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Home-based palliative care needs among caregivers of stroke patients in Yogyakarta, Indonesia: a qualitative phenomenology

Original article

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Abstract: **Objective:** A stroke with the consequence of permanent disability leaves the sufferer dependent on the family to fulfil basic needs. Palliative care is essential for patients and their families, as caregivers, to optimize the care process and quality of life. Therefore, it is crucial to identify palliative needs for families during care. Palliative care is still limited in Indonesia. This study aimed to explore the palliative care needs of families caring for stroke patients in a home care setting in Indonesia.
Methods: This qualitative study employed a descriptive phenomenological approach and was conducted between October and November 2023 through in-depth interviews. Interviews were conducted with 10 family caregivers of stroke patients selected through purposive sampling. Interviews were also conducted with the doctor provider of homecare service as triangulation participants. The Colaizzi method was used for data analysis.
Results: Palliative care needs of family caregivers classified into five themes: (1) family perception of palliative care, (2) informational needs, (3) financial needs, (4) family members as primary care support, and (5) end of life care needs.
Conclusions: This study identified caregivers' palliative needs during patient care. The extended family and children are main care support in palliative care for family caregiver. This finding suggests that nurses should provide informational support by educating and collaborating with them regarding the provision of palliative care at home.

Keywords: *caregiver • family • homebased care • palliative care • stroke*

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1. Introduction

Stroke is the leading cause of long-term disability in adults. According to the Global Burden of Disease Study report, stroke led the percentage of second deaths globally in 2019.[1] Indonesia, a middle-income country in Southeast Asia, has a high stroke prevalence of 10.9% or around 2.1 million people.[2] After a stroke attack, 25% of stroke patients can experience death, and 50% are likely to experience lifelong disability.[2,3] High morbidity

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rates mean that more than half of post-stroke patients are dependent on others for daily activities and needs.[4] They require palliative care to improve the quality of life of the patient and family carers, while also reducing suffering for the family as the caregiver.[5]

The focus in palliative care is not only on the patient but also involves the family as the main caregiver, especially in home care services. Family involvement in palliative care is essential because the family plays a role in caring for patients, improving their welfare, facilitating palliative care, and taking responsibility for the care provided.[6] Family participation in care has the potential to overcome challenges that may occur during the treatment process and can prepare themselves to care for patients at home, thereby increasing family satisfaction with the care provided.[7] Families also participate in the management of physical problems and the provision of emotional support.[8]

In the long and arduous process of caring for stroke patients at home, families face many challenges and difficulties without much help from medical personnel at home.[9] Qualitative studies explore the problems experienced by caregivers, such as feelings of lack of appreciation, sub-optimal services, physical limitations, administrative limitations, fatigue, and uncooperative patient conditions during care.[10] In facing these challenges, palliative care needs must be identified to determine family readiness in providing care for stroke patients.[11,12] Families may need information on physical and psychological care, support information, and even end-of-life care.[13] Family perspectives are important to explore because they are actively involved in the care process, allowing families to understand the problems that occur in patients and the solutions required to overcome these problems.[6]

Supported by the culture in Southeast Asia, the majority of post-stroke patients are cared for by family members, especially spouses or offspring who are able to provide care in the home environment.[14] Families are strongly advised to be actively involved in the care process of post-stroke patients as an effort to improve the quality of patient care management.[15] Nevertheless, the issue that frequently arises is that family involvement in the palliative care of stroke patients is still not optimal due to their limited knowledge and support, resulting in the inability of families to meet the palliative requirements of stroke patients.[10] Furthermore, the primary focus of hospital care has been on clinical patient care, with little consideration given to the family's perspective. In Indonesia, palliative care remains limited and unfamiliar to caregivers, and there has been little contextual research in this area. It is critical to examine family perspectives on palliative care needs while caring for patients, as the findings can help policymakers and hospitals develop training programs that empower families as primary caregivers. The objective of this research was to investigate and identify the palliative care requirements of families of stroke patients in Indonesian home care settings.

