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Problems and needs when caring for stroke patient at homes

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ABSTRACT

The Thailand health policy aim to develop the patient care system in a community level, especially, the home rehabilitation program for stroke patients. Currently, stroke patients have long term disabilities and recurrent stroke leading to the serious life-threatening and death. The study investigated the problems and needs of caregivers for taking care stroke patients after hospital discharge and caring at home. A qualitative study was conducted in 80 key informants that comprised of 25 post stroke patients, 25 caregivers, 10 local health care officers at the community, 10 community leader, and 10 health volunteers. An in-depth interviews and focus group discussions were designed to collect the data. Caregivers were not confident about ability and skill to care stokes patients at home. Additionally, they were not understood the policy and health care service system. Health volunteers lacked of experience for supporting stroke patients in the community. The community leader and local health care officer needed more knowledge and skills including budgets, equipment, and facilities for caring the stroke patients. Ability, knowledge, skill and experience for caring stoke patients of the health care team should be addressed. Moreover, resources, facilities, equipment and budgets must be properly supported.

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1. INTRODUCTION

Stroke is a serious life-threatening medical condition in which poor blood flow to the brain causes cell death. This cerebrovascular disease is a major global public health problem around the world. The world stroke organization (WSO) reports that stroke is the leading cause of the second highest mortality in the population over 60 years [1]. About 80% of the world's population is at risk of stroke. Each year there are 13.7 million new stroke cases a year. Of the 17 million people who have had a stroke worldwide in a year, 6.5 million people die from a stroke [2], [3].

In Thailand, stroke is the leading cause of death. It is particularly fatal for females [3]. From 2016 to 2019, the stroke mortality rate increased more than 40% each year, with increases of 40%, 43% and 44%, respectively [3]. The medical expenditures for taking care stroke patients were high. The patient cost for the stroke unit per patient-day was three times higher than the average unit cost per patient-day for the regular neurological ward. The Ministry of Public Health estimated that overall health expenditure and social care costs for the treatment of stroke patients was extremely high in every year [4].

The Ministry of Public Health has been reforming the Thai health service system. It has been increasing access to health care services for the entire Thai population. A shortage of doctors and medical staff in primary health care settings is a big problem in the Thai health care system. Currently, the government launched a health

policy called the "Seamless Service Network," which strives to connect health services between the primary, secondary and tertiary health care levels [5]. This policy aimed to reform the primary health service system by creating a Primary Care Cluster project to provide people with access to health services and with inclusive health promotion. The family care team consisted of family medicine physicians and multidisciplinary public health staff [6]. These personnel provide health services to the people in their houses and communities [7], [8].

The family care team for stroke patients provided stroke care services for cerebrovascular patients at home. The care team focused on stroke patients' rehabilitation and supported caregivers or relatives caring for stroke patients. Moreover, this team provided money to pay for transportation of patients to visit the hospital. There was also a budget to help the patients that are cared for by family [7], [8]. Currently, the guidelines for caring for stroke patients at home has not been published. Caregivers and community leaders lack the skills and confidence to care stroke patients. Therefore, the family care team for stroke patients is vitally important to improve the health service system in primary care setting [9].

The Chonburi province is located in the eastern part of Thailand. Currently, there are many recurrent stroke patients. The number of stroke patients have been increasing every year in this province. Typically, stroke patients suffered from several symptoms such as hemiplegia, lessening the ability to walk. From 2015-2020, the incidence rate of stroke was more than 250 cases per 100,000 population. The mortality rate from stroke was more than 70 deaths per 100,000 population. Less than 10% of stroke patients experienced good rehabilitation. In addition, 30% of stroke patients had complications with ulcers and 20% of patients had infection. Almost all stroke patients that stayed at home experienced disability or death [10]. Therefore, the objectives of this study was to investigate what problems caregivers experienced with stroke patients after they left the hospital. We also aimed to understand how practices of home caregiving and how coordination of the family care team and communities could influence health outcomes of stroke patients.

