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Family caregivers' experience in providing home-based palliative care: A descriptive phenomenological study

Karolin Adhisty[1*], Mutia Nadra Maulida[1], Siti Sarahdeaz F[2], Zesi Aprilia[3]
[1] Departement of Maternity, Nursing Study Program, Medical Faculty, Universitas Sriwijaya, Palembang, Indonesia
[2] Departement of Physiology, Medical Faculty, Universitas Sriwijaya, Palembang, Indonesia
[3] Departement of Pediatric, Nursing Study Program, Medical Faculty, Universitas Sriwijaya, Palembang, Indonesia

***Corresponding Author:**
Karolin Adhisty
Departement of Maternity, Nursing Study Program, Medical Faculty, Universitas Sriwijaya, Palembang, Indonesia
Email:
karolin.adhisty@fk.unsri.ac.id

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Abstract

Background: Families, as a vital part of palliative care, need to be identified and their roles and functions explored in order to improve patients' quality of life at home following hospitalisation.
Objective: This study aims to identify the current situation regarding patient care at home.
Methods: The method used in this study was a qualitative approach employing a descriptive-phenomenological methodology. informants were selected based on purposive sampling criteria, with a total of nine informants. Interviews were conducted using a semi-structured interview technique, in the Sakatiga Village Health Center.
Results: The results of this study indicate that experiences of caring for palliative care patients vary; families, as a vital part of patient care, must be able to provide care for patients, even though family carers are likely to face various challenges, such as a lack of knowledge regarding care provision. The findings further examine the conditions of care provided at home, including: the assessment of the patient's and family's condition; the patient's complaints regarding their condition; the family's feelings towards the patient's condition; the family's coping mechanisms; dilemmas in meeting the patient's care needs; and medical information required to understand the patient's condition.
Conclusion: The results of this study indicate that families in providing palliative care need a forum to discuss, talk, and express their feelings while providing patient care at home. This is necessary because apart from being an important part of care, families are also required to always be able to carry out their functions optimally.

Background

The role of the family in palliative care has a positive effect on improving the quality of life of patients during their treatment. This involvement can make the family a policy maker if the patient has limitations in making decisions regarding the palliative care method that will be undergone by the patient. Palliative care is not only provided in hospital; rather, it continues at home, where families face various challenges (Isenberg et al., 2021). These challenges arise primarily during the care process and due to a lack of information, which can place an emotional burden on the patient's family (Cruz et al., 2026; Mensah et al., 2026). Palliative care is a treatment given to improve the quality of life of patients and their families from the initial diagnosis or further diagnosis. This treatment not only provides curative care but is also interpreted as providing comprehensive supportive care, namely Psychosocial-Spiritual (Kan et al., 2025; Kantabanlang et al., 2023). The development of palliative care is marked by the increasing need for this service.

Data related to palliative care notes that 56.8 million people worldwide are said to need palliative care in terms of early/basic intervention and advanced palliative care intervention. (World Health Organization, 2020). Interventions that can be given to patients and families can not only be given by the care team in the hospital but should also be continued in the community setting and especially at home (Alizadeh et al., 2024). Palliative care in its development still has several obstacles so that this palliative care is felt to be uneven in all existing sectors, an estimated 56.8 million people, including 25.7 million people in the last year of life need palliative care, but only about 14% of people receive palliative care (WHO, 2020).

The policy of palliative care programs in Indonesia has been legally regulated in the Decree of the Minister of Health of the Republic of Indonesia Nomor HK.01.07/Menkes/2180/2023 About the

Guidelines for the Implementation of Palliative Care Services which contain the decision of the Minister of Health regarding palliative care throughout Indonesia. The decree is an official instruction given to all health care institutions in Indonesia to develop palliative care services. However, in its implementation, many health care institutions optimize the palliative care service program and there are only a few specific hospitals in six major capital cities, namely DKI Jakarta, West Java, DI Yogyakarta, East Java, Bali and South Sulawesi that have implemented this program. (Alfons et al., 2020).

Family in the implementation of palliative care has a very important role because the family can also act as a care giver. Optimization of this role can be given by the family if they have the motivation and are trained in carrying out palliative care. The family has the advantage of a bond that has been established so that patients will find it easier to express their condition, especially during the palliative care period which is very vulnerable to causing psychological disturbances in patients. (Zendrato et al., 2019). Family tasks based on their roles consist of 5 things, namely: recognizing problems, making decisions in patient care, caring for sick family members, modifying the family environment and using health facilities. (Taufik et al., 2022). Support for this family task requires an approach by both related medical personnel and a community approach by Level I service personnel.

