

FAMILY EXPERIENCE IN PROVIDING PALLIATIVE CARE FOR ADVANCED CANCER PATIENTS AT HOME**^{1,*} Mariam Dasat, ²Sigit Mulyono, ²Uswatul Khasanah and ³Dian Angraini**^{1,3}Krida Wacana Christian University, Indonesia²University of Indonesia, Indonesia²University of Muhammadiyah Jakarta, IndonesiaReceived 24th July 2024; Accepted 20th August 2024; Published online 30th September 2024

Abstract

Introduction: The survey conducted by WHO in 2019 found 194 countries, palliative care funding is available in 68% of countries and only 40% of countries where palliative care costs are affordable. Family assistance in palliative care for advanced cancer patients is very important to improve the quality of life of patients. The purpose of this study was to explore the experience of families in providing palliative services to advanced cancer patients at home. **Methods:** The method in this study is a qualitative research design with a phenomenological approach model with data collection techniques with in-depth interviews (In Depth Interview) of six participants and snow ball sampling data collection methods. **Result:** Two themes were found from the family's experience of undergoing a palliative service program for advanced cancer patients, namely the patient is aware of his condition and the family is worried and sad about the patient's condition. The palliative care program that families do to patients at home is a very valuable experience for families as patient companions. **Conclusion:** The family feels sad about the patient's condition but the family must also sincerely accept one of the family members experiencing a sick condition, because the patient is also aware of the condition experienced, so it needs a qualified patient companion role in caring for patients

Keywords: Family, Palliative care, Advanced cancer.**INTRODUCTION**

Patients with complex conditions require special treatment from the palliative care team from health workers. (Koerner *et al.*, 2021) Pendekatan perawatan paliatif lebih mengutamakan kemanusiaan. Tujuan perawatan paliatif memprioritaskan kualitas hidup pasien dengan pendekatan kenyamanan fisik, emosional dan spiritual (Kurniawan *et al.*, 2023). The community has poor knowledge about palliative care, so it takes an understanding of palliative care for the community so that the community is able to understand good care about palliative care. (Mallon *et al.*, 2021). Palliative care is given according to the level of complexity of each individual who experiences masalah. Whether it is a physical, psychosocial, spiritual or ethical problem of the patient himself. (Knobloch *et al.*, 2021) One of the health problems that must be addressed with palliative care is cancer. Indonesian Basic Health Research (2018) also shows that cancer is ranked seventh in diseases that can cause death. Cervical cancer, breast cancer, lung cancer, and liver cancer. The prevalence of cancer in Indonesia is increasing: from 1.4 per 1000 population in 2008-2013 to 1.79 per 1000 population. from 2013 to 2018 (Riset Dinas Kesehatan, 2018). In the midst of the increasing number of cancer patients and the budget deficit of BPJS Kesehatan in recent years, palliative care for cancer patients at home is a step that deserves to be used as a model in addition to hospital treatment. Steps in that direction can begin with socialization to the public about the importance of treating cancer patients at home and preparing facilities and medical personnel to support these treatments. The Covid-19 pandemic caused a massive shift in healthcare distribution the high number of patients requiring hospitalization and intensive care unit treatment, nurses are often transferred to the Covid-19 treatment room,

this has the potential to jeopardize the care of other patients, such as oncology patients. Cancer patients and those with co morbidities are at high risk of developing Covid-19-related morbidity and mortality. This occurs in lung cancer patients, with a mortality rate of 25-55% (3-6). Palliative care can improve a patient's quality of life, mood, and survival. During the Covid-19 pandemic, palliative care of patients is threatened both physically, psychologically, socially, and spiritually (Schoenmaekers *et al.*, 2020). Obstacles in implementing palliative care include a lack of awareness among policymakers, health workers and the public. In addition, cultural and social barriers, such as beliefs about death and misconceptions about palliative care (Fuanida & Natalia, 2020). According to The role of family-caregivers of patients with advanced cancer is very complex and varied in providing texts related to symptoms at home; It often requires family caregivers to have diverse knowledge and skills in managing various cancer-related symptoms. Healthcare professionals can support family caregivers by anticipating needs, tailoring evidence-based information to those needs, and ensuring family caregivers have the right point of contact for advice or help. The results of an interview conducted with the management of the Indonesian Cancer Foundation in the Jakarta region in January 2021 said that cancer patients during the Covid-19 pandemic are still fostered through palliative cadres who work in sub-district health centers spread throughout Jakarta. Assistance to patients and their families and families is carried out more online because they are worried about being infected with Covid-19. Patients and families assisted by YKI are outpatients with varying types of cancer with an unknown exact number. During interviews conducted on four families who have patients with cancer in the Kedoya area of West Jakarta and Kembangan West Jakarta in January 2021, they said that during the Covid-19 pandemic the support of YKI in the Jakarta region, especially through palliative cadres assisted by YKI in the Jakarta region, YKI