Previous studies in many countries found that the strategies of caring for stroke patients were stroke's caregivers should have knowledge for taking care stroke patients, family-center should be developed [11], [12] and interdisciplinary care teams and health worker in community should strongly coordinated. Home care for caring patients at home should be supported by quality and specific teams [13]. Additionally,the role of nurse for patient rehabilitation should be increased responsibility [14].

The rehabilitation for stroke patient was the essential treatment to recover as soon as for any critical symptoms of stroke. Our study presented the stroke patient care system in a community-level by the health care team that consisted of the caregivers of stroke patients, the family care team and health worker in community. After discharging from the tertiary hospital level, patients were transferred to Bo Thong Hospital as the secondary hospital level after that they were transferred to the health center as primary hospital level and their home by taking care from the multidisciplinary team in community. All people in health care team for caring stroke patients provided the treatment, rehabilitation and support services for stroke patients [15]. Of 25-32% of stroke patients had disabilities, serious complications and recurrent. Moreover, they had problems with missed appointments for follow-up more than 50% (in 2012 to 2017). Therefore, this study interested in investigated the community-based care problems and needs among those who took care of stroke patients at the community level to improve the most effective care for patients.

2. RESEARCH METHOD

2.1. Study design and participants

We conducted a qualitative research study in Bo Thong District, Thailand. Chonburi in home care clinics of Bo Thong Hospital which is a secondary care center there were 118 patients with stroke in care. The study period was from August to October, 2020. All participants were selected using a convenient randomized method. Participants in the study consisted of three groups: i) 25 patients diagnosed with stroke were enrolled at home care clinics. In the responsibility of Bo Thong Hospital in 2019, received continuous care at home after leaving the hospital for six months or more, able to communicate in language; ii) 25 caregivers of stroke patients took care of their relatives, iii) the community health care team consisted of eight community leaders, 10 village health volunteers and 10 health professionals who worked in the area for at least three years. Provide written consent before participating in this study.

2.2. Data collection and analysis

The study was approved by the human research ethics committee of the human research ethical consideration of Thammasat University number of COA 236/2020. In this qualitative study, the investigators gathered concealed information for which the respondents did not know the true state of the local data acquisition. All participants gave their written consent before participating in this study. We design an interview guide based on our literature review. It consists of the following questions: Questions for patients and caregivers: i) patient health problems that arise during home care; ii) the need is supported by the health team.

Oppose social assistance and resources to support health care of community health teams, community leaders and public health volunteers: i) what are the problems in caring for surviving stroke patients and returning to care at home?; ii) how is it necessary to help support the care of surviving stroke patients in the community? and verified by experts by selecting a specific sample group based on research objectives, stroke patients and their caregivers were interviewed at home individually using the interview guide.

All interviews are in Thai and recorded on audio tapes. The record was copied in Thai text, which was later translated into English. We generally spend about 1-1.5 hours in each interview (three counts) to achieve saturation. We collect information from community health care teams through audiences (public health officer public health volunteer and community leaders) in every health service unit in Bo Thong District. We asked about health care problems at home of stroke patients. We also asked health care teams about what is needed to make home health care better for stroke patients. We also spent 1-1.5 hours talking with discussion group participants to gather enough information to reach saturation point. We used content analysis to analyze the qualitative data from this study and use a predefined 3-step identification list to categorize the data. Creating relationships and grouping data into language structures.

3. RESULTS AND DISCUSSION

3.1. Overview of respondents

Twenty-five stroke patients were enrolled in our study. Stroke patients ranged from age 25 to 81 years old (mean=61.97, standard deviation (SD)=19.86). More than half of patients were female (52%). Most patients had experienced ischemic stroke (80 %). Almost half of stroke patients had hypertension (40%) and almost a quarter of them (24%) had diabetes mellitus (DM). More than half (64%) were admitted at the stroke unit. When patients stayed at home, about half (52%) experienced ankylosis is stiffness or fixation of a joint by disease and motion with ankyloses as the complication. At the six month follow up visit with a village health volunteer, patients had an average Barthel activities of daily living (ADL) index of 98.15 considered high (SD=54.55). Within 28 days after their initial discharge as a stroke patient, most patients were readmitted into the hospital less than one time or not at all. A little over half (52%) of stroke patients did not have a physical disability. We summarized results in Table 1.

