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Palliative Care Needs in Stroke Patients According to Family Perspectives in Yogyakarta: A Phenomenological Study

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Abstract

Background: Stroke patients have complex problems that require palliative care to optimize the patient's quality of life. Identifying palliative care needs is the first step in providing palliative care.
Objective: This study aimed to explore the palliative care needs of stroke patients according to family perspectives in Yogyakarta.
Methods: This is a phenomenological approach involving 10 family members providing care for patients with stroke. Participants were obtained through a purposive sampling technique with data from the homecare of Dr. Sardjito Hospital, Yogyakarta. Semi-structured interviews and observations were conducted with each participant until data saturation. Verbatim transcripts of the interviews were analyzed using the Colaizzi method. The reporting of this study was based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.
Results: Seven themes emerged from the analysis: physical needs, psychological needs, social needs, cognitive needs to cope with dementia, spiritual needs, end-of-life care needs, and homecare service needs for stroke patients.
Conclusion: This finding suggests that health workers should provide comprehensive palliative care by paying attention to the primary needs of stroke patients.

Keywords: family perspective; needs; palliative care; stroke patients; qualitative

INTRODUCTION

Stroke is a neurological disorder characterized by obstruction in the brain vasculature (Kuriakose & Xiao, 2020). Stroke is among the cerebrovascular diseases that cause second mortality and third morbidity in the world (World Health Organization, 2020). One year after a stroke attack, the mortality rate for stroke patients is 25%, and 50% of stroke patients experience lifetime morbidity (Stroke Association, 2016; Vos et al., 2016). World Stroke Organization (2022) states the need for proper stroke management as the prevalence of stroke in the world today is still high, which is 12.2 million each year with a mortality rate of 1.5 million people. Indonesia is one of the countries with a high prevalence, which is 10.9% or around 2.1 million people (Kemenkes RI, 2018). One of the provinces in Indonesia, Yogyakarta, ranks second out of 34 provinces, with the prevalence of stroke at 14.6% of the total population (Kemenkes RI, 2018).

Stroke patients can experience physical, psychological, social, and spiritual problems. Complex problems and a high risk of death in patients require comprehensive care to overcome them, with palliative care (Kendall et al., 2018). American Heart Association guidelines (2014) state that palliative care can be aimed at stroke patients with severe or serious life-threatening conditions. Neuropalliative care is needed in stroke patients with severe conditions (Creutzfeldt et al., 2023). Severe stroke conditions are characterized by impairments in motor, sensory, visual, language, cognitive, and affection systems (Elendu et al., 2023). The complexity problems, severe symptom burden, history of chronic comorbidities, and the need for symptom control are also indications for palliative care in stroke patients (Creutzfeldt et al., 2023).

Identification of needs is the first thing that is important in carrying out palliative care to determine the readiness of families to provide care and improve the quality of care for individuals with advanced diseases (ElMokhallalati et al., 2020; Sabrina et al., 2017). Delays in identifying palliative care needs will have a negative impact on the patient's quality of life because the provision of care does not meet the needs (Cotogni et al., 2018). Family perspectives are important to explore because families are actively involved in the patient care process. In Indonesia, strong family ties are part of the culture, so families are involved in patient care (Kristanti et al., 2019).

The results of previous research show the need for palliative care in the homecare setting, which includes the accessibility of healthcare, patient-centered care, multidisciplinary approach, and quality improvement (Hofmeister et al., 2018). Another study conducted by Lloyd et al. (2019) related to palliative care needs in stroke patients from a doctor's perspective are functional disability, physical burden, psychological needs, social problems, caregiver burden, counseling needs, spiritual needs, and problems at the end of life care. These results indicate that the identification of palliative care needs in stroke patients is important because it is related to the patient's quality of life and the care that the patient will receive.

Identification of palliative care needs in stroke patients is important because it is the main and first thing that must be done in carrying out palliative care. Early identification also can improve the readiness of families or caregivers to carry out palliative care. In Indonesia, there has been no research that explores how palliative care needs in stroke patients according to the family perspective. This is a consideration for researchers to conduct research with the aim of exploring how palliative care needs in stroke patients from the perspective of families in Yogyakarta.

METHOD

This study used a qualitative research design with a descriptive phenomenological approach. The reason the researcher used a phenomenological approach is because the researcher wanted to explore the palliative care needs of stroke patients from the family perspective. The reporting of this study is based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. The population of this study consisted of families who were caregivers for stroke patients at home in Yogyakarta. Researchers obtained data from the Dr. Sardjito Hospital.

