

Unveiling the patient-centered approach: exploring the needs of Javanese stroke patients in home health services

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ABSTRACT

Home-based care can be effective, efficient, safe, and affordable, if this care is performed using a patient-centered approach. Patient-centered care prioritizes the patient's needs and preferences. The issue of patient-centered care remains the focus of various parties. This study aimed to explore the expectations of patients who have experienced a stroke, their family caregivers as recipients of home-based care services and healthcare workers as home-based care providers. This study used a qualitative explorative model. Semi-structured interviews were conducted with 19 participants, in addition to 4 focus group discussions. Data was analyzed using a content analysis approach with open code 13 software and the results were presented in COREQ systematics for qualitative studies. There were four main themes present in the results: physical well-being, self-actualization, psychological condition and balance between family burden and coping. Physical limitations were highlighted as the most burden some for the majority of the participants. At the time of the study, the majority of the patients, their family and health workers were diligently working towards to achieving the best outcome regarding physical well-being. Physical well-being is a fundamental need. Reaching this goal, could lead to better self-actualization, better physiological condition and improving the burden on families. This study may be useful as preliminary data to compile a home-based care construct indicators for stroke patients.

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1. INTRODUCTION

The issue of quality of health services remains the focus of various parties such as hospital, primary health service, and home health care provider [1]. In health care systems, efforts to establish health quality by incorporating or combining patient perspectives are crucial in order to provide patient-focused health services [2]. The quality of home-based care services are more difficult to assess than hospital services because it is greatly influenced by the role of family as caregiver [3]. Discrepancy in the quality of their health care often influenced by the desires of patients. The involvement of patients and families in these health services will enable the creation of new frameworks that can better reflect the needs of those involved in home-based care services [4].

The condition of post stroke patients who are treated at home is often living with disability. A recent similar study concluded that many needs were conveyed by patients and their caregivers but could not be fulfilled optimally. Unmet needs in stroke survivors ranged from health-related demands to re-integration into the community, whereas unmet needs in stroke caregivers ranged from information needs to help in caring for stroke survivors and themselves [5], [6]. Even though stroke patient needs have been identified, but because of wide range of needs, it is still necessary to assess patients' multifaceted requirements and help them in actively participating in their own care. Furthermore, as the issues faced by stroke survivors and caregivers vary over time, it is critical that these needs be assessed on a regular basis to ensure that appropriate intervention, management, and support are provided. Understanding their requirements would also enable the health system to provide patient-centered and culturally appropriate rehabilitation services [7].

It is essential to deeply understand what the home-based stroke care need from a patient, service provider and stakeholder perspective [8]. Furthermore, it is important to take action to examine the status of home-based care services in Indonesia, particularly for patients of Javanese ethnic background in Yogyakarta. The involvement of patients, families and health workers in the preparation of home-based care service in patients who have experienced stroke has not been widely implemented or assessed. This study aimed to explore the needs from the perspective of patients who have experienced stroke, their family carer, and their health workers regarding the home-based care the patients received.

2. METHOD

This study was conducted from April 2017 until October 2017 using a qualitative explorative model. Data was collected used semi-structured interviews and focus group discussions. Data was analyzed using a thematic analysis approach [9] and presented with consolidated criteria for reporting qualitative studies (COREQ) systematics for qualitative studies [10].

The main participants the study were stroke survivors and family caregivers. Participants were selected by purposive sampling from patients who had experienced stroke that had been visited by home-based care officers from three primary health care services. The inclusion criteria was determined using a maximum variation approach, such as age, gender, religion, socioeconomic status and education. The inclusion criteria for patients included being over 18 years, male and female, able to communicate and had previously been visited by home-based care officers at least once. Meanwhile, the inclusion criteria for healthcare workers included a home-based care team for patients with stroke with a minimum one month duration. A total of 19 participants consisting of 10 patients with stroke and 9 family caregivers were interviewed, while focus group discussions were performed with home-based care service providers at primary health care facility as many as 4 focus group discussion (FGD). Minimum sample size for data saturation in qualitative study was 9-17 interviews or 4-8 focus group discussions for homogenous population and narrow defined objectives [11].