Table 1. Baseline characteristics of stroke patients

Characteristics of stroke patients	Number **(%)**
Gender	
Male	12 (48.00)
Female	13 (52.00)
Age (years), Mean±SD	61.97±19.86
≤35	7 (28.00)
>35	18 (72.00)
Types of stroke	
Ischemic stroke	20 (80.00)
Hemorrhagic stroke	4 (16.00)
Transient ischemic attack (TIA)	1 (4.00)
Underlying disease	
Hypertension	10 (40.00)
Diabetic mellitus	6 (24.00)
Dyslipidemia	3 (12.00)
Heart disease	1 (4.00)
More than two diseases	5 (20.00)
Type of unit patient was admitted to	
Intensive care unit (ICU)	9 (36.00)
Stroke unit	16 (64.00)
Complications experienced by patient	
Bedsores	5 (20.00)
Ankylosis and motion with ankylosis	13 (52.00)
Infection	1 (4.00)
Barthel ADL index at 6-month follow-up visit (Mean±SD)	98.15±54.55
	83.24 (N=18)
Re-admission to hospital less than 28 days after initial discharge	
Never readmitted	3 (12.00)
Readmitted less than one time	17 (68.00)
Readmitted more than one time	5 (20.00)
Disability	
Physical disability	7 (28.00)
No physical disability	13 (52.00)
Not assessed for disability	5 (20.00)

Table 2 shows the demographic characteristics of caregivers of stroke patients at home. Most caregivers were female (88%) and had a primary school or higher educational level (52%). A majority of caregivers were married (84%) and worked in agriculture (60%). Most of them received caregiver training (88%). Most of them did not have a congenital disease (56%). Table 3 presented demographic characteristics of community leaders, village health volunteers, and health professionals. Most health care team members were female and over 50 years old. A majority of community leaders (75%) and of health professionals (80%) graduated with a bachelor's degree. However, all village health volunteers had less than a bachelor's degree. Most community leaders (87.5%) and most village health volunteers (80%) were married, while most health professionals (70%) were single. Most of them worked more than three years at this community.

Table 2. Demographic characteristics of home caregivers

Characteristics	Male (n)	(%)	Female (n)	(%)
Gender	3	12.00	22	88.00
Age (years) (Mean±SD)	45.4±18.6		58.3±22.1	
≤35	0	0	4	16.00
>35	3	12.00	18	72.00
Education level				
Lower than primary school	1	4.00	11	44.00
Higher than primary school	2	8.00	11	44.00
Status				
Married	2	8.00	19	76.00
Single	1	4.00	3	12.00
Occupation				
General contractor	1	4.00	9	36.00
Agriculturist	2	8.00	13	52.00
Received training for caregiving				
Yes	2	8.00	20	80.00
No	1	4.00	2	8.00
Had congenital disease				
Yes	2	8.00	9	36.00
No	1	4.00	13	52.00

Table 3. Demographic characteristics of community leaders, village health volunteers, and health professionals

Characteristics	Number (%)		
	Community leaders (n=8)	Village health volunteers (n=10)	Health professionals (n=10)
Gender			
Male	1 (12.5)	1 (10)	2 (20)
Female	7 (87.5)	9 (90)	8 (80)
Age			
≤35	1 (12.5)	2 (20)	8 (80)
>35	7 (87.5)	8(80)	2 (20)
Education level			
Below a bachelor's degree	2 (25)	10 (100)	2 (20)
Bachelor's degree	6 (75)	-	8 (80)
Marital status			
Married	7 (87.5)	8 (80)	3 (30)
Single	1 (12.5)	2 (20)	7 (70)
Duration of service at the community level			
Less than three years	3 (37.5)	2 (20)	3 (30)
More than three years	5 (62.5)	8 (80)	7 (70)