2. Methods

2.1. Study design

This research is a qualitative study employing a descriptive phenomenological approach to explore participants' experiences in depth.[16,17] The reporting of this study was based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.[18]

2.2. Participants

We conducted the study in the Special Region of Yogyakarta with participants from Dr. Sardjito Hospital home care from October to November 2023, involving families of stroke patients who were treated at home. Participants who agreed to be in this study were recruited through purposive sampling. The inclusion criteria for participants in this study were as follows: families who have blood relations or close relatives who care for severe stroke patients, families who care for patients with palliative care needs, families who provide intensive care, and families who carry out home care. The number of participants was determined based on data saturation, there were 10 participants involved. All participants agreed to be involved in this study.

2.3. Ethics considerations

Appropriate ethical research approval was obtained from the Ethics Committee of the Faculty of Medicine, Public Health, and Nursing, Gadjah Mada University, Indonesia (number: KE/FK/1470/EC/2023). The researchers provided a detailed description of the study and explained the associated procedures to each potential participant prior to signing the informed consent form. Researchers maintained ethical principles of participants' autonomy, voluntariness, anonymity, and confidentiality throughout the study.

2.4. Data collection

The data collection process was conducted using in-depth interviews and face-to-face observations at the participants' homes. There were two research teams in this study; RBS as the main researcher, who conducted the data collection process individually and BTW as the second researcher. RBS and BTW are Master of

Nursing students who have had qualitative study experience in their previous education. The interview process was conducted using an interview guide that was previously pilot-tested. The interview guide can be seen in Table 1. The duration of the interview ranged from 40 min to 60 min in one meeting and was recorded using a voice recorder with the consent of the participants. The researcher also made field notes to record observations. Transcripts were made by the researcher and returned to the participants to confirm the accuracy of the data.

2.5. Trustworthiness

In a qualitative study, rigor is established and maintained by considering the trustworthiness of the study. Researchers used various methods for data credibility, namely source triangulation, member checking, peer debriefing, and thick description, to increase trustworthiness in this study. To ensure transferability, the report is structured and clear so that readers can understand it. To support dependability, an audit trail was maintained to record the entire research process conducted by members of the research team. Meanwhile, confirmability was ensured by bracketing assumptions by the researcher so that the findings fully reflected the experiences of the participants.

2.6. Data analysis

The recordings of interviews were transcribed verbatim, and we used Colaizzi's phenomenological analysis. The process of transcribing and analyzing was conducted in Bahasa. The use of Bahasa facilitated the researchers to understand the real meaning of the words by considering the use of language and the context. The researchers had regular and continuing discussions to verify the appropriateness and gain agreement on the conceptual meanings and terminology. This process also allowed clarification of information from the data and ensured an accurate meaning of the data from the transcripts. The quotations in English may appear grammatically incorrect since we made minimal grammatical corrections when necessary to preserve the natural essence of the data.

The data analysis used in this research uses the Colaizzi method to explore a phenomenon. Transcripts were prepared in Bahasa Indonesia by the main researcher (RBS). The coding process was done by RBS, while the process of forming sub-themes and themes was carried out through in-depth discussions between RBS and BTW. The data analysis process was conducted manually using Microsoft Excel for data management. There were 52 codes, 12 sub-themes, and 5 themes in this study. The results of the themes were returned to the participants, but there was no feedback on the findings.

No.	Questions
1.	Have you ever heard of treatments that aim to relieve suffering and provide comfort to stroke patients?
2.	What is your understanding of stroke or treatments to relieve suffering in stroke patients?
3.	Where do you get information about providing care for stroke patients at home?
4.	How do you treat complaints or reduce patient problems?
5.	What do you need when caring for patients at home?
6.	What are the costs involved in providing patient care at home?
7.	What do you need to know about dying care for patients?

Table 1. Interview guide.

3. Results

Eleven participants, who were family caregivers of the patient and doctor, were interviewed in depth. All participants were Javanese ethnicity and provide palliative care for patients. The majority of participants had a high school education and worked as housewives. Participants' relationships with patients were as children, wives, doctors, and grandchildren. Details of the participants' characteristics are displayed in Table 2.