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still fully supports the treatment provided both online and in person, to help families in caring for cancer patients to continue to undergo treatment at home and routine treatment at hospitals that have become referrals for treatment. Likewise, the medical personnel in the hospital are very cooperative in providing care and treatment.

The obstacles experienced are almost non-existent, there are only a few medicines that are not paid by YKI which are quite expensive, but from the Jakarta Regional Government itself, all medicines are free. The thing that is a family problem is the fear of patients and families being infected with Covid-19 both when visiting the hospital and at home, so that if it is not too important they take care of the patient themselves according to what has been taught by palliative cadres and health workers. If there are things that are not understood, they can communicate through whatsapp or call directly.

The results of the interviews also showed that from the four families who experienced cancer, 3 of them were cancer with advanced stage cancer and one family that had cancer patients with early stages, there was a difference in experience in caring for the family, where in the advanced stage, it was seen that the family was more emotionally disturbed by family experience of three years or more compared to families who had family members with early-stage cancer who were calmer and had good experience in caring for the family. In just a matter of months, the patient's condition was also still able to carry out daily activities. The family will be responsible for caring for the patient's suffering (Review, 2023).

The same thing was revealed in other studies that the importance of the role of family in caring for cancer patients is such as meeting daily needs (Kurniawan, 2021). Another role needed is that the family must care for the patient, provide motivation and support during treatment and the family must also be able to overcome if there is a conflict of roles (Najjuka *et al.*, 2023).

Families in carrying out their duties as patient companions require physical and mental readiness (Saun & Rochmawati, 2020). Families must also be equipped with nutrition for patients, the ability to make decisions and be able to manage stress both for themselves and for patients (Yang *et al.*, 2023).

The family's experience in caring for patients is influenced by several factors, namely socio-demographic factors, health systems, public health, politics and socio-culture Patients need support from various sources, especially the nuclear family, extended family and other social support (Utami & Sutantri, 2022)

Seeing the above phenomenon, researchers are interested in digging deeper into the family's experience in undergoing palliative care programs at home. Caregivers will have their own values and satisfaction when caring for patients together with nurses at home. Caregivers take care of useful people when they can fulfill the wishes of family members to care for patients at home. Patient companions will feel satisfied and happy if they can take good care of the patient at home, They will be useful if they can meet the needs of the patient (Johannesen *et al.*, 2023).

Seeing the above phenomenon, researchers are interested in digging deeper into the family's experience in undergoing

palliative care programs at home. Where this study differs from other studies is that the main companion who accompanies patients in treating patients is the patient's family itself, which is carried out at home with the patient's condition in the outpatient period.

MATERIALS AND METHODS

The method in this study is a qualitative research design with a phenomenological approach model with in-depth interview data collection techniques for six participants and a snow ball sampling data collection method. Data analysis techniques using the Nvivo 11 plus application. The study was conducted in May 2021 on six participants living in the Jakarta area of Indonesia. Participants are families who have family members suffering from advanced cancer who are undergoing outpatient treatment with an age range of 35 – 60 years and a duration of treatment of 3 to 10 years.

RESULTS

The following will describe the results of the research on family experiences in caring for cancer patients who are undergoing an advanced cancer palliative program. **Theme 1** (Patients are aware of their condition). One of the factors that affect the effectiveness of palliative care is the awareness of patients with their condition suffering from terminal diseases. On the theme of the patient being aware of his condition, three participants were found that stated, namely Mr. C, Mr. F and Mrs. B.

The following is an interview with Mr. C. According to Mr. C, his wife also understands more about her condition, what can be done and what is not allowed, such as food and drinks that are recommended and prohibited and it is all regulated by the patient.