3.2. Qualitative results

Figure 1 (a) presented stroke patients shared the health problems they experienced. Here are excerpts of comments from their interviews:

> *"Initially, there was a problem in the left limb. I am't slip at all. To walk you need equipment. But when you command your legs, you cannot move at."* (Stroke patient B, 49 years old)
> *"I had a lot of walking and sliding problems at first. When I drink water, water flows out to my corner of the mouth. I don't have the strength to pick up anything. But I want to do it. But my hands don't have the strength to pick up things."* (Stroke patient E, 38 years old)

"Mental health problems of stroke patients. I have found that after the first few months after being home, almost all stroke patients have mental health problems. (Stroke patient F,68 years old).
"When the doctor made an appointment for examination, there was no car to go to the hospital. I made doctor appointments but could not go. Sometimes the medicine runs out, the caregiver will pick them up instead because I couldn't ride a motorbike during the first 1-2 months after having a stroke." (Stroke patient Y, 38 years old)

Stroke patients discuss the socio-economic problems that they faced in these excerpts from their interviews:

"I haven't been doing my job for nearly 4 months since I have had a stroke. I have no income and still have the burden of car payment. The money that I usually use for my child's school expenses is being used instead for medicine and travel expenses to the doctor at the hospital. I think the main problem is finance during my illness." (Stroke patient C, 47 years old)
"This money is the main problem. During the time I am sick, I have lost income. But I still have an obligation to pay electricity *bills every month. The costs of certain drugs and of using this device are very expensive. I feel pity for my wife. She has to spend time to take care of me and take care of children, and still have to make money to pay for things. Money problems have been putting pressure on me since the first few days upon returning from hospital*." (Stroke patient L, 49 years old)

In summary, in terms of health, stroke survivors had physical problems with accomplishing daily activities such as eating, bathing, walking, and excreting. They also had psychological problems such as anxiety and feeling depressed, especially during the first month of returning to home for care.

3.3. Needs of stroke patients at home

Here are vignettes of stroke patients describing their needs when receiving care at home:

"The most common problem is care during the first month of discharge from the hospital. Patients are extremely concerned. They need a medical team or Public Health Officer with expertise." (Stroke patient W, 41 years old)
"I need a team of doctors to come to help take care me during the first period after I come home because I want to get better quickly. Let the medical team help teach and explain to me how to behave so that I can walk again.' Stroke patients." (Stroke patient B, 49 years old)
"I would like to receive support for a recovery device because the cost of equipment is exceedingly high stroke patients." (Stroke patient O, 52 years old)
"I want the agency in the community to help improve the home environment such as bathroom and bedroom." (Stroke patient J, 46 years old)

In summary, the problems and needs of stroke patients at home are varied. There is a need for a team of doctors, nurses, public health academics to help take care of patients' physical and mental health. There is also a need for assistance to pay for necessary equipment. Patients also want the government agencies in the community to be involved in addressing their needs. Patients also support the improvement of the environment at home. They also indicated that they wanted help with transportation to doctors' appointments for exams and treatment. They also sought out direct help for their family expenses to cover medical costs and other liabilities.

3.4. The problems of the home caregivers of stroke patients on the health and stress

Home caregivers of stroke patients also identified the problems that they experienced. Here are some excerpts from their focus group discussions:

"*I have a lot of body aches when helping the patient. This is due to the patient having a very heavy body weight."* (Caregivers A, 18 years old)
"I have frequent headaches. I am exhausted. Sometimes I have a burning pain in my stomach because he did not eat on time." (Caregivers C, 22 years old*)*
"While taking care of the sick for an extended, prolonged period, I was very frustrated. I have diabetes and high blood pressure. During some months, the doctor informed me that I had high blood pressure. Since I have diabetes, I simply cannot control my blood sugar levels." (Caregivers E, 46 years old)
"Mental health and stress are one of the problems of the home caregivers of stroke patients.'Until I can come to terms with my wife's illness, I am admitting to being stressed as well as having

insomnia and irritability. I have not spoken to anyone. It feels as if I have been cut off from my friends and society since my wife got sick." (Caregivers G, 35 years old)

