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ORIGINAL RESEARCH

The need for home-based palliative care among patients with stroke and their families: A phenomenological study

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Abstract
Identifying the problems faced by stroke patients is crucial due to their diverse and complex nature. Attention to family issues is also essential, as the primary focus of palliative care encompasses both the patient and their family. This study aims to explore the challenges experienced by stroke patients and their families who require home-based palliative care in Yogyakarta. A qualitative design with a descriptive phenomenological approach was employed. Ten family participants were involved in this study, selected through purposive sampling from the homecare unit of Dr. Sardjito Hospital, Yogyakarta. Data collection methods included interviews and observations until data saturation was achieved. The transcripts were analyzed using Colaizzi's method, which involves seven stages. Six themes emerged, describing the problems of patients and families: physical problems, psychological issues, social disorders, cognitive impairments, spiritual difficulties, and financial challenges. These findings illustrate the complex nature of the problems faced by stroke patients and their families. Healthcare providers are encouraged to deliver palliative care that addresses these multifaceted issues. Future research should explore the barriers and challenges in providing palliative care, with a particular focus on the specific problems of patients and their families.

Keywords: Nursing care; qualitative study; phenomenological research; stroke care; family management

Introduction

Non-communicable diseases (NCDs) remain a significant concern in several countries, with high morbidity and mortality rates posing substantial burdens on patients and their families (Kusuma et al., 2019; WHO, 2018). Among these, stroke demands particular attention due to its severe outcomes. According to the World Stroke Organization (WSO), effective stroke management is crucial given the alarming global incidence of stroke, which affects approximately 12.2 million individuals annually and results in 1.5 million deaths (World Stroke Organization, 2022). In Indonesia, stroke incidence is notably high, affecting 10.9% or about 2.1 million people (Kemenkes RI, 2018). Yogyakarta, a province in Indonesia, ranks second among 34 provinces with the highest stroke incidence, affecting 14.6% of its population (Kemenkes RI, 2018). Stroke patients present various problems depending on the lesion's location and size in the brain, impacting brain function. Common physical issues include hemiparesis, hemiplegia, aphasia, apraxia, dysarthria, and dysphagia (Black & Hawks, 2013). Additionally, cerebrovascular disorders can lead to cognitive impairment and dementia in stroke patients (Chohan et al., 2019). Psychosocial disorders, such as post-stroke depression, emotional lability, mood changes, interaction disorders, and reduced social activities, are also prevalent (Wray & Clarke, 2017). Home care for stroke patients necessitates family involvement as caregivers (Reigada et al., 2015). Families often face uncertainty about prognosis, leading to tension (Creutzfeldt & Holloway, 2012). They report a heavy caregiving burden, lack of information, and emotional distress. Given these complex family problems and the high mortality risk in patients, comprehensive care, including palliative care, is essential (Kendall et al., 2018).

Palliative care aims to improve the quality of life for patients and families facing terminal illnesses by preventing and alleviating suffering through early identification, accurate assessment, and treatment of physical, psychosocial, and spiritual issues (WHO, 2020). The American Heart Association (2014) advocates for palliative care for stroke patients in severe and life-threatening conditions (Holloway et al., 2014). This care is also necessary for patients and families dealing with complex problems, requiring treatment adjustments and symptom control

(Holloway et al., 2014). Stroke patients undergoing home care often experience decreased cognitive and psychological functions, body fatigue, prolonged exhaustion, and reduced participation in social activities. Most care focuses on environmental support for patient mobility and daily activities, often neglecting the interaction between stroke sufferers and their home environment. Home care is vital due to limited family knowledge about the rehabilitation process for stroke patients (Marcheschi et al., 2018). Identifying problems is the first step in providing effective palliative care (Detering et al., 2010). Previous studies in India have identified functional disability, physical burden, psychosocial issues, caregiver burden, counseling needs, spiritual problems, and end-of-life care concerns from the physicians' perspective (Lloyd et al., 2019). While general problems in stroke patients are known, the specific issues of those requiring home-based palliative care remain underexplored, especially in Indonesia.

Currently, no research addresses the challenges faced by stroke patients and their families in need of palliative care in Yogyakarta. This study aims to explore these issues through a descriptive phenomenological approach, providing deeper insights into the problems of stroke patients and families requiring home-based palliative care in Yogyakarta. This research could significantly enhance our understanding and inform the development of targeted interventions to improve care for these patients and their families.