Family knowledge of home-based palliative care needs to be identified and trained in the care needed by palliative patients at home, this requires a sustainable and comprehensive approach. The health center service, which is a primary service, is the spearhead of this palliative service, it was recorded that within a period of 1 year there were 10 most common diseases in the Indralaya health center which were dominated by degenerative diseases and complications such as hypertension and diabetes mellitus. The data recorded that in 2021 there were 7629 visits to the Indralaya health center for hypertension per year and 1988 visits for diabetes mellitus. The number of visits in 2022 decreased by 5,013 for visits of hypertension patients and 1,946 for visits of diabetes mellitus patients. The number of visits increased again in 2023 by 7,736 for hypertension patients and 1987 for diabetes mellitus patients. This figure is a trigger that palliative care should include home care, so that patients are still able to socialize and live their lives independently. They also show that home care can be effective if families are able to provide optimal care; this requires good cooperation between healthcare workers and families so that families have a point of contact to ask questions and obtain reliable information about proper care at home (Guan et al., 2026).

The aim of this study was to understand the experiences and roles of families in providing palliative care to patients at home through an in-depth exploration of the families' perceptions, feelings and experiences.

Methods

Study Design

This study used a qualitative research design with a descriptive phenomenological approach. This approach was considered capable of exploring and describing the informants' experiences in qualitative research. This study was conducted and reported in accordance with the Standards for Reporting Qualitative Research (SRQR) to ensure transparency, rigor, and completeness in reporting the qualitative research process.

Participants

The participants in this study were family members of patients registered in the medical records at the Sakatiga Village Health Center. The research sample was selected using a purposive sampling technique based on predetermined inclusion and exclusion criteria. The inclusion criteria were family members of palliative care patients who had been receiving treatment for less than three to six months since diagnosis, were aged over 18 years, were currently caring for or had previously cared for palliative care patients, and were willing to participate as informants in the study.

A total of nine people took part in this study, having met the criteria for maximum diversity and data saturation. The key informants who assisted in this study were health workers who, together with the researchers, carefully identified informants based on inclusion and exclusion criteria as well as the diversity of informant characteristics, including: age, gender, education, family relationships, duration of patient care and the patient's palliative condition. Data saturation was determined when no further new information was obtained from the interviews conducted. A total of 10 informants who met the criteria were contacted in sequence and asked if they were willing to participate. The first nine informants all agreed to take part in this study. Data from the

informants was not collected from the tenth person as data saturation had been reached; consequently, this study involved a total of nine informants.

Data Collection

The data was obtained through in-depth interviews using a semi-structured interview guide with triangulation involving health workers at the Indralaya Community Health Center. This research was conducted at each participant's home for 30–45 minutes, in accordance with the agreed schedule. The interviews were recorded using a digital voice recorder with the participants' consent, and member checking will be carried out as part of the trustworthiness process. Field notes were used by the researcher to add key details to the interview transcripts in order to support the research findings. Interview transcripts made manually to ensure that no part of the conversation gets missed.

Data Analysis

Data analysis based on the steps from Collaizi through the following stages, The researcher conducted in-depth interviews using a semi-structured interview guide, produced interview transcripts and carried out member checking; data reduction was performed by the researcher to establish coding, categories and research themes. The study utilised computer software to assist with data analysis. The themes identified were integrated into a comprehensive description of the role of the family in the care of palliative patients at home. Data triangulation was carried out once the themes had been established to validate the participants' responses.

Trustworthiness

This study employed the principles of credibility, transferability and confirmability; credibility was established through source triangulation, which involved comparing information obtained from participants and village midwives. Transferability is ensured by presenting the participants' characteristics in detail, maximising the variety of factors including age, education, relationship with the patient, duration of support, and the patient's illness. Member checking is also used to ensure dependability and confirmability in this study.

Ethical Consideration

Research ethics number 421-2024 from the ethics committee of RSUP DR. Mohammad Hoesin and the medical Faculty, Sriwijaya University have approved this research. The ethical principles applied in this study included: respect for human dignity by providing explanations and seeking permission through informed consent from the informants; respect for privacy and confidentiality by using initials and not disclosing the informants' names; and respect for fairness and inclusivity by providing transcripts of the interview results once the interview was complete, reconfirming the results of the interview, and not giving preferential treatment to any one informant.