Patients with stroke and family caregivers were interviewed for a duration of about 45-60 minutes per session. All data was recorded with a tape recorder and field notes for information that could not be recorded, such as non-verbal information. To ensure the validity of the qualitative data obtained, triangulation with 3 attempts was conducted, i.e. the data source that obtained from the patient, the family and the home-based care officer, peer de briefing with other investigators to deepen analysis and conducting check-ins with the patients and healthcare workers to ensure that the data we got was in accordance with what the informant said. Four FGDs were conducted with home-based care providers with a duration around 1-1.5 hours. This information was collected until data saturation was obtained.

There were two questions asked to participants: What kind of patient condition is expected after receiving a home-based care service? and What kind of family condition is expected after a home-based care service? All interview data was transcribed with a verbatim transcription style. Determination of coding to theme was completed with software open code version 13. Content analysis was completed by the study team. From the verbatim transcript, then it was turn into coding, which was then reduced by categories. From the resulting categories they were then grouped into themes that reflected the purpose of study. The study obtained a letter of ethics number KE/FK/0314/EC/2017 from the Ethics Committee of the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada. The interviews were conducted after informed consent was obtained from the participants.

3. RESULTS AND DISCUSSION

3.1. Demographic characteristics of participants

The Javanese ethnic group consists of individuals who speak Javanese, and are entrenched in Javanese culture, customs and ways of thinking. They live from the west regions of Yogyakarta to East Java. Majority of Javanese people are muslim, but they remind also the faith based on Hindus or Buddhas [12]. So

Javanese life is colored by religious values and myths, and believing in magical powers [13]. In carrying out life, the Javanese have many philosophies, which are the lifelong grip of Javanese life.

Based on the content analysis data provided by the patients, family and home-based care officers, 4 themes were identified: physical well-being, self-actualization, psychological condition, and balance between family burden and coping. A new theme that emerges from this study which did not find in the previous study was the family coping. Several previous study more concern on family need in health education, but an effort to overcome family burden has not been explored. In depth interviews were performed with ten patients with stroke and nine family caregivers who cared for the patient at home on a 24-hour basis. Most of the family caregivers were spouses of the patients, beside patients' son. All of stroke survivors were Moslem. There were 19 participants involved in the study consisting of nine males and ten females, aged from 40 to 80 years old as shown in Table 1.

Table 1. Demographic characteristics of patients and caregivers

Characteristics	Patient (n=10)		Caregiver (n=9)	
		n (%)		n (%)
Age				
Min-Max	48-80 years		40-75 years	
Median	60 years		54 years	
Period of stroke attack				
Min-Max	4 months-27 years			
Mean±SD	5.43 years ± 7.7			
Types of stroke				
Ischemia stroke		10 (100%)		
Current symptoms				
Upper and lower limb hemiparesis	Sinistra	7 (70%)		
	Dextra	2 (20%)		
Dysarthria		1 (10%)		
Gender				
Male		6 (60%)	3 (33.3%)	
Female		4 (40%)	6 (66.7%)	
Education				
University		1 (10%)	1 (11.1%)	
Senior high school		2 (20%)	1 (11.1%)	
Junior high school		1 (10%)	1 (11.1%)	
Elementary school		2 (20%)	4 (44.4%)	
SR (a primary school during Japanese colonialism)			1 (11.1%)	
Never get formal education		4 (40%)	1 (11.1%)	
Employment				
Traders		3 (30%)	3 (33.3%)	
Wifehouse		2 (20%)	3 (33.3%)	
Government officer		2 (20%)		
Parking attendants		2 (20%)		
Teacher		1 (10%)		
Farmer			1 (11.1%)	
Laborer			1 (11.1%)	
Unemployed			1 (11.1%)	
Caregiver status				
Wife			5 (55.6%)	
Husband			2 (22%)	
Son/daughter			2 (22.2%)	

A caregiver is a person who treats and accompanies patients every day, they can either stay with the patient or live apart from them. A study by Tsai *et al.* [14] mentioned that most caregivers are the children of the patients themselves. Indonesia has a patrilineal culture, married couples or single adult children will still live together with parents as a big family. This culture also has the consequence that if a parent becomes sick then the caregiving duties fall to the children or the child's wife/husband. This duty of the child taking care the parents is also influenced by the islamic belief "birrul waalidain" which mean devoted to parents as stated in Al-Quran surah Al-Isra 23-24, An-Nisa 36, Al-Ahqof 15-16 [15].

