditions.

Similar research conducted by Aviyah and Farid (2014) with breast cancer patients in Malaysia found that many use traditional medicine as an alternative to traditional medicine due to recommendations from friends and family, sanctions by family, the perceived benefits and suitability of the treatment, the credibility of traditional medicine therapists, and objections to the Western medical system and its systematic delays.

Some of our participants sought alternative, nonmedical treatment in accordance with the patient's psychological needs in dealing with illness. In the bargaining stage, the family's and patient's minds and feelings are calmer, and the patient can slowly come to accept that they have cancer, which is closely associated with death (Directorate General of Disease Prevention and Control, Republic of Indonesia, 2017).

Transcultural nursing aims to provide care that suits the patient's cultural values and practices. Cultural knowledge plays an important role in dealing with patients, especially in helping to understand and respect cultural diversity in patient care. Knowledge of the patient's culture helps medical personnel think flexibly about the patient's care, even considering spiritual healing practices, such as meditation, or whichever alternative treatment that, according to the family, could have the best psychological and spiritual effect on the patient.

Transcultural nursing emphasizes how a patient's cultural background is linked to their health. It uses that knowledge to develop a nursing plan that will help the patient be healthy and the family and health workers remain sensitive to the patient's culture or beliefs. The psychological treatment of patients in palliative care, including the five stages outlined above, and transcultural nursing theory can thus provide a basis for families to care for patients. Moreover, in caring for patients, families and health workers must pay attention to cultural and spiritual aspects. Each patient will respond differently to their illness. If treatment is felt by the family or patient to be inadequate in meeting their spiritual needs, then alternative treatments can be pursued.

These considerations accord with the claim that, in the bargaining and acceptance stages, the patient and family may begin to look for other treatments before finally surrendering and accepting the patient's condition. According to Lofandjola et al. (2017), factors that have a negative impact on patient care include scarcity and inaccessibility of painkillers, economic insecurity, poor quality of treatment, lack of psychological counseling, searches for alternative solutions, and poor communication between nurses and patients. On the other hand, this research also shows that relatives who care for patients often receive support from extended family and local religious leaders.

Subtheme 2: The Patient is Resigned to and Honest About Their Condition. A terminal-stage illness is a condition in which an ill person has no hope of recovery or is very close to death. In this condition, the best thing a patient can do is to be honest about their condition. On this theme of patients surrendering and being realistic, participants were found (Mr. C, Mr. E, and Mr. F) who suggested that both patients and their companions had submitted to God Almighty in terms of the patient's sick condition while still trying to undergo treatment patiently and sincerely.

According to Kristanti et al. (2019), this submission reflects caregivers' belief that care provision is an important value that motivates strength. The assistance provided is a combination of spiritual and religious values and motivations with care, and it is motivated by contextual factors. This can help patients build good values for themselves by strengthening their spirituality.

According to Nidhi and Basavareddy (2020), 74% (148/200) of caregivers are women (71. 62%). When surveyed, the majority (72.9%) stated that cancer cannot spread from one person to another, and they were positive (70.9%) that cancer can be cured. Caregivers (76.3%) thought that a cancer diagnosis should be conveyed to family members. About 50% of the participants were aware that environmental toxins and tobacco can cause cancer. Although most of them (87.8%) believed that cancer treatment has adverse side effects, they (93.2%) were satisfied with the hospital facilities. Among the quality-of-life parameters, most participants complained of a general deterioration in physical health, difficulty coping with problems, reduced concentration, sadness over the first treatment, illness, and interruptions to household activities. Among the spiritual parameters, the participants expressed sufficient support from religious activities, prayer, and spiritual well-being.

The six participants in this study were Muslims. Islamic religious teachings suggest that one way to solve problems is to be sincere and grateful. Sasongko (2020) noted that humans must be realistic and acknowledge that whatever happens is God's will. This is the first thing we must remember: And in the sight of God are the keys of all that is unseen; no one knows it except He Himself, and He knows what is on land and in the sea, and not a leaf falls but He knows it (also), and not a seed falls in the darkness of the earth, and neither anything wet nor dry, but it is written in a real book (Lauh Mahfuzh) (The Noble Qur'an, Al An'aam, 59).

Second, caregivers and patients must be patient with God's provisions and their effects. Patience does not mean simply surrendering, but rather making an effort. With more time at home, they should increase their prayers—not only the obligatory ones, but also the sunnah prayers. Praying, reciting the Qur'an, reading Islamic books, and discussing religion with family are all helpful. The afflicted must increase their prayers and accompany patience with prayer. Allah SWT says: O you who believe! Ask for help with patience and prayer. Indeed, Allah is with those who are patient (The Noble Qur'an, Al Baqarah, 153). Third, gratitude is crucial. We must be grateful that we are still given the blessings that Allah has granted us, both in health and sickness.

The same is expressed in the Word of Allah SWT: And indeed, We will give trials with fear and hunger, lack of goods, souls and fruits. And give good news to those who are patient, to those who, afflicted by calamity, say, '*innaa lillaahi wainnaa ilaihi rajiuun'* (Behold, we belong to God, and we will return to him) (The Noble Qur'an, Al-Baqarah, 155–156).