Method

This research employed a qualitative design with a descriptive phenomenological approach. Descriptive phenomenology focuses on understanding and explaining significant phenomena related to human experience (Collaizi, 1978). This research design aligns with the study's objective, which is to explore the problems faced by stroke patients and their families who require home-based palliative care in Yogyakarta. The study reporting adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. Participants in this study were family members caring for stroke patients at home. Participants were recruited using a purposive sampling technique from Dr. Sardjito General Hospital, Yogyakarta. The sample size was determined by data saturation, resulting in a total of 10 participants. Inclusion criteria included: a) families providing intensive care to stroke patients, b) families caring for patients with severe stroke conditions (National Institute of Health Stroke Scale/NIHSS score >14), c) families caring for patients with palliative care needs (Supportive and Palliative Care Indicator Tools/SPICT showing ≥2 general indicators and ≥1 impaired clinical indicator), d) families providing home care, and e) families able to communicate effectively. Exclusion criteria included families unwilling to participate. All participants consented to be involved in the study, and the researcher had no prior acquaintance with them.

The research process was conducted from October to November 2023. The researcher identified the key informant, the homecare coordinator at Dr. Sardjito Hospital, who then contacted potential participants meeting the criteria. The researcher confirmed home visit appointments with participants via WhatsApp. Data collection occurred at the participants' homes through face-to-face semi-structured interviews conducted by the main researcher (RBS), a master’s nursing student at Universitas Gadjah Mada. An interview guide, pilot-tested beforehand, was used. Interviews were recorded with a voice recorder. Data collection also involved unstructured observation to assess the patient's condition, palliative care needs, daily living activities, participant and patient activities, and living conditions. Research assistants assisted in observations and produced field notes. Data collection was completed in one session lasting 40-60 minutes. The interviews and observations were transcribed verbatim and analyzed.

Data analysis utilized Colaizzi's (1978) method to explore the phenomenon, involving stages: 1) reading transcripts repeatedly, 2) identifying significant meanings, 3) forming codes, 4) forming sub-themes and themes, 5) developing a comprehensive description, 6) describing the fundamental structure of the theme, and 7) validating findings with participants. Coding was performed by RBS, while theme formation was conducted by RBS, HSP, and WAN. Analysis was done manually using Microsoft Office. The results yielded 62 codes, 13 sub-themes, and 6 themes. Trustworthiness in this study addressed credibility, transferability, dependability, and confirmability. Credibility was ensured through source triangulation with other family caregivers and homecare doctors, member checking, peer debriefing, and thick descriptions. Researchers' experience in qualitative studies also bolstered credibility. Transferability was achieved by systematically and comprehensively writing the report. Dependability was ensured through an audit trail, and confirmability was maintained by bracketing through self-reflection to mitigate researcher assumptions, ensuring the results reflected participants' phenomena. This research received ethical approval from the ethics committee of the Faculty of Medicine, Public Health, and Nursing at Universitas Gadjah Mada, with the approval number KE/FK/1470/EC/2023.

Results

The participants involved in this study comprised 10 families, including 5 children, 3 wives, and 2 grandchildren who cared for stroke patients. All participants were female and of Javanese ethnicity, and they were caring for patients aged over 60 years, categorizing them as elderly. Among the patients, 7 were diagnosed with non-hemorrhagic stroke, 2 with hemorrhagic stroke, and 1 with both non-hemorrhagic and hemorrhagic stroke. Screening with the National Institute of Health Stroke Scale (NIHSS) revealed that 6 patients had severe neurological impairment. The Barthel Index indicated that 9 patients had total dependence, and the Supportive and Palliative Care Indicators Tools (SPICT) screening results showed that all patients required palliative care **(Table 1)**. This study identified six themes: physical problems, psychological problems, social disorders, cognitive disorders, spiritual problems, and financial problems **(Table 2)**.

Physical Problems

Physical problems in stroke patients include decreased motor and sensory functions, as well as wounds from prolonged bed rest. The motor and sensory disorders observed were hemiplegia, hemiparesis, lack of limb movement, and reduced sensory stimulation. These issues lead to significant mobilization impairment in stroke patients. The meticulous detailing of participants' demographics and patient conditions provides a clear understanding of the study's scope. Addressing physical problems comprehensively highlights the profound impact of stroke on motor and sensory functions, emphasizing the need for effective management strategies in home-based palliative care.

"Hands and feet when moved, they move, if she is in this position, she will stay like this until afternoon when she takes a shower. For example, if you don't notice her legs are crossed, until the afternoon it will be crossed, you know it's just swollen over here (pointing to the leg). The problem in my mother is she cannot move at all" (Participant 8).