3.5. Socio-economic problems of caregivers

Caregivers also shared having socio-economic difficulties. Here are relevant excerpts from interviews:

"When it comes to finance, I think that's a problem with my family. There are obligations which must be paid every month. There are a lot of regular expenditures. And my husband, who is sick, also earns money for the house. Sometimes I must borrow money from my friends. It's good that they can help me." (Caregivers B 58 years old)

"During my husband's illness for the past 1-3 months, I did not participate in any social activities. Also, there were some relatives who visited." (Caregivers I, 34 years old)

3.6. Needs of a home stroke caregiver

Home caregivers also mentioned specific needs in the following comments from their interviews:

"I need someone to help me during my husband's illness. I want the medical team to teach me how to take care of patients such as my husband. I felt that I handled my husband's recovery well. It gives me more confidence and does not cause anxiety." (Caregivers J, 24 years old)

"Now the main thing is diapers. The situation is very bad because my father is a bed addict. He needs to use the diapers every day. The price of diapers is quite high. Can the government help support me cover the costs? Are there any organizations that can help? (Caregivers A, 29 years old)

"I want the state to help reduce some of my expenses during my family's illness. I have no income. I need support to reduce my water and electricity bills for the next 3-6 months." (Caregivers F, 55 years old)

In summary, most caregivers encounter problems with stress and anxiety. Some caregivers feel their body is exhausted. They also complain about having aches and pains. They have sleep problems due to a lack of confidence when taking care of their patients, and a lack of time to do other activities. Some caregivers feel that they must bear the family burden when taking care of the stroke patient.

3.7. Problems facing community leaders and village health volunteers in home care for stroke patients

The comments made by community leaders and village health volunteers about the problems they face when attempting to assist stroke patients at home were:

"Community leaders, I do not yet know what caused the stroke. I only know how it has crippled our community member. I do not know how to help and care for him."
(Community leaders C,48 years old).

"Health volunteers, *an important problem is that I do not have a clear understanding about how to care for people with stroke. I have no knowledge of patient rehabilitation skills. But if I receive the training and the ability, then I would be happy to help people in my community."* (Village health volunteers C, 52 years old)

In summary, community leaders face the problem of still lacking knowledge of cerebrovascular disease and patient care. And more importantly, they do not yet know the exact role that health systems should play in caring for stroke patients in the community. In their workplace, which is the homes of stroke patients, health volunteers lack practical skills regarding providing care for patients with stroke, such as this could be delivered by means of a Nasal feeding tube, physical therapy, and individualized care for stroke patients.

3.8. The need of community leaders and public health volunteers to care for stroke patients at home

Community leaders and public health volunteers also identified specific needs that they had when caring for stroke patients in these excerpts from the focus group discussion:

"Community leaders, *most importantly, home care needs to be given. The team is built at the community level. We need to know what are the problems and needs of patients and caregivers and what areas of government policy can support patients and caregivers."* (Community leader A, 51 years old)

"Health volunteers, *we should have a collaborative approach including medical teams and communities. There are government policies to support the care of patients in the community."* (Village health volunteer A, 47 years old)

In summary, community leaders and public health volunteers want to have additional training and education about stroke. They want to learn more about patient care, including correct practices for taking care of stroke patients at home. They would also like clear guidelines for the care of stroke patients at the community level.