This recalls the story of the Prophet Job. Job was a very wealthy man. Job owned livestock, slaves, and land. He was also blessed with a wife and good, good children. But one day, with

God's permission, Satan's flocks destroyed the wealth of the Prophet Job.

The cattle died, and then the fields and gardens became dry, and the burned houses were eaten by fire. In a very short time, the rich prophet Job suddenly became poor, having nothing but his faithful heart, piety, and patient and captive soul. Facing these various tests, there are several attitudes that a believer can assume. First, we must remain confident or optimistic that God's help will come to us.

Second, when faced with a disaster, we should immediately say, *innaa lillaahi wainnaa ilaihi rajiuun* (we belong to God and o him we return). The next important attitude is to rely on God. Tawakal is one of the requirements for someone to receive God's help. There are things we pay attention to when captive. First, do not rely on anyone other than God. If we rely on someone other than God when faced with a problem or calamity, God's help will be further removed from us. Second, in captivity, we must not make efforts whose harms outweigh the benefits—just as in any other part of life.

Finally, we can surrender ourselves completely to God from the beginning to the end of the ordeal. "By surrendering to Allah, we will be calm so that we can accept whatever the results of our efforts are. Therefore, do not be half-hearted in surrendering to Allah." (Sasongko, 2020).

As believers, we must be patient with restraint and spaciousness, and ward off excessive anxiety. We must return everything we experience to Allah the Great and All-Knowing, because patience will always lead to happiness. As Umar bin Al Khattab said, "We can feel pleasure in life when we are able to be patient." Patience is not an attitude that we can easily assume, but it is not impossible to adopt, even if we sometimes must say, "I have exhausted my patience." (Sasongko, 2020).

Relatedly, individuals must be grateful and sincere in living life. Individuals who are grateful for whatever they gain in life and show patience in accepting trials will minimize the stress they experience. Honesty is the final level between gratitude and patience that perfects the individual in positioning themselves to remain equally positioned between reproach and praise from others, which makes the heart calmer.

Research conducted by Ernadewita and Rosdialena (2019) suggests that fosters good mental health. Good mental health is reflected in a person's daily attitudes and actions, such as being able to control themselves, accepting the realities of life, thinking calmly and carefully, being firm and not easily giving up, remaining calm, not feeling inferior, not being in a hurry, being sincere, and controlling their emotions.

Subtheme 3: Patients Are Helped by Treatment. Palliative care benefits patients because it uses an approach that improves their quality of life and that of their families, who are coping with life-threatening-illness-related problems. The interviews above show that when a disease has been declared terminal, patients and families still try to adhere to the treatments provided by the hospital and hope for a cure.

The Ministry of Health, Republic of Indonesia (2016) states that humans are biological, psychological, social, cultural, and spiritual creatures. These needs must be met so that the quality-of-life increases. Changes in patient behavior are a heavy mental burden on families, and often, patients' families suffer both physically and psychologically. Family fatigue and boredom stemming from caring for patients can be treated with the assistance of palliative care cadres.

In Heydari et al. (2019) data analysis, 511 initial codes were extracted, which were categorized into two main categories—home-based palliative care challenges and opportunities—and 10 subcategories. The subcategories for challenges included deficiencies in intersectoral and interprofessional cooperation, lack of infrastructure for end-of-life care, challenges related to mortality management, challenges in moving home, nonacademic palliative care provision, lack of political commitment by the government, and spiritual vacuums. The opportunity category included the subcategories of cost-effectiveness, movement toward health socialization, and health system structures.

Family experiences with caring for breast cancer patients are influenced by culture, beliefs, social norms, traditional practices, and religion. The most positive emotion that a family can feel is togetherness, and the most negative feeling is that caring for patients is a burden (Rochmawati & Wiechula, 2023). In addition, family companions must understand the patient's condition according to the condition for which they are being treated. Caregivers' priorities in assisting patients who are about to pass away include meeting the needs of the patients, understanding and embracing their culture, and providing quality palliative and end-of-life care services (Kemathad & Tatiyaworawattanakul, 2023). This is reflected in the results of a study that revealed a relationship between fatigue and quality of life in colorectal cancer patients ($p < 0.05$), as well as a relationship between depression and quality of life ($p < 0.05$). Depression was the factor most closely related to quality of life ($p < 0.05$) (Nuridah et al., 2019).

The limitations of this study include the researcher no longer being in contact with the respondents, as well as the use of masks during interviews, which prevented participants from being able to share their experiences in detail. However, this was necessary because the interviews were conducted during the COVID-19 pandemic.

Conclusion

This study exmained the general theme of participation in a palliative care program for cancer patients at home. Three subthemes emerged: the family administering additional treatment, the patient being resigned to and honest about their condition, and the patient being helped by treatment. The perceptions of the family in caring for cancer patients at home were positive, and the patients demonstrated adaptive coping. This attitude needs to be supported by health workers to maintain a positive outlook. Training can help family members provide assistance to sick individuals so they can be good companions. If it is administered correctly, family assistance provided to patients can improve the patients' quality of life, which has a positive impact on the family and the patient themselves. The goal should be to meet all of the patient's needs, whether they are physical, social, spiritual, or psychological.

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