The observations of patient 8 revealed hemiplegia in both upper and lower extremities, finger deformities causing the fingers to curve and making them difficult to open, stiffness, and decreased muscle strength in all extremities. The patient’s muscle strength was assessed at 1/5 in all extremities. Bedrest conditions in stroke patients often lead to physical complications such as wounds. Patient 8 exhibited decubitus ulcers, which were in a wet condition. These detailed observations underscore the severe physical challenges faced by stroke patients, particularly those confined to bedrest, and highlight the critical need for comprehensive care strategies to address these issues effectively.

"... there are decubitus wounds above the tailbone and on the back, but the one on the back is getting better anyway." (Participant 8).

Observation results revealed the presence of grade 2 decubitus wounds above the coccyx and on the waist. The family had made efforts to prevent further decubitus formation by placing the patient on a specialized mattress pad designed to alleviate pressure sores. In addition to the patient's physical challenges, the family caregivers also experienced significant physical strain. They reported feeling fatigued and burdened by the continuous demands of daily care, indicating a need for medical personnel's assistance to manage their own well-being. These findings highlight the dual burden faced by both patients and their caregivers, underscoring the necessity for holistic care approaches that support the physical health of caregivers as well as patients.

“How come it's like this, it happens that the children are far away. I am alone so I feel tired", sorry I cried (participant cried)" (Participant 7).

Psychological Problems

The results of this study obtained data that the family as a caregiver did not know the psychological problems in patients. This is because the majority of patients experience communication disorders. The problem of unstable emotions in patients mostly occurs in stroke patients who can still communicate. The family explained that during the stroke, the patient's emotions became unstable, the mood went up and down, and the patient became irritable.

"My father after stroke is more sensitive so he is easily offended... more sensitive is even to grandma so not to us haha. Maybe my father asking for attention, so this is his form of protest" (Participant 6).

Signs of depression were also seen in the patient, family said that the patient now expresses things by crying, being quiet, keeping problems to himself, and the patient does not seem enthusiastic.

"Father is a typical person who cannot open up, so if there is a problem, he keeps it to himself... Maybe this is not strong enough because the conflict in the family is quite bad" (Participant 6).

The results of observations on patient 5 during the study were the patient seemed to cry when the researcher invited communication.

Table 1. Respondent profile.

Code	Age	Gender	Diagnosis	Duration of stroke	Barthel index score	NIHSS score	Main Problem
PS1	93	Female	Non-hemorrhagic stroke	9 months	2	23	Muscle weakness
PS2	95	Male	Hemorrhagic stroke	31 years	1	31	Muscle weakness
PS3	81	Female	Non-hemorrhagic stroke	5 years	7	15	Cognitive impairment
PS4	63	Male	Hemorrhagic stroke	6 years	2	25	Bedridden
PS5	67	Female	Non-hemorrhagic stroke	7 years	3	21	Muscle weakness
PS6	80	Male	Non-hemorrhagic stroke	5 months	3	20	Psychological problems
PS7	78	Male	Non-hemorrhagic stroke	4 years	4	27	Muscle weakness
PS8	90	Female	Non-hemorrhagic stroke	14 months	1	33	Decubitus
PS9	65	Male	Non-hemorrhagic stroke	10 years	1	31	Muscle weakness
PS10	73	Female	Non-hemorrhagic stroke & Hemorrhagic stroke	14 years	1	15	Bedridden

The family also experienced psychological problems. The psychological problems felt by the family are the family feeling sad to see the patient's condition, feeling stressed, and then the family also feels that no one supports the patient's care. The family thinks that the focus of care is not only on the patient, but the family as a caregiver also needs attention.

"At the same time, it was stressful, the decision was in my hands, especially when I entered the hospital, I had to start getting into the car, taking it to the hospital, waiting, taking care of the administration" (Participant 3).

Social Disorders

Communication disorder is a social problem that occurs in stroke patients. Communication problems that occur can include aphasia, apraxia, dysarthria, one-way communication, and speech becoming out of sync. This becomes a problem because the family as a caregiver does not know the patient's intentions and desires, especially during treatment.

"The problem that he can't talk so I don't know what he wants. I don't know what's wrong, he can't tell me !!!" (Participant 7).

Overall, during observation in data collection, the patient had aphasia, dysarthria, and apraxia. Social problems that occur in family are changes in roles due to the patient's illness and leaving other activities to prioritize caring for the patient.

"I leave other activities to take care of the patient, for example, I don't participate in neighborhood activities, but now that the patient's condition has stabilized, the important thing is that someone is taking care of him. In the past, I didn't participate in these activities because I was caring for my mother hahaha" (Participant 5).

Cognitive Impairment

There were 3 patients with dementia out of a total of 10 patients involved in this study. Dementia causes some disturbing problems for patients and families as caregivers. The family said that the patient is currently forgetful, has short-term memory impairment, cognitive function is not running, and the patient has difficulty in making decisions.