Five themes were identified as the home-based palliative care needs of the patient's family. In palliative care for stroke patients at home, there are findings regarding family perceptions of palliative care, families' informational needs, financial needs, family members as primary care support, and end-of-life care needs. Details of themes and sub-themes are displayed in Table 3.

3.1. Family perceptions of palliative care

The results of the interview showed that the majority of participants did not know what palliative care was, but the explanation from the participants could describe the definition, purpose, and principles of palliative care. The family explained that the current focus of care was tailored to the patient's problems. Participants explained that the treatment was aimed at improving mobilization and symptom management.

> *"Now for my mother, the focus is on her mobilization, so the current treatments are towards mobilization training…"* (Participant 10).

> *"The focus of treatment is to overcome the cough and shortness of breath, then I was given a prescription for medicine to overcome the problem, not the stroke"* (Participant 4).

Characteristics	N	Percentage (%)
Age		
30–69 years old	11	100.0
Gender		
Female	10	90.9
Male	1	9.1
Education		
Senior High School	5	45.4
Associate	1	9.1
Bachelor	2	18.2
Graduate	2	18.2
Post Graduate	1	9.1
Work		
Housewife	5	45.4
Retired	2	18.2
Businessman	1	9.1
Doctor	2	18.2
Ethnic group		
Java	11	100.0
Relationship with patients		
Child	5	45.4
Wife	3	27.3
Grandchild	2	18.2
Doctor	1	9.1
Long time of care, years		
<5	5	45.4
5–10	3	27.3
>10	2	18.2

Table 2. Characteristics of participant.

Themes	Sub themes
Family perceptions of palliative care	Treatment according to patient condition Definition of palliative care Aims of palliative care Principles of palliative care
Informational needs	Sources of care information Advanced information needs
Financial needs	Financial support Treatment according to financial status
Family members as primary care support	Extended family support Child support in caring for parents
End of life care needs	*ACP* Funeral preparation

Note: ACP, advanced care planning.

Table 3. Themes and sub themes.

According to participants, palliative care is care that does not focus on healing, focuses on optimizing the patient's quality of life, does not worsen the patient's condition, and focuses on improving patient comfort. The participant's statement is as follows:

> *"… we do optimize the quality of life, so what makes the mother comfortable is what we pursue, so we are no longer chasing to go back to the way it was, but how not to worsen the situation"* (Participant 10).

The family explained that the purpose of the current care was to stabilize the patient's condition, keep the patient in good condition, prevent complications, and prevent the patient from suffering at the end of his life. This participant's statement is in accordance with the goals of palliative care.

> *"If I don't have physiotherapy, my mother will be stiffer. It's to keep her stable, right? So I think taking care of her mother will make her stay stable"* (Participant 8).

As a caregiver of patient, family has their own perception about the principal while their providing care. The family said that in providing care, they must be patient, sincere, enthusiastic, not look tired in front of the patient, not be burdened, and provide as much care as possible.

> *"You have to be patient, if you can't be patient, you really can't, because it's hard"* (Participant 9).

> *"The important thing is that as long as our father is alive, we do what we can, as much as we can, yes as much as we can…"* (Participant 2).

The explanation from the family aligns with the doctor's statement, which clarifies that the palliative care category for stroke patients refers to those in severe condition and bedridden, to improve the patient's quality of life.

> *"In my opinion, stroke patients who require palliative care are those who are already bedridden, unable to perform further activities. If the stroke patient can still walk, that is in the rehabilitative phase, but palliative care is for those who are bedridden, unable to communicate, or have diminished consciousness"* (Doctor).

3.2. Informational needs

The results obtained data that the family wanted further information about the treatment that had been carried out, and the family, as caregiver, needed information from various sources for caring stroke patients at home. Families as caregivers try to find information about the right treatment for patients. The family tries to find information on care from various sources, from reading books, explanations from medical personnel,

or relatives. Families also exchanged experiences with relatives who were caring for stroke patients.