The sampling technique used in this study was purposive sampling. The number of participants was determined based on data saturation. There were 10 participants in this study, with inclusion criteria: families as caregivers who are a nuclear or extended family, families who care for severe stroke patients with NIHSS (National Institute of Health Stroke Scale) assessment score >14, families who provide intense care, families that are able to communicate well, and provide care at home. There were no participants who refused, and the researcher did not know the participants before.

Table 1. Interview Guide

No	Question
1.	Have you heard treatments that aim to ease the suffering and provide comfort in stroke patients?
2.	How is your understanding of stroke or treatments to alleviate the suffering of stroke patients?
3.	What is the patient’s current problem?
4.	How did you treat the patient’s complaint or alleviate the problem?
5.	What are the needs of patients when they are treated at home?
6.	What is the patient’s current health condition?
7.	What do you need to address the patient’s psychological distress?
8.	What do you need to address the patient’s social impairment?
9.	What do you need to address the patient’s spirituality?
10.	What do you need about end-of-life care for patients?

This research was conducted in October-November 2023. Data was collected from face-to-face semi-structured interviews and unstructured observations. Only the main researcher (RBS) conducted the in-depth interview process. Interviews were conducted using an interview guide that was previously pilot-tested (see Table 1). Interviews and observations were conducted once at the participant's home, lasting 40-60 minutes. The interview process was recorded using a voice recorder and mobile phone. A research assistant assisted in the implementation of the observation process using field notes. The data analysis method used Colaizzi, with stages: reading transcripts repeatedly, extracting significant statements, coding, forming sub-themes and themes, making a complete description, describing the fundamental structure of the phenomenon, and validating the results. Transcripts were conducted using Bahasa Indonesia by the main researcher (RBS). RBS carried out the coding process, while the research team carried out the forming of sub-themes and themes (RBS, HSP, WAN). There were 100 codes, 22 sub-themes, and 7 themes in this study. The data analysis process was carried out manually using Microsoft Office for data management.

The researcher conducted source triangulation (with other family and doctors), member checking, peer debriefing, and thick description to increase the credibility of the research. The researcher also has experience conducting qualitative research before. Transferability is done by writing reports systematically and clearly so as to increase the reader's understanding. Dependability is done by conducting an audit trail to audit the entire research process with research members. Confirmability is achieved by auditing the trail and bracketing or locking the researcher's assumptions so that the findings describe the results of the participants' experiences. This study was ethically approved by the ethics committee of the Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Indonesia (number: KE/FK/1470/EC/2023). All participants received an explanation and signed an informed consent form. The researcher also guaranteed the confidentiality of the identity of the participants by using the participant identity code (P1, P2, P3).

RESULT

There were 10 participants involved in this study, and Table 2 describes the characteristics of the participants. There were 7 themes obtained in this study (Table 3).

Table 2. Participants' Characteristics

Participant code	Age Family	Age Patients	Gender	Religion	Last Education	Jobs	Relationship with Patients
P1	64	93	Female	Islam	High School	Housewife	Child
P2	61	95	Female	Islam	Associate	Housewife	Child
P3	37	81	Female	Islam	Postgraduate	-	Grandchild
P4	60	63	Female	Islam	High School	Retired	Wife
P5	37	67	Female	Islam	High School	Housewife	Child
P6	30	80	Female	Islam	High School	Businessman	Grandchild
P7	69	78	Female	Christian	High School	Housewife	Wife
P8	58	90	Female	Islam	Bachelor	Housewife	Child
P9	65	65	Female	Islam	Bachelor	Retired	Wife
P10	39	73	Female	Islam	Graduate	Doctor	Child

Table 3. Themes and Sub-Themes

Theme	Sub Theme
Physical needs	Physiotherapy Non-aggressive treatment Wound care Decubitus prevention Physical comfort
Psychological needs	*Emotional support* from family Counseling by counselors with family intermediaries
Social needs	Specific communication strategy *Companionship support* Speech therapy by family
Cognitive needs to cope with dementia	Pharmacology management Involving patients in care
Spiritual needs	Facilitate the worship process Improving connection with God Clergy presence
End-of-life care needs	Clergy assistance in EoL Bereavement support by the community
Homecare service needs	The positive influence of homecare Team and caregiver collaboration Interdisciplinary team Therapeutic communication skills Supportive care needs

Theme 1: Physical needs. Physical problems due to stroke disease need to be treated with the aim of rehabilitating the patient's physical function. The physical needs required by patients are physiotherapy, non-aggressive medication, proper wound care, prevention of decubitus, and providing physical comfort. According to the family, physiotherapy aims to prevent muscle stiffness, improve comfort, train the motor system, improve movement, and prevent atrophy.