Results

This study involved nine family caregivers who provided home-based care for palliative patients registered at the Sakatiga Village Health Center. The participants varied in age, gender, educational background, relationship with the patient, occupation, duration of care, and the patient's illness. Most participants were female family members who had been directly involved in caring for patients for approximately three to six months. The characteristics of the informants are presented in Table 1.

The research findings identify 10 categories and 5 reseach themes: the assessment of the patient's and family's condition; the patient's complaints regarding their condition; the family's feelings towards the patient's condition; the family's coping mechanisms; dilemmas in meeting the patient's care needs; and medical information required to understand the patient's condition.

The assessment of the patient's and family's condition

Palliative patients are chronic patients who will or have undergone various treatments and care to overcome the symptoms or diseases they feel. Complaints are feelings felt by patients related to their condition. Patients experience this with feelings that continue to change every day, patients sometimes accept their condition but can also feel stress and even deep grief when symptoms cannot be overcome by themselves. Family informants who know the patient's feelings express feelings about, among others:

"Well, it's the gout, you see, the bones—that's the thing. Because of the diabetes, his leg hurts and his knee's stiff, isn't it? So he's got pain in his leg; sometimes it swells up if he keeps it hanging down for too long, like this, or if he sits for too long, like this. There's also sometimes, when it flares up, that intense itching all over the body. Yeah, itching, red spots like that, you know.." (I1)

"It's so painful. There are so many complaints. All sorts of difficulties. The children are out and about, eating and drinking. The bleeding just won't stop. They've tested her, but there's no hope left that the child will survive. There's no hope left that she'll survive.." (I2)

"That's it—the pain in his leg is what he's complaining about. Back then, his mum had this condition—I think it's called spinal stenosis. He'd been taking her to a spine specialist in Palembang for about five years. Well, because he's getting on a bit now, after taking the medication for about a year, he said he was tired of it—or rather, he'd had enough— so he stopped taking the medicine. But, thank God, he can still walk. At first, walking was a bit difficult, but now, he can't walk long distances anymore, though he can manage inside the house—he can get to the bathroom and go out. Age is a factor too." (I5)

"Well, she's weak, isn't she? I mean, she can't move, she has to lie down; she just wants to sleep, that's all she wants. Especially when her blood sugar is too high." (I7)

"As for the pain, well, of course there is. I am ill, after all. So how could I not be in any pain at all? When I was being massaged, it really did hurt. But we're still trying to hope for a full recovery." (I9)

The family's statements regarding the patient's illness were strengthened by triangulation by cadres who also said that the symptoms felt by the patients often caused the patients pain and difficulty in carrying out daily activities.

Table 1. Characteristic of Informant

Informant	Age	Gender	education	Relationship status	Occupation	Patient care period	Patient's illness
I1	40	F	Senior High School	Daughter	Housewife	6 Month	Diabetes; Hypertension
I2	55	F	Senior High School	Wife	Housewife	3 Month	Diabetes
I3	40	F	Undergraduate	Daughter	Housewife	6 Month	Hypertension; Asthma
I4	51	F	Elementary School	Daughter	Housewife	6 Month	Hypertension; Stroke
I5	49	F	Junior High School	Daughter	Housewife	6 Month	Hypertension
I6	31	F	Junior High School	Daughter	Housewife	6 Month	Hypertension
I7	41	F	Elementary School	Daughter	Housewife	6 Month	Diabetes
I8	38	F	Junior High School	Daughter in law	Housewife	6 Month	Hypertension
I9	50	M	Junior High School	Sibling	entrepreneur	6 Month	Hypertension; Stroke

The patient's complaints regarding their condition

The family sees the patient's condition in their daily life with the complaints and pain that the patient has, making the family feel worried, especially regarding the patient's physical and mental condition.