"Sometimes I see it on my mobile phone, and then there are books, so I get additional information" (Participant 4).

"I also talk a lot with people, coincidentally here some friends are also facing almost the same situation, so I exchange experiences" (Participant 3).

Families want additional information from health workers because of the limited information they have. The family wants a more comprehensive explanation regarding palliative care and its implementation.

"So far I have never received any kind of counseling or explanation like that. So perhaps it is necessary to explain again what palliative care is…" (Participant 8).

According to the doctor, providing information to the family about palliative care for stroke patients is very important because initially, the family may not know the appropriate care.

"Hemorrhagic stroke patients who really can't do anything, in the early visits, we have to teach the family, such as how to feed through an NGT (nasogastric tube), clean the body, and assist with defecation." (Doctor).

3.3. Financial needs

Financial issues are one of the problems felt by families in patient care because treatment takes a long time. Families need financial support in providing care to patients, and families try to provide care according to financial conditions. Families as caregivers need financial support to fulfil their care needs. The financial support that families get comes from family, especially children, loans from others, or using savings.

" 'We help as much as we can, don't be shy,' the children say that, but I also feel sorry for them, they have their own problems haha so they are compact to help, yes as much as they can." (Participant 7).

The treatment that has been carried out adjusts to the family's financial condition. Care is provided by the family themselves to minimize expenses. The family also thought that the patient's current needs must be met, and the family put aside their own needs. The family thinks that care should be as much as possible by fulfilling all the patient's needs.

"Yes, we can adjust, you know, if people who are well-off can hire a nurse … The family can take care, if people are really well-off, they can use a nurse or something, so we adjust our situation" (Participant 2).

"If mum's needs must be met, I if mum has to eat, medicine, diapers… I try to do my best to fulfil them" (Participant 5).

The family's statement is supported by the doctor's opinion, which states that palliative care is adjusted according to the patient's family's financial ability. The doctor does not force any specific care to be given to the patient.

"In my opinion, deciding to stop treatment should be left to the patient's family. I can't force it because the costs are not covered by health insurance" (Doctor).

3.4. Family members as primary care support

This theme explains that family members play an important role in supporting patient care. The extended family has an important role to support the patient's care by providing direct care to the patient. The extended family also provided prayers for the patient's recovery.

"In terms of religious matters, thank God my family, my brothers and sisters, they helped me, so when they come here, they pray, they often pray…" (Participant 9).

"Both of my son-in-law also want to bathe, they want to help, they all want to care for patients. I'm really grateful because not all children want to be like that, they don't even want to come close" (Participant 9).

Families think that caring for parents is an obligation that must be fulfilled by children. All participants were Javanese, and this influenced their care. Families also believed that the choice to be cared for by their children was due to the emotional closeness between the child and the patient. Participant 3 explained that there was self-efficacy in caring because he had the ability to provide care.

"Javanese culture still influences family care. Yes, it's a hereditary obligation, if in the west, the child pays for the nursing home, if here, it's not possible…most of them are still cared for by their children" (Participant 1).

"I took care of it because of the one in Jogja, it was just loose, then there was knowledge, then what was mandated from my grandfather so everything was passed down to me" (Participant 3).

3.5. End-of-life care needs

According to the family, end-of-life care is important for stroke patients with severe conditions. The family starts discussing advanced care planning (ACP) and needs to prepare a funeral for the patient. The family has started to do ACP by discussing the patient's death with the family and finalizing the patient's affairs before death. The participant's statement is as follows:

> *"There has been a discussion with my father and my family. When my mother will be like what, a place has been prepared for the funeral… the steps of the funeral, then where to be buried, what we use, we are more there"* (Participant 10).

Participant 6 said that the patient had had time to convey the will to the family, while some participants had not had time to make a will because the patient had a communication disorder. The family had also started to carry out the patient's message before death.

> *"From the beginning of the stroke, father had already started to order, 'no one knows the age, I will be taken by Gusti Allah when I don't know, the point is that I order you to keep getting along, you must continue to pray 5 times, you can't leave it. Then later, if I'm not there, I'll ask to be buried together with my mother.' At the beginning of the illness, I already ordered that"* (Participant 6).