The following is an interview with Mr. F. Mrs. F herself obeyed her advice and health workers, she ate and drank only what was allowed and did not eat and drink that should not be consumed such as offal, flavorings and fried or burned food was no longer consumed by.

The following is an interview with Mrs. B. if she is tired, she herself immediately says that her condition is not healthy, usually what her child feels is fever, vomiting and weakness and immediately rests, if it does not go down, the fever is immediately taken to the hospital and usually the patient himself invites the family to take him for treatment. Patients are often given intravenous fluids and red blood cell transfusions.

The results of the interview showed that awareness of the patient's condition would make the patient able to do activities according to his portions and change his daily consumption pattern so that he could live a better life. Awareness of the patient's condition is also needed to immediately seek treatment at the hospital in order to get help when experiencing symptoms of illness.

Theme 2 (Sad and worried about seeing the patient's condition). The family as a companion to the patient in carrying out the palliative care program generally feels sad and worried about the patient's condition. On the theme of sadness and concern about the patient's condition, six participants were

found who revealed, namely Mr. C, Mr. D, Mr. E, Mr. F, Mrs. A and Mrs. B.

The following is an interview with Mr. C. The family also feels sad until when the patient's condition is like this. The following is an interview with Mr. D. My experience of caring for cancer patients is sad, worried.

The following is an interview with Mr. E. Mr. E said that he was sad, worried about seeing his wife's condition, Mr. E also felt dizzy, because in addition to having to earn a living, he also had to help his wife do housework. The following is an interview with Mr. F. Mr. F said he was sad to see his wife's condition.

The following is an interview with Mrs. A. My experience of treating cancer patients is sad and worried about the patient's condition, if it is recurring, the patient feels sick and screams because he endures extraordinary pain, his body is weak, he has no energy, his face is pale, he has diarrhea and feels like he wants to die after chemotherapy. I was very sorry to see him, sad and stressed to see the patient until he cried, and I also became crying.

The following is an interview with Mrs. B. My experience of caring for cancer patients is very sad and worried about the patient's condition, if it is recurring, the patient immediately goes limp and I recommend resting, he should not be cape, his child likes to play with his friends,

The results of the interviews showed that the patient's companions all felt sad, and concerned about the patient's condition even to the point of crying and stress because they witnessed and listened to the patient's complaints when the symptoms of pain came and when doing chemotherapy.

DISCUSSION

The following will describe the discussion of family experience research in caring for cancer patients who are undergoing advanced cancer palliative programs. Theme 1 (Patients are aware of their condition). Three participants were found that stated, namely Mr. C, Mr. F and Mrs. B. The role of the family is increasing in patients who are outpatient. This affects the health of the family, especially if the patient in the family has experienced the aging process (Ferrell *et al.*, 2019). There are some patients who are aware of their condition, which is certainly a positive thing for the family, because it will be easier for the family to take care of the patient (Arisanti *et al.*, 2019). Patients and families must be motivated to use good coping, because the use of good coping will improve the health of the family and the patient himself (Aydogan *et al.*, 2016). Patients who receive support from their families will reduce their stress levels. The support provided such as social support feels cared for, loved, and valued and shares the burden, increases confidence and fosters good expectations for patients (Watson *et al.*, 2018). The same thing was stated by the Directorate of Infection Control and Prevention (2016) that in patients who are aware of their condition, their families are required to be able to know the course of the disease from the early stages to the advanced stages and the process towards death. The palliative approach is holistic in nature, including physical, psychological, social and spiritual symptoms. Physical symptoms such as pain, cough, shortness of breath, fatigue, fever and others. Psychological symptoms, such as

worry, fear, sadness, anger. Social symptoms are family needs, food issues, work, housing and interpersonal relationships. Spiritual symptoms are questions about the meaning of life and death. It can be concluded that patients who have high self-awareness will easily receive advice and advice given by their families and health workers, thereby accelerating the patient's recovery and improving the patient's quality of life. Patients who are aware of their condition must continue to be motivated and assisted in fulfilling the physical, psychological, social, cultural and spiritual needs that the family gives to patients so that their quality of life improves.