Figure 1 (b) presented the focus group of 10 community health workers, consisting of professional nurses and the public health officers, on caring for stroke patients at home and support needs. Here are excerpts from the focus group discussion in which community health workers talked about issues around caring for stroke patients at home and brainstormed on areas where they needed more support:

> *"*There *is now no confidence in the required home care for stroke patients. Sometimes I go to look at patients'* symptoms*, but I don't have skills in rehabilitation of the patient, such as physical therapy of the patient, walking practice, and administering certain medications."* (Health professional E, 24 years old)
>
> *"Policy issues are not* clear *in practice at the community level. Sometimes at the community level there is a lack of doctors, physical therapists, and pharmacists. Health professionals serving stroke patients could benefit from specialized expertise to support working together as a team. Teams could work together in a Primary Care Cluster or within the primary health service system."* (Health professional J, 30 years old)

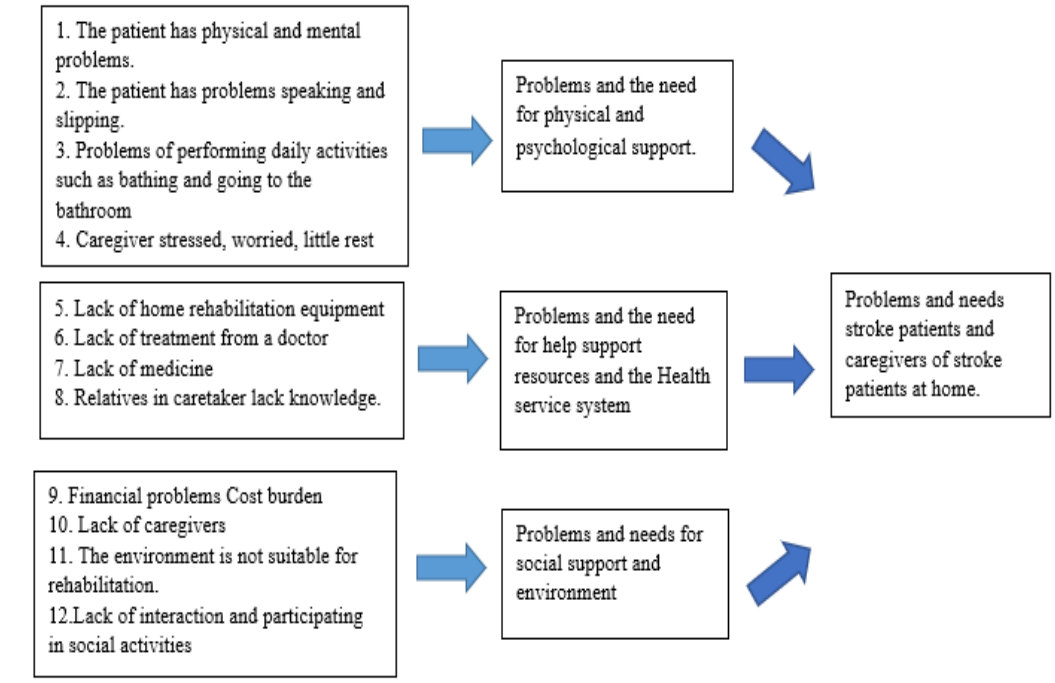
In summary, the community system health team found that an important problem was an unclear community care system for stroke patients. There is also a lack of specialized professional teams containing doctors, physical therapists, and mental health workers. There is for a collaboration of community personnel to assist stroke patients. Ideally public volunteers and government agencies at the community level could come together to support and care for stroke patients holistically. Data classification code building data relationships grouping the data into (open coding) a language structur.

The objective of this study was to gather information on the needs surrounding home care for stroke patients by interviewing stroke patients, caregivers, community leaders, public health volunteers and focus group, a group of public health workers in the community. The results of the interview revealed that Patients and their caregivers encountered three main types of problems: i) physical health problems, ii) daily activities and mental health problems, concerns including stress and health problems, iii) economic, financial, debt and social problems [16]. Patients and caregivers lack social activities and often experience dismissal [17], [18]. This includes previous research indicating the importance of social factors to quality life after stroke. Stroke is related to quality of life [19].