Families have started preparing for the funeral process. Two families had already started looking for a place to bury the dead. Participant 3 said that he was not able to take care of the body himself; therefore, he wanted to find a place that could take care of the body. Participants had also started to prepare a funeral place for the patient. According to Participant 1, in Javanese culture, the family must prepare the land for the funeral.

> *"In Jogja, there is a funeral parlour like that, from bathing to mourning… my family hasn't done it yet, I said 'well, we haven't done it yet so we need to be prepared' "* (Participant 3).

> *"Javanese custom if there is a rich family, buy land for the funeral"* (Participant 1).

The doctor explained that most families have accepted the patient's death and prefer that the patient pass away at home, which is why palliative care is provided at home.

> *"There are also those who eventually pass away at home, but the family accepts it because they understand the patient's condition is palliative, so they prefer for the patient to pass away at home…"* (Doctor).

4. Discussion

The results of the study explain that the implementation of palliative care is adjusted to the patient's condition. This is in accordance with previous research, which explains that rehabilitation in stroke patients serves to optimize function and relieve symptoms, especially in patients with severe stroke.[19] Rehabilitation can start during an acute stroke until the condition stabilizes.[20] Care is currently provided to improve the patient's quality of life rather than cure the disease itself. This is in accordance with the explanation from WHO regarding the definition of palliative care, which is an approach aimed primarily at improving the quality of life of patients and families when facing life-threatening illnesses. Palliative care focuses on reducing suffering and providing comfort through early identification, appropriate assessment, treatment for pain and other physical, psychosocial, and spiritual problems.[21]

The goal of current care is to stabilize the patient's condition, provide comfort, and avoid suffering at the end of life. The goal of palliative care is to reduce physical, psychological, social, and spiritual suffering. These goals can be achieved if palliative care decisions are made early on and achieved through medical and non-medical measures.[22] The ultimate goal of palliative care is to improve the quality of life of patients and families as caregivers facing life-threatening illnesses.[21] The principle of care for stroke patients is to provide care with patience, sincerity, enthusiasm, and provide the maximum possible care. This is in accordance with the principles of palliative care, which include caring for someone with advanced illness, family, and those closest to them. Caring can also be done on the principle of autonomy or taking care according to the patient's choice regarding the chosen treatment plan.[23]

The results showed that families need additional information about current care, especially about palliative care. This statement is in accordance with the results of other studies, which explain that caregivers do not have sufficient knowledge to care for patients at home. Support from health professionals is considered important in providing optimal information. Lack of knowledge about symptom management causes anxiety in caregivers and the need to contact others for information.[24] Additional information is essential for caregivers to help care for patients with terminal conditions. Caregivers need information on prevention, healthy lifestyle, proper nutrition, medication side effects, and basic nursing care.[13] Families get care information from various sources.

Informational needs focus on the importance of access to information to be able to manage various conditions in patients, especially in relation to disease symptoms and treatment. Access to relevant information can assist families in understanding and accepting the diagnosis of terminal illness and the treatment to be undertaken.[24,25]

The results revealed that families face significant costs when providing home care, leading them to require financial assistance. Costs associated with palliative care include caregiver costs, out-of-pocket costs in care, and other costs.[26] Financial support in this study was obtained from family, loans from others, or using savings. Families as informal caregivers are the majority of the main palliative care providers at home.[27] Appropriate financial support can reduce the burden on family caregivers.[28] A six-country study on financial support in palliative care found that the type, scope, and extent of financial support varied across countries. The majority of financial support is managed by multiple agencies; the eligibility criteria for receiving financial support are numerous and complex, and there are disparities in the provision of support.[28]

According to the family, the care that had been carried out was adjusted to the family's financial condition. Families apply cost-effectiveness in daily care. Cost-effectiveness in palliative care is largely due to cost difficulties in providing care. Palliative care will be at risk of costing a lot of money because costs will be prioritized to meet the needs of the patient.[26] Some people may have a choice of whether or not to care financially, but those with limited means and limited financial reserves have fewer choices, as the alternatives are very limited.[27] An appropriate intervention in overcoming this is the regulation of the government to provide palliative care costs, similar to the National Health Service (NHS) in the United Kingdom; however, there is no organization in Indonesia that provides funding for palliative care at home.