Theme 2 (Sad and worried about seeing the patient's condition). Six participants were found who revealed, namely Mr. C, Mr. D, Mr. E, Mr. F, Mrs. A and Mrs. B., The six participants interviewed with different spiritual backgrounds and disease conditions, as well as different social statuses will have different mindsets. Families who treat patients in terminal conditions and are sentenced not to recover will have deep feelings of sadness, because they are undergoing chemotherapy treatment with chemotherapy effects such as extreme pain and hair loss as well as weight that is getting thinner and thinner and their condition is very weak even until bleeding and fainting in the patient. The conclusion of the theme of sadness and family worry is caused by two factors, namely because of the patient's condition and because the patient also has to do his homework and work. The same was revealed in another study that the experience of family caregivers in caring for patients affected the patient's mental, dependency and emotional instability. Caregivers will experience a bad psychological condition because they are worried about the patient's condition (Bahrami & Nasiri, 2024). Families have a sense of empathy for the patient's condition, including psychological responses that the researcher found from the participants, including panic, fear, disappointment, confusion, and sadness in dealing with the patient's condition. (Dwijayanti, 2015)

The statement of some of the above studies is supported by the statement of the Directorate of Infection Prevention and Control that caring families will experience psychosocial disorders that arise such as anxiety, depression, behavior changes, adjustment disorders with various accompanying complaints, to severe mental disorders. This is not easy to evaluate, especially in families. Familial psychosocial disorders are sourced from the patient's disease condition, personality, life background of the sufferer, family, culture, religion and so on. This is also in accordance with Kubler Rose's statement that every individual when experiencing a psychological disorder will have 5 stages, namely denial, anger, bargaining, depression and acceptance (RI, 2017). The thing that the research that researchers are doing today with other people's research is that they are sad, stressed, anxious and worried because they see the patient's condition, the patient has to help with homework while still working. The reason that is different from other researches is that they are also sad because the family in carrying out care is afraid of being wrong in providing care and treatment, the family has to change places of residence, no longer works and feels unfree.

In the family, it was found that they did not change their place of residence and were afraid of making mistakes in carrying out treatment and treatment because the family already had their own house, and all the families who cared had a good relationship with health workers and cancer palliative cadres.

So that when the family is taking care of it, they also get companionship from cancer palliative cadres and health workers. The family felt that they were not free and did not work anymore was not found in this study because the family is the nuclear family of the patient, they are also sincere and patient in caring for the patient and want the patient to recover quickly.

The family also all works even though there are participants whose jobs are not permanent, to meet the family's financial needs receive support from other family members. Another factor that affects the participants' sadness towards the patient's condition in the study conducted by the author is the length of the day of treatment. The average length of time to care for a family is 3 to 10 years. Participants with a treatment time of 6 to 10 years had a greater rate of acceptance with a patient's condition compared to participants who treated for less than 6 years. Based on the results of the assessment, the facilitator must plan a strategy and palliative support next. It is important to be able to assess whether the complaint is still adaptive or descriptive.

This assessment is carried out periodically and the support strategy provided is adjusted to the patient's condition. The family will have a sense of security and comfort when caring for patients influenced by 3 factors, namely internal factors from the family itself, health workers and also from professional organizations, so that to achieve optimal care support is needed from health workers and professional organizations as well as families (Barlund *et al.*, 2021).

The most appropriate strategy to reduce and even cure sadness and anxiety is to return everything to the destiny of Allah SWT which must be accepted patiently and sincerely and try to help the patient to improve his quality of life and also continue to pray for the patient's recovery. This is in accordance with the vision of Ministry of Health of the Republic of Indonesia so that the family spirit remains stable, it is recommended periodically to reflect on the noble original goal of helping others and returning all destiny to the Creator so that the family remains enthusiastic in caring for patients. (Ministry of Health of the Republic of Indonesia, 2017)

Conclusion

The palliative care program carried out by the family to the patient at home is a very valuable experience for the family as a companion to the patient. The family feels sad about the patient's condition, but the family must also sincerely accept that one of the family members is sick.

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Conflict of interest

There was no conflict of interest, before conducting an interview, the researcher asked for the consent of the respondents first. Respondents' data is kept confidential. The

application of ethical principles in this study is to respect dignity and autonomy, as well as autonomy, by filling in informed consent first. Passed the research ethics test by the Ethics Committee with the number 0859//F.9-UMJ/VII/2021.

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