"She remembers her memories, but now she forgets them. Sometimes she forgets if she has eaten, forget if she has prayed. Sometimes she asks me maid, "How come I'm not getting food?" even though they she just been fed. Then praying too, "How come I'm not praying?" even though she just prayed. So, the short-term memory is reduced," (Participant 10).

Table 2. Themes.

Sub-Themes	Themes
The patient's motor and sensory disorders	Physical problems
Wounds on the patient's skin	
Families experience physical exhaustion caring for patients	
The patient's psychological condition was not assessed	Psychological Problems
Emotionally unstable in patients	
Signs of depression in patients	
The emotional impact of the family caring for the patient	
Decreased communication abilities in patients	Social Disorders
Social changes in the family	
Decreased patient cognitive function	Cognitive disorders
The patient's spiritual distress	Spiritual problems
Disruption of the patient's worship process	
Financial impact of patient care at home	Financial problems

"If you say it becomes like a child, yes, it's like that. It's not that she can't eat or go to the bathroom by himself, it's more like her decision-making is strange, she's like having 2 emotions, she's happy or sad. So, it's like having angel and demon in one person hahaha," (Participant 3).

Spiritual Problems

Spiritual distress is a spiritual problem that occurs in patients. Two patients experienced spiritual distress. The family said that the condition of spiritual distress occurred because the patient considered that they could no longer walk so they can not want to worship as before. The family also said that there was a spiritual change in the patient who previously still wanted to listen to spiritual songs, but now did not want to. The family explained that currently the patient cannot be guided to pray, the patient also unable to pray.

"...at first, he still wanted to listen to spiritual songs. I listened to him from YouTube, just for a long time he didn't want to" (Participant 7).

"He can't pray anymore; he can't be guided..." (Participant 9).

Financial Problems

Palliative care takes a long time and requires a lot of money. Families feel that family finances are affected when caring for patients at home, especially families using homecare which cannot be covered by insurance. The family explained that there were many expenses for daily patient care.

"It's disrupted, because I'm retired so I have a lot of limited funds..." (Participant 7).

"The most expensive is for the nanny, the salary is very large, extraordinary, and it is often not suitable so it often changes" (Participant 3).

Discussion

Previous research has examined the issues faced by stroke patients from a medical perspective. Patients experience a range of functional disabilities, including decreased physical function and communication difficulties, physical burdens such as central pain, psychosocial issues like depression and anxiety, caregiver burdens, the need for counseling, spiritual problems, and end-of-life care concerns (Lloyd et al., 2019). This aligns with our findings that stroke patients in homecare settings face physical issues such as motor and sensory disorders and decubitus wounds, psychological problems such as unstable emotions and signs of depression, social issues such as communication disorders and changes within the family, cognitive problems such as dementia, spiritual distress, and financial burdens on the family during patient care. The decrease in motor and sensory function due to stroke can significantly impact the patient's mobility, ability to perform daily activities, community participation, and chances of returning to normal activities, ultimately lowering the overall quality of life. Motor paresis and sensory deficits (touch, temperature, pain) are common in stroke patients, with prevalence rates ranging from 11-85% (Hatem et al., 2016). Ongoing paralysis, significant loss of motor function, and persistent disability necessitate palliative care to optimize the quality of life for stroke patients (The University of Edinburgh, 2023). Another prevalent physical problem is the presence of wounds, particularly decubitus wounds, which are common in stroke patients with prolonged bedrest due to reduced motor function. Factors such as advanced age, severe neurological disorders, low hemoglobin levels, a history of diabetes mellitus, and peripheral vascular disorders increase the risk of decubitus in stroke patients (Liao et al., 2019). Limited mobility post-stroke also contributes to the development of decubitus wounds (Chen et al., 2022).

Families caring for stroke patients experience physical strain from providing daily care, transporting patients to health facilities, performing home activities, and planning daily routines for patients (Kumar et al., 2022). Caring for patients with functional disabilities, cognitive impairments, and significant care needs can lead to caregiver fatigue, stress, and depression, adversely affecting their physical health (Schulz & Sherwood, 2008). The "primary caregiver syndrome" described by Córdova et al. (2016) highlights the physical toll on families who provide intensive care, often leading to weakness, loss of energy, and fatigue. These findings are consistent with our observations that families feel physically burdened by the demands of caregiving. Psychological conditions in stroke patients are often overlooked due to communication disorders such as aphasia. Most patients do not express psychological complaints, and healthcare providers tend to focus on visible symptoms like fatigue, pain, and dizziness (Tjokrowijoto et al., 2023). Screening for mood disorders, including depression and anxiety, is essential. The Stroke Aphasic Depression Questionnaire-Hospital version (SADQ-H) can be used by medical personnel to assess the psychological issues of stroke patients with aphasia (Burton & Tyson, 2015). Psychological problems, including unstable emotions and signs of depression, are significant in stroke patients. Mental health considerations are crucial, as one in three stroke patients may experience emotional disturbances and mood disorders (Towfighi et al., 2017). Post-Stroke Depression (PSD) is associated with increased risks of stroke recurrence, disability, mortality, reduced patient participation, and poor quality of life. Addressing psychological issues in palliative care is essential to improve patients' quality of life and prevent early mortality (Perusinghe et al., 2021).