Family for Javanese people is a place to foster a sense of mutual assistance and so family members have deep trust and loyalty with each other [16]. Another Javanese principle is also well known, "*Rukun Agawe Sentosa* (happiness in harmony)" and describes the relationship between siblings, namely that fellow brothers must help to other. It means the goodness of a person will bring out the good of the whole family, and a loss suffered by one brother will be felt by another. Harmony in the family will make the family strong,

even the family of the second generation (grandparents), they are still involved in the nuclear family. Another philosophy in the relationship of siblings in the family is “bear the pain but can’t bear to die. Even if it is not a child or brother, but loses if die” (*Tega Larane ora tega patine, dudu sanak dudu kadang, yen mati melu kelangan*). This proverb is a picture of the close ties of brotherhood in Java. Even though brothers often fight, but if there are difficulties and suffering, they will still help each other. Likewise, even if there is no relationship, if a good relationship is established between members of the community, then it will be considered as a brother [16].

FGDs for health workers were conducted four times with each FGD having 6 to 10 participants, in total there were 4 males and 23 females, distributed across various types of healthcare professions and educational levels ranging from diploma to master. Participants were chosen from three primary health care services. The characteristics of the healthcare worker participants involved in the FGDs in the study are listed in Table 2.

Table 2. Demographic characteristics of health workers

Characteristics	n (%)	Characteristics	n (%)
Age		Profession	
Min-Max (30-55 years)		Nurse	12 (44.4%)
Mean±SD (40.85 years±8.58)		Doctor	4 (14.8%)
Gender		Nutritionist	3 (11.1%)
Male	4 (14.8%)	Health analyst	2 (7.4%)
Female	23 (85.2%)	Pharmacist assistant	2 (7.4%)
Education		Physiotherapist	2 (7.4%)
Master	2 (7.4%)	Psychologist	2 (7.4%)
Bachelor	7 (25.9%)	Ethnic	
Diploma III	15 (55.6%)	Javanese	26 (96.3%)
Vocational school	1 (3.7%)	Javanese-Sundanese	1 (3.7%)
SPK (Junior high school)	2 (7.4%)		

3.2. Theme determination

Analysis with open code obtained 145 codings, which was then grouped into 9 main categories related to the quality of home-based care services for stroke survivors which were independently completing daily living activity, free of complication, positive psychological condition, negative psychological condition, social activity, role in family, health counseling, family independence in patient care, and family coping. The nine categories were then reduced to four themes i.e. physical wellbeing, self-actualization, psychological conditions and balance between family burden and coping as shown in Table 3.

Table 3. Determination of themes, category and code

Theme	Category	Coding
Physical well-being	Independently completing daily activities	Completing activities, washing, sweeping, working, eating, walking, riding a motorcycle, drug management, motor function back to normal, talking, seeking a doctor, cooking, independence, bathing, routine therapy, health education
	Free from complications	Arm not stiff, the illness does not recur, healed, no decubitus, no complication
Self-actualization	Social activity	Gathering with friends, family visit, singing “keroncong” (traditional song), joining in social activities
	Role in the family	Gather and play with grandchildren, take care of grandchildren, visit son/daughter and grandchild, taking children to school
Psychological condition	Positive psychological response	Praying at the mosque, long life, praying in a congregation, motivated to recover, praying more often, sincere, consciousness, self-awareness
	Negative psychological response	suicidal ideation, depression
Balance between burden and coping of family caregiver	Health counselling	Health consultation, nutrition consultation
	The family caregiver is able to independently care for the patient	Taking care of patient independently, training diligently, returning to work, family caregiver keep healthy, remembering to take the drugs from the health service, be patient in caregiving, persevering, be patient, empathy, motivating, capable of making decisions, understanding the problem, complying with the health worker’s directions, family caregiver at peace
	Coping of family caregiver	Can go outside, his/her son/daughter will care on them in elderly period, no stress, taking care in harmony, no shy, accept the condition, sincere for taking care

3.2.1. Physical wellbeing

The participants indicated wanting to walk again, wanting to ride a motorcycle again, hoping that motor function can become normal again and can take medication regularly. Complete independent for daily activities was expressed in some answers told by the participants.