The therapy really helps so that his body is not too stiff and does not shrink. I think that is really important. What is clear is that it doesn't shrink, it doesn't immediately stiffen, so it's still normal from the beginning, and until now, it is still the same. (Participant 9).

The current treatment does not focus on the stroke disease but treatment to overcome the problems that exist in the patient. Non-aggressive treatment is also done by giving medicine or vitamins to optimize the patient's health.

“So the medicine is for the existing problems, just additional vitamins. If patients cough, Dr. S told to give lasering or ginger water” (Participant 1).

The results also showed that wound care must be carried out immediately and routinely so that wound healing can be good. The physical need for decubitus prevention is also important, as the majority of stroke patients experience bed rest. The patient's family has prevented the patient from experiencing decubitus by using lotion, using a decubitus mattress, and changing the patient's position on the right and left side.

That is why I take care of his back with lotion so that it does not hurt. It is not a cream for wounds, but I am using lotion or olive oil. I took care of it, and I was told that his back is usually attacked (Participant 7).

Observation results showed that the patient received amlodipine, donepezil, folic acid, and clopidogrel. Patients also use decubitus mattresses to prevent decubitus. Physical comfort can be seen by providing a clean environment, opening room windows, and bright enough room lighting.

Theme 2: Psychological needs. Psychological needs in stroke patients with the palliative category require emotional support from the family. Patients also need psychological support to overcome the patient's psychological problems if a family cannot resolve the problem. The results of the interview stated that family plays an important role in overcoming psychological problems by maintaining the patient's mood, providing affection, and maintaining conversations with the patient.

We take care of their father's mood; lately, the father has asked for recreation, so we follow him; he uses a wheelchair and sometimes uses a car. Last Sunday, he wanted to go to the beach, so we took him to the beach ... because his father has complained several times that "I am bored in the room ...", because he cannot walk yet, so his activities are just at home in the room maybe he is also bored (Participant 6).

Participant 6 explained that patients still need psychologists, but the counseling process is carried out through family intermediaries. The participant thought that this method was more effective than meeting the psychologist directly because the patient had decreased communication function.

The family asks, for example, what he wants and what he feels, but we still suggest it to the psychologist, even though it is not directly, but we suggest it to the psychologist; if the patient's condition is like this, then what should the patient do? Later, from the psychologist, there is advice on what we do, so the patient needs a psychologist, but through the intermediary of the family, if directly, the patient is very difficult to open ... (Participant 6).

Theme 3: Social needs. Families as caregivers need specific strategies to be able to communicate with stroke patients who have communication disorders. Each patient has a different communication disorder, and each family has a different strategy for communicating with the patient.

“So we talk more even though the patient only answers yes, yes, yes, does not respond much, but at least we talk a lot, chat a lot. We are active in talking to him” (Participant 6).

Participant 4 explained that the family effectively carried out speech therapy. She explained that the patient had progressed in such a way that she was able to say simple words.

“When I do not use professional speech therapy, patients can talk a little bit. If he is with me, I force him to talk” (Participant 4).

The results of the interview with Participant 3 show that the patient currently needs companionship support. Companionship support is able to provide emotional, social, and psychological support for patients whom many people surround.

Actually, stroke people need to be surrounded by many people. It happens to be in the direction of cognitive function; for example, some people lead to the introverted type. Maybe there is no problem with their solitude by being stimulated by TV or with others. It is just that my grandmother likes to be with many people, and she likes to be surrounded by many people (Participant 3).

Theme 4: Cognitive needs to cope with dementia Three patients had dementia. Important pharmacological needs were met by routinely administering medication for dementia. Participant 7 stated that the patient was given donepezil to optimize his cognitive function. The majority of families also think that restoring the patient's cognitive function is done by involving the patient in making decisions about care for himself and helping to remind the patient if the patient has forgotten.

"Involved in making decisions, for example, asked what to cook today, then later taken to the kitchen ... so she is involved in the decisions that want to be done" (Participant 3).

We do not ask difficult questions, so it's easy to remind; for example, if it's off, remind. So, for example, if my father comes and thinks it is her father and not his husband, I remind her that it's her husband like that (Participant 10).

Theme 5: Spiritual needs. Spiritual needs are one of the needs considered by the family, but the family has not met some needs. The family explained that spiritual needs in patients can be met by facilitating patients to worship, helping patients to do *tayamum*, guiding patients when praying, and increasing connections with God by guiding prayer.