Research has also highlighted the emotional impact on families, indicating that caregiving can be a stressor leading to physical, mental, social, and economic problems (Ramirez et al., 2015). Families often experience stress, financial anxiety, emotional strain, and depression throughout the caregiving process (Kumar et al., 2022; Alam et al., 2020; Schulz & Sherwood, 2008). These issues are linked to patient problems, cognitive impairments, functional disabilities, the duration of care, and family relationships with patients (Schulz & Sherwood, 2008). Social impairment is a significant concern for stroke patients, with over 50% experiencing communication disorders post-stroke. These disorders affect speech, expressive language, and comprehension (Hemsley et al., 2016). Research shows that 64% of stroke patients experience communication disorders, including aphasia and dysarthria, exacerbated by advanced age and severe stroke conditions (Mitchell et al., 2021). These communication problems necessitate palliative care due to ongoing difficulties with speech, communication, and swallowing (The University of Edinburgh, 2023). The impact on family life includes excessive activity, changes in family member behavior, financial difficulties, neglect of work, and social isolation. The excessive caregiving burden can lead to burnout syndrome, associated with severe stress conditions (Tripodoro et al., 2015).

Dementia and cognitive impairment are common post-stroke, particularly in elderly patients. Factors such as stroke severity, lesion volume, lesion location, and recurrent strokes influence the risk of cognitive impairment and dementia. Preventing stroke and cognitive impairment is vital for maintaining optimal brain health (Rost et al., 2022). Palliative care is necessary for patients with continuous cognitive decline despite optimal therapy (The University of Edinburgh, 2023). Spiritual distress arises from impaired motor function preventing patients from performing religious activities. Spiritual well-being is directly related to the quality of life. Patients and families with progressive diseases can experience a loss of meaning or purpose, feelings of hopelessness, isolation, and fear of death (Boston et al., 2011). In this study, patients with bedrest conditions faced spiritual distress due to the inability to worship independently. This aligns with Cipta et al.'s (2021) findings, which show that increased spiritual distress is significantly associated with high symptom burden and poor mental well-being. Spiritual care is a crucial component of palliative care, as recognized by the WHO, aiming to improve patients' quality of life by addressing physical, psychosocial, and spiritual issues (WHO, 2018). Financial problems and lack of financial support are significant burdens for caregiving families. Major financial adjustments are often needed for patient care, with direct (transportation, food, medication) and indirect (employment) costs affecting care. The context of palliative care can increase costs, as meeting patient needs becomes a priority (Gott et al., 2015). Studies indicate that 65% of families caring for stroke patients report moderate to heavy burdens, with 81% experiencing job loss impacting family finances (Kumar et al., 2022).

Conclusion

The problems faced by stroke patients in need of palliative care are intricate and multifaceted. It is crucial to consider not only the patients but also the family issues, as palliative care aims to support both patients and their families. In a home-based setting, the problems experienced encompass physical issues, psychological struggles, social disruptions, cognitive impairments, spiritual distress, and financial burdens. The findings of this study highlight the complexity of these problems, providing valuable insights for healthcare professionals. It underscores the necessity for health workers to adopt a holistic approach in palliative care, addressing the myriad of challenges faced by both patients and their families. The study's results serve as a vital reference for health workers, encouraging them to focus on comprehensive palliative care strategies to effectively manage and alleviate these issues. Furthermore, this study lays the groundwork for future research, particularly in exploring the barriers and challenges faced by healthcare providers in delivering palliative care tailored to the needs of patients and their families in a home-based setting. Such research can further inform and improve palliative care practices, ensuring they are responsive to the complex and diverse needs of those affected by stroke.

Author's declaration

The authors made substantial contributions to the conception and design of the study and are responsible for data analysis, interpretation, and discussion of results. For manuscript preparation, all authors read and approved the final version of this article.

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Availability of data and materials

All data are available from the authors.

Competing interests

The authors declare no competing interest.

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