“Yes, I just want to as it used to be, can sweep, can wash, can do anything like that. So if I eat want to use my right hand, it's okay to wear your left hand.” (P9, female, 65 years)

Understandably most post stroke patients wish to recover and be able work again because they are not become an illness people permanently. Javanese residents define illness and want to go to health facility when only they cannot work anymore. As a result of strokes causing weakness and limb paralysis means that almost all of the study's participants could not work anymore. In Javanese residents define mild illness if they can still walk, still able to work, can still eat and drink, and simply by taking traditional medicines. While severe illness is defined if the body is weak, unable to perform daily activities, insomnia, weight loss, should seek treatment to doctors or primary health care and even hospitalized at the hospital with expensive cost. A person is said to be sick if suffering from chronic diseases or other health problems that cause work or daily activities disrupted, so that even if someone is sick such as cough, cold, but if not interfere their activities, then someone is considered not sick [17]–[19].

Neurophysical impairment is the most common effect of stroke and causes motor function disability. Mutai *et al.* stated in their study, that stroke patients in the home experienced a reduction of motor function after one until two years after discharge from inpatient care [20]. It was related with Barthel index score, the score for predicted dependency level, 20% of patients with stroke had deteriorated after three years rehabilitation compared to at their one year assessment, due to recurrent strokes and other co-morbidities. Old age and other disabling conditions, may cause the rehabilitation progress to slow [21]. In this study the physical well-being was the most common theme present in the data. Patients with stroke expressed their desire to be able to eat, drink, take a bath and complete any other physiological need independently. According to the Abraham Maslow theory, physiological needs are the most basic needs that must be satisfied. When physiological needs are met, it can reduce an individual's stress level. If every need cannot be fulfilled, then an individual will place physiological needs first as the highest priority that must be fulfilled. Undoubtedly physiological needs are the most prepotent of all needs [22].

3.2.2. Self-actualization

Self actualization was reached through social activities. Social activities description were supported by the expectations of participants who want to stay together with friends and the desire to visit sibling's house again.

“Yes, I want to meet my friends like that, but the foot cannot walk, so it can't be helped.” (P8, female, 48 years)

Self-actualization in this study refers to patients' expectations regarding being a part of their community and family. Involvement in social activities tends to be important for stroke patients and can in turn enhance their physical condition. The study by Mutai *et al.* showed that social-dwelling participation was significantly associated with improvement of daily living activities in long-term care [20]. This underlines that interventions targeting social or community function are crucial for maintaining and improving patients' capability in daily living activities for stroke survivors. The Barthel index score on admission phase for 10 days post stroke was found to be an important factor that can predict the social performance of patients with stroke [23]. Patients who were more independent with self-care (ADL) showed better social participation [24]. By doing basic daily activities, leisure activities and other domestic work patients can improve muscle strength and endurance, which leads to improved motor function [20].

3.2.3. Psychological conditions

Psychological condition was explained through the participants wished could worship more diligently than before getting sick, wanted to go to the mosque and attend the praying. Health workers also expected patients and families to remain motivated to recover. But, there were also patients who hope to die soon because cannot withstand with illness, had tried to end life by hanging himself, and often confined himself in the room.

“.. my wish is just die soon, miss..” (P7, male, 56 years)

In addition to improved physicality, psychological conditions were also expressed as a concern for home-based care patients who experienced stroke. Psychological responses are closely related to one's mental. Indeed, there was even one patient who expressed a desire to end his life because he could not stand the illness. The patient's statements formed the main keywords because they indicated the patient's negative psychological condition, requiring intervention and becoming a concern for health and family workers.

Psychological burden from unresolved chronic illness can lead to more severe problems such as depression. Booker *et al.* mentioned that the impact of illness can cause patients to become unable to work meaning family income decreased [25]. Concerns related to family finances and children's school tuition made patients short-tempered. Another study, relating to thirty patients who experienced stroke found that more than 50% experienced depression and mood disorders such as anger and anxiety [26].