"Yes, guided, invited to pray, already unable to do it alone. In the past, it was still, "let's imitate, let's we pray !!!", but now it's all blank, so the family helps" (Participant 7).

Every maghrib with my mother, she often plays the murotal, so that he don't forget the prayers, the memorization. Before he was sick, he used to read the Quran so he would not forget. That is why my mother often plays murotals to keep him remembered (Participant 6).

Another spiritual need that patients require is the presence of clergy. According to the family, it is very important to bring clergy in palliative stroke conditions to restore the patient's religious activities and provide encouragement. Clergy are also needed to guide worship and provide spiritual guidance to patients.

"We have tried through our faith, our beliefs, calling a pastor, calling a prayer warrior to wake up his spirit, we can work together, together "let's fight together!!!" (Participant 7).

Observation results showed that the patient watched a TV with spiritual broadcasts and listened to Al-Quran murotals.

Theme 6: End-of-life care needs. The family thought that bringing in a clergy or pastor was beneficial to make the patient closer to his religion at the end of his life. Interviews with participants 1 and 7 found that the community needs bereavement support. Participants explained that bereavement support is carried out by providing labor in taking care of the body, the existence of a grief team, and assistance from residents.

My sister in Jakarta is planning to find an ustadz to approach my father ... the child wants that before my father is gone, he will still be close to Allah, and there will still be a religious side if it can be strengthened, which is important at the end of his life (Participant 6).

Spiritual groups in the community have prepared shrouds and other equipment. The needs have been prepared so that whoever dies will be helped (Participant 1).

Theme 7: Homecare service needs. The majority of families reported a positive effect of integrating home care in their daily care. Families said that homecare can help patients to be treated appropriately, restore mobility, and make patients feel comfortable.

"If we don't use homecare ourselves, frankly it's overwhelming, we won't be able to monitor the father's condition, if there is a doctor and nurse, we can monitor him, we also feel very monitored" (Participant 6).

Families as caregivers also play an important role in patient care by working together with the interdisciplinary team. Complex patient problems are also important to treat with an interdisciplinary team approach. Another need is therapeutic communication skills for stroke patients. The family said therapeutic communication can be done by encouraging the patient, communicating softly, being open with the patient, and practicing breaking bad news communication.

Home care also requires supporting care, which is needed for daily care, wound care, and emergency medication.

"I prepare all medicines and injections at home. I provide emergency medicines, injections for vomiting. I inject by myself, insert infusion, etc" (Participant 10).

DISCUSSION

The theme results of this study, in accordance with Lloyd et al. (2019), which explains the need of palliative care in stroke patients from the doctor's perspective, consist of the need to cope with functional disability, physical burden, psychological needs, social issues, spiritual needs, and end of life care issues. New findings in this study are cognitive needs and homecare services needs.

The physical need that stroke patients need to rehabilitate motor and sensory functions is physiotherapy. Neural rehabilitation is important to reduce the burden on stroke patients. It is done to overcome motor and sensory disorders that affect patients to stand, walk, or use limbs properly (Morone & Pichiorri, 2023). Physiotherapy can improve brain function and modulate the level of pro-inflammatory and neurotrophic factors to provide analgesic effects (Ma et al., 2022). Physiotherapy integrated into palliative care is able to improve functional levels in patients, increase independence, and improve skills in performing daily activities (Navarro-Meléndez et al., 2023).

Palliative conditions require non-aggressive treatment. Treatment aims to manage stroke risk factors, alleviate symptoms, and supplement vitamins. In palliative care, medication selection prioritizes options with minimal side effects on the patient's health (Star & Boland, 2018). The need for decubitus prevention is also important in stroke patients with bed rest. Sharp et al. (2019) explained that an effective way to prevent decubitus wounds is to use an anti-decubitus mattress. Physical comfort is still important, as it should be provided by positioning the patient comfortably, maintaining the environment, and providing adequate nutrition. Comfort in patients with palliative needs can also be achieved by providing interventions; one of the interventions is using Guided Imagery, which can increase patient comfort (Coelho et al., 2018).

The psychological needs of patients include emotional support from their families. Psychological well-being in patients can be seen in the presence of spiritual well-being, comfort, and social support from the closest people (Redondo Elvira et al., 2023). Counseling by counselors through family intermediaries is also important. Patients experience communication barriers (aphasia, dysarthria), so counseling is more effective through family intermediaries. Patients with aphasia are prone to psychosocial problems, such as anxiety, depression, reduced social relationships, and social isolation. Emotional regulation is important in influencing life participation after a stroke (Manning et al., 2022). Good counseling with patients or families can help overcome the problems faced and make the situation better (Lloyd et al., 2019).