"I do feel a bit sorry for you with that illness of yours; it's a proper old-age ailment, isn't it? Yeah, it's a proper old-age ailment." (I1)

"We were worried back then, almost to the point of despair. But we didn't show it. If we'd shown our worry, it would only have made things worse. We didn't let him see our concern. Besides, he'd lost all

hope, lost all will to live. He'd lost all his will to live. So, even though we were worried, we didn't really know what to do. We didn't really know. We didn't say anything. We didn't show it to him. He'd lost all hope of living." (I2)

"I'm afraid of collapsing—they call it 'going under'—my blood pressure drops, I'm afraid it's serious." (I5)

"Worried he might die, what's the point, he's not fat—that's what happens when there's a duet: you have to treat him while the old man's still alive." (I6)

"It's a right hassle, having to take him all over the place; we don't have a car, so we're at a loss as to who to call, especially in the middle of the night—at one in the morning—it's a real struggle for us to find a motorbike taxi; there aren't any vehicles around at that hour. Just the other night at 1 am, three of us were in agony; he had a stomach ache yesterday, and the pain lasted until midday. So, we took him to Ar-Royyan, but he didn't want to be treated, so we went straight back.." (6)

"Well, I've just accepted it. Yeah, that's right, I've accepted it. He doesn't eat much, he just wants to lie down; he just wants to sleep because he's so lethargic. When his blood sugar rises, that's it. That's just how it is—he can't do much of anything. He just wants to sleep. He wants to work, or go out for a walk, or do whatever he can manage. If he's feeling well, like he is now, then that's fine. But when he's unwell, he just wants to sleep. If his blood sugar gets too high, that's when it happens." (I7)

"When he's having one of his fits, well, never mind, mate; we're just cowering down there, scared stiff. If anyone knocks on the door, it's all over—we won't get a moment's peace." (I8)

The family's feelings towards the patient's condition

Family management in dealing with situations that occur in their families needs to be improved, families as the core part of palliative care certainly have complaints and situations that are sometimes not beneficial for them. This coping mechanism is a description of what is felt by the family in caring for palliative patients.

"Sometimes I get annoyed, mate. I just want to tell him off: 'Sir, you really shouldn't worry so much about your high blood pressure, and you shouldn't have told those kids off like that—it's only natural for their blood pressure to go up a bit." (I1)

"Well, if death comes calling for you soon, I won't be able to do anything about it, but I do pray that you stay healthy. Of course, my dear child, I hope you stay healthy. It's not that you're unwell—we've tried everything we can: we've prayed, taken medicine, seen the doctor, seen the midwife, and tried whatever else we've bought. The main thing is to pray for good health. So, thank God, he's healthy." (I2)

"It's down to age, really, so whenever we pray, we ask for the easiest path for the old man; so, making an effort and praying is what matters as his children." (I5)

"We shouldn't complain about our elderly, should we? Yes, it's harder to look after them." (I7)

"Look after them properly, really. Take care of them properly, as best I can. No need to complain here or there. I mean, don't make a fuss." (I7)

"Make them happy, make them smile. When you're near them, don't let yourself get stressed too. When they roll over, we help them, roll them over. We gently move their arms and legs. Ask if they want medicine, if they want to eat this or that. They're sad, and we end up looking sad too. Of course, that's what he was thinking just now. It must be the same as him. It's fine for now. Later, if he takes a turn for the worse, well, he really won't be able to go anywhere. A week in bed. Too lazy to get up, even peeing right there. Pooping there too." (I7)

The family's coping mechanisms

Families in carrying out palliative care functions have their own dilemmas because families who care for patients certainly have other roles besides caring for patients. The role of the family as a mother/father who already has their own family often creates various dilemmas in their daily lives.

"We're all in this together, so be patient. As for the money, that's not the main thing; with the help we've had so far, we can manage. If we don't have the money, let's chip in together—that's how we'll manage if we need to buy anything, or buy medicine." (I1)

"Besides, we need money for medical treatment, and for food. One child is at university, and there's another one still studying too. They need to study, eat, and drink. Basically, all of this means eating at

home. As for the schoolchildren, they're boarding in Palembang. So that's the difficult part. Luckily my child is capable, and we have a car. So we can take the coastal route as well. If we go to Palembang, we can get three or four. When will you come back? That's the thing. When you come back from university, look for work too. When you get money, buy oil. Sometimes you still get enough money to buy rice." (I2)

"The problem is the money, you know. Yeah, going to university needs money. So it's the money, you know." (I2)

"The problem is, if she's not feeling well, she just lies there, so we get worried too, and with our solution, here at home there are four or five of us discussing it, we cook this, a big pot of pindang chicken, to make her healthy; the main thing is the money comes out, she gets well—the point is, as long as there's money, she'll be healthy." (I5)

Medical information required to understand the patient's condition

The family as a substitute for medical personnel at home, must have information and even the ability to continue the care that was previously received in the hospital. The family has a statement that they get information from various sources:

"From the internet, yes, from the doctor, yes. You see, every time there's a posyandu, there's always something for the elderly—health education sessions—those are always there. They cover things like illnesses, what they're called, what you can eat, what you can't, and which vegetables are okay and which aren't." (I1)

"Not the internet, the doctor, that's where I found out from the doctor." (3)

"From the doctor, the community too, advice from neighbours, from family, we just go with it; if they give an opinion like this, we follow it; neighbours say this, that, take medicine, take medicine, hospitalisation—hospitalisation, we just go with it." (3)

"From the children; the younger siblings were studying medicine, weren't they? So when this got a bit worse, we rang up, and their older sister gave some advice." (5)

"No. We went to the doctor there, you know, that clinic at the back. He looked weak, his body was. We took him there, they checked his blood pressure and so on. At that point, he told us he had a condition with his blood sugar levels. That's diabetes, isn't it?." (I7)

"Well, if you look online, you just search for treatments first, you know, have a look on your mobile—there's loads of stuff, all those bottles, so those are the medicines, right? Herbal medicines, stroke medicines—you can buy them online, there's plenty of them. So if you search online, you ask around, you know, talk to anyone you can. We met up, had a chat, and asked where people can get treatment for a stroke." (I9).

Discussion

Palliative care is continuous and comprehensive care that looks not only at physical problems but also at psychological, social, spiritual and cultural problems (Muntamah, 2020). This is in accordance with the palliative program policy in Indonesia based on the Decree of the Minister of Health of the Republic of Indonesia number HK.01.07/Menkes/2180/2023 which regulates the guidelines for the implementation of palliative services in Indonesia. The family is also regulated as one part of palliative care that allows for obtaining knowledge related to the care provided. The family makes it possible to improve the quality of life of palliative patients. This regulation clearly states that families are entitled to receive explanations and information on how to provide appropriate care at home through the home care programme (Oğuz Karaalp & Kalanlar, 2026).

Quality of life is a person's ability to live a normal life according to their goals, hopes, standards and views which include physical, emotional and functional aspects. (Goodrich et al., 2025; Hara et al., 2021). Low quality of life can lead to inappropriate behavior, such as frustration, anxiety, fear, worry, and loss of enthusiasm and motivation to live in the long term (Ardiyanti et al., 2020). The quality of life of palliative patients can certainly cause the symptoms felt to be increasingly severe so that the patient's psychology can also be increasingly disturbed (Svop et al., 2025). This condition is what makes patients need the maximum role of the family.

Family as caregiver or Family Caregiver is an individual who provides unpaid care or as an assistant to a family member who has cancer (Lim et al., 2017). Family as a caregiver is someone who provides care to family and loved ones who are

weak, aging, or have mental and physical limitations (Lestari et al., 2026). If one family member suffers from a health disorder, the other family members take on the role of caregiver. (Firdaus, 2019). The role of the family as a caregiver is to help provide care to members who experience health problems.

The duties of a family caregiver range from taking over household tasks, assisting with personal care, performing complex physical tasks and care tasks such as support and coordination with medical personnel (Given et al., 2005). The function of the family as a caregiver is to care for clients who suffer from an illness, including providing food, taking clients to health services, and providing emotional support, affection and attention (Missesa, 2020). The family as caregivers also helps clients in making decisions or in the final stages of their illness and is a very important advisor. (Missesa, 2020).

Research on the role of the family is also explained through research entitled "Description of family knowledge about palliative care in a private hospital in West Indonesia", which explains that good knowledge of palliative care possessed by the family can maximize its role in fulfilling spiritual needs and the family has good emotional connections (Zendrato et al., 2019). This study supports research that has been conducted that with good discussion and cooperation between family members can make palliative patients feel more cared for. This task and role requires assessment, informational and emotional support in forming a psychological approach (Taufik et al., 2022).

Conclusion and Recommendation

The theme of this research indicates that families, as a key component of palliative care, are able to prepare themselves and define their roles so that they can become an integral part of palliative care at home. Families may also face various dilemmas and burdens whilst providing palliative care, such as psychological, financial and environmental burdens; however, they will still find ways to persevere and provide the best possible care for patients.

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Declaration of conflict of interest
The authors declare no competing interests.

Declaration on the Use of AI
No AI tools were used in the preparation of this manuscript.

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