One Javanese philosophy related to sickness is "accept the fate" (*Nrimo ing pandum*) which means that humans must be patient, thankful and accept every situation they experience because everything has been destined by Prayekti [27]. This does not mean humans should surrender without effort, but with belief in resigned, that can make someone more active in working but not excessive and as an effort to curb themselves from the adverse effects of the disaster experienced [28]. As such when an individual is sick, they must reach a stage of acceptance and should not give up on life, but make efforts to reduce the severity of suffering such as by seeking treatment. One way to reduce the potential for depression in patients and families is to tell the health workers about the problem. Meeting with health workers can be helpful and can also be completed through electronic media. However, most patients prefer to be visited by health officers directly in comparison to telemedicine because many patients are unable to utilize technology and prefer to consult directly with the health professional who visit them [29].

3.2.4. Balance between family burden and coping

Some expectations of participants related to burden and coping related to health were able to counsel related to food to health workers and the type of exercise that can be done at home. Families also hope can be independent in taking care the patient, not much dependent on other family members, still able to work and still keep healthy. In the end, how much big the burden facing by the family, the health workers hope that the family does not stress and the comfort circumstance in the family can be achieved.

"Yes, do it slowly, I am grateful, my sister can replace each other even though used to taken care by mother, who make a living is mother, the father is happy to be alone, but my sister and I do not think negative things, do not think of the past, thinking of my old father's mistake, so my sister was thinking she was caring for the parents so tomorrow also cared for by her son so, do not want to ask for replies." (K3, female, 40 years)

Stroke is a chronic disease that requires long term treatment, especially amongst elderly. Long-term home-based care can cause a burden for the family caregiver, cause the stress and interfere with their quality of life. A study of many caregivers showed that family health status contributes most significantly to family burden in caring for elderly patients. The burden experienced by the family is usually caused by several factors such as the physical exhaustion and lack of sleep. Psychologically families often complain about anxiety about the condition of patient who do not recover causing families to become pessimistic and embarrassed [30]. The burden on the family can also be caused by social problems such as the schedule of caring for the patient, as the family can no longer gather with neighbors or friends, cannot engage in social activities, and due to financial problems related patient care costs, and family members being unable to contribute financially due to their caring commitments. Families experience a double burden because as the primary care giver for the patient as well as the financial provider.

Family health status becomes an important factor that should considered by home-based care officers in addition to the health status of patients. Healthy, happy families will have an impact on a patient's treatment, and when the family is less stressed the patient will have better care. Orfila *et al.* stated that families who experience a high burden in caring for patients are at higher risk of abuse towards the elderly both verbally and physically [31]. Other factors related to family burdens were family age, family knowledge and family satisfaction. Younger families will experience higher caring expenses due to a lack of emotional maturity resulting in a risk of conflict with patients [32].

A study by Lines *et al.* [33] mentioned that according to the experience of home-based care recipients, one of the home-based care patient's needs is to receive education from health workers according to the condition of the patient and their family members. This study supported another research which concluded that stroke patients indicated a need for tailored health information, psychosocial services, pro-active follow-up care and improved coordination of care [34]. Health worker visits are one way to reduce family burdens and increase family coping to adapt to their current living conditions. Families who have knowledge of caring for patients have lower caring burden than families who have no knowledge. A high

level of education or knowledge will make a person wiser in handling problems [35]. Health education provided to families will reduce the risk of families becoming affected by stress because it can increase self-esteem and family competence in nursing patients at home [36]. Health education being provided to the family in the form of psycho education has been proven to reduce depression, caring burden, and improve family knowledge [37].

4. CONCLUSION

Patients who have experienced stroke expectations of home health care outlined four themes that affected them namely physical well-being, self-actualization, psychological conditions and balance between family burden and coping. The main perspective expressed by patients was directed towards their physical capabilities. Physical inability was the most burdensome for the majority of the participants. Currently many patients, family and health workers were work hard towards achieving the best physical well-being they could. Reaching this goal, will in turn lead to better self-actualization, better physiological condition and reducing the burden on the family. Further studies to explore the expectations of stakeholders could continue to involve all the sectors of home-based care services such as hospital leaders or health centers, health offices, regional heads as well as communities around the patient's residence as a primary support system for patients. Further studies could also expand the area of focus outside of the province of Yogyakarta and also compare patient's needs between those from a Javanese ethnic background with other ethnic backgrounds in Indonesia.

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