The need for specific communication strategies is important to overcome communication disorders and improve the patient's social function. According to the National Aphasia Association (2023), the communication strategies needed in aphasia patients are communication with easy-to-understand language, simple sentence structures, and reducing the speed of speech. Other strategies that can be used are communicating with pictures, writing, gestures, and facial expressions. Companionship support is also important in stroke patients. Companionship is part of social support that can be done by the person closest to the patient by providing verbal encouragement to boost the patient's spirit. Some patients also feel loved if they are surrounded by people closest to them during treatment (Rutkowski et al., 2018).

Dementia impacts a patient's cognitive and affective functions. The main need for stroke patients with dementia is pharmacological therapy. Prevention of cognitive impairment in patients after stroke can be provided with antiplatelet therapy, antihypertensives, statins, and anticoagulants (Mijajlović et al., 2017). Patient involvement in the care process is also one of the interventions carried out by the family to restore the patient's cognitive function. Cognitive rehabilitation is a complex therapeutic intervention with the aim of improving cognitive function after stroke, limiting the impacts or severity of a disability, and improving quality of life. Cognitive rehabilitation plays an integral role in stroke rehabilitation and should begin immediately after the onset of stroke and several years after stroke (Mijajlović et al., 2017; Mulhern, 2023).

A decline in spiritual function can occur due to a decline in physical function and spiritual distress in stroke patients (Septian et al., 2024). Spiritual needs needed by stroke patients with bedrest conditions are worship can be facilitated. Worship is a strategy used by most stroke patients to overcome the tension caused by the disease and to achieve peace. Worship is also important for stroke patients to face the problems they faced. Most patients regard worship as a source of peace and believe that remembering God is integral to maintaining their spirit (Azar et al., 2022). Another need in patients with terminal conditions is the need for the presence of clergy to restore the patient's religious activities. Clergy in palliative care plays a role in being present together with patients in conducting joint religious activities, providing spiritual support, meeting practical needs, and giving trust in God (LeBaron et al., 2016).

The necessary needs of patients when approaching death are spiritual assistance. The clergy plays a role in bringing the patient closer to religion at the end of his life. The provision of spiritual care in end-of-life refers to the act of care by providing holistic care, humanizing the patient at the time of death, and helping the patient die with dignity (García-Navarro et al., 2021). The opportunity to present a clergy at the bedside will also add to the patient's spiritual and psychological support (Mahmoud et al., 2022). Bereavement support is also important in end-of-life care. The presence of a social support system at the time of death gives the patient the opportunity to resolve social, religious, and world affairs. The presence of family and relatives at the bedside during the end of life also ensures the proper implementation of religious rituals and offers the patient a peaceful death experience (Mahmoud et al., 2022).

Palliative care at home has more positive results than in hospitals because of easier accessibility, the presence of family support, patient-centered care, and the ability to improve the quality of care (Hofmeister et al., 2018). Homecare services can run well because of the cooperation of interprofessional teams with families as caregivers. Collaboration is also important among health workers. Pornrattanakavee et al. (2022) describe an interdisciplinary collaboration capable of setting treatment goals well, supporting the quality of life, and relieving symptoms suffered in patients with terminal conditions. Therapeutic communication skills are important for health workers in patient care. Engel et al. (2023) explain that the communication expected of patients in palliative care is being open, providing honest information and empathy, and using easy-to-understand language. Communication practices in palliative care also need to apply appropriate breaking bad news techniques when conveying terminal conditions (Holmes & Illing, 2021).

The thematic findings explain the comprehensive need for palliative care in stroke patients so it can become a reference in providing care to patients. The limitation of this research is that there was no varied sample because all participants were women. The observation process was carried out in an unstructured manner, so not much data was obtained from the observation. Another limitation is that researchers did not get validation findings from participants regarding the themes and sub-themes that had been formed.

CONCLUSION

The complex problems faced by stroke patients necessitate a wide range of palliative care needs. These patients require support for physical, psychological, social, cognitive, and spiritual needs, as well as end-of-life care and homecare services to integrate palliative care at home effectively. However, certain needs, such as psychological, cognitive, spiritual, and end-of-life care, remain unmet in some patients. Families and interdisciplinary teams are addressing these needs. Follow-up is needed to ensure that palliative care is provided in accordance with the specific needs of stroke patients, and further exploration of the palliative care needs of families as caregivers is essential. The findings regarding the palliative care needs of these patients can guide nurses in developing interventions that appropriately address these needs.

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