When faced with a crisis in patient care, the support of family members for each other is very important for each family member to ensure good family functioning.[29] The nuclear family, especially children, plays an important role in patient care at home. Participants believed that caring for their parents is an obligation that must be done by their children. Other studies support this finding, stating that caring for parents in old age is a clear choice for all caregivers. The decision to take on the role of carer is motivated by the child's desire to give back to their parents and to provide dignified care toward the end of life.[30]

Participants explained that there is an influence of Javanese culture in caring for patients. Caring for parents is a child's obligation that must be done according to Javanese culture. Ethics in Javanese culture refers to two fundamental principles, namely the ethics of respecting elders and harmony.[31] Someone who has a higher position must be respected, while the higher position must have a fatherly or motherly character for the lower position.[32] Palliative care with a cultural approach can provide holistic nursing care. Javanese values that can be adopted in providing palliative care are explained in some Javanese terms: *temen* (earnest), *nrima* (sincere), *sabar* (patient), and *rila* (accepting).[33]

The family needs to do ACP by discussing the patient's death preparation with the extended family and finalizing the patient's affairs before death. ACP is defined as an individual's ability to determine goals and preferences for future medical treatment and care, discuss these goals and preferences with family and health care providers, and record as well as review these preferences if necessary.[34] The results of previous studies show that family readiness to perform ACP is an important requirement to receive the benefits, but this can be done if the family is familiar with the ACP process itself. Another requirement is openness, which refers to patients feeling comfortable and open about their preferences for the care they will receive.[35]

The last necessity that families need to prepare for is funeral arrangements. The family needs a place for the body to be disposed of and a burial place for the patient. Practical preparations can be classified as related to funerals and preferences for places to die. Other results showed that all respondents stated that they preferred to die at home. However, preferences for this outcome varied. The choice of place of death can be temporary, depending on the state of the developing illness and the family's ability to provide care at home. The desire to avoid being a burden during the end of life was also expressed by patients who wanted to die at home.[36]

4.1. Implication of the study

This study explains the needs required by families for palliative care of stroke patients at home. The family has identified the necessary needs, but some of these needs have not yet been met. This can be a source of concern for healthcare workers as part of the interdisciplinary palliative care team at home, as they strive to provide care that takes into account the patient's needs. An interesting finding in this study is that the family, as caregivers, also needs support from other family members. We found the role of extended family and children as the main care support in palliative care for the patient's family. The study took place in Indonesia, where family values and bonding among relatives remain strong in Indonesia's cultural context. We suggest that future researchers explore in more depth how the extended family plays a role in palliative care for patients at home.

4.2. Limitation

Palliative care is a term that is still unfamiliar to the participants; they are aware of the care provided to optimize the patient's quality of life, but do not yet understand how this care is implemented. This becomes a limitation of the study, as the researcher struggles to explore in depth the palliative care that has been provided. This is due to the participants' lack of information regarding palliative care.

5. Conclusions

The results of this study indicate that families do not have a thorough understanding of palliative care, however, based on the explanations of participants' it can be concluded that they have carried out palliative care at home. In addition to patients, families as caregivers also require palliative care needs when caring for stroke patients with severe or life-threatening conditions. Families need informational and financial support, family members as the main support for care, and end-of-life care. Based on these findings, the needs of palliative care in families are less considered, which raises expectations for health workers to pay more attention to families as caregivers when providing palliative care at home.

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Ethical approval

This study received ethical approval from the ethics committee of the Faculty of Medicine, Public Health, and Nursing, Gadjah Mada University, Indonesia (number: KE/FK/1470/EC/2023).

Conflicts of interest

All contributing authors declare no conflicts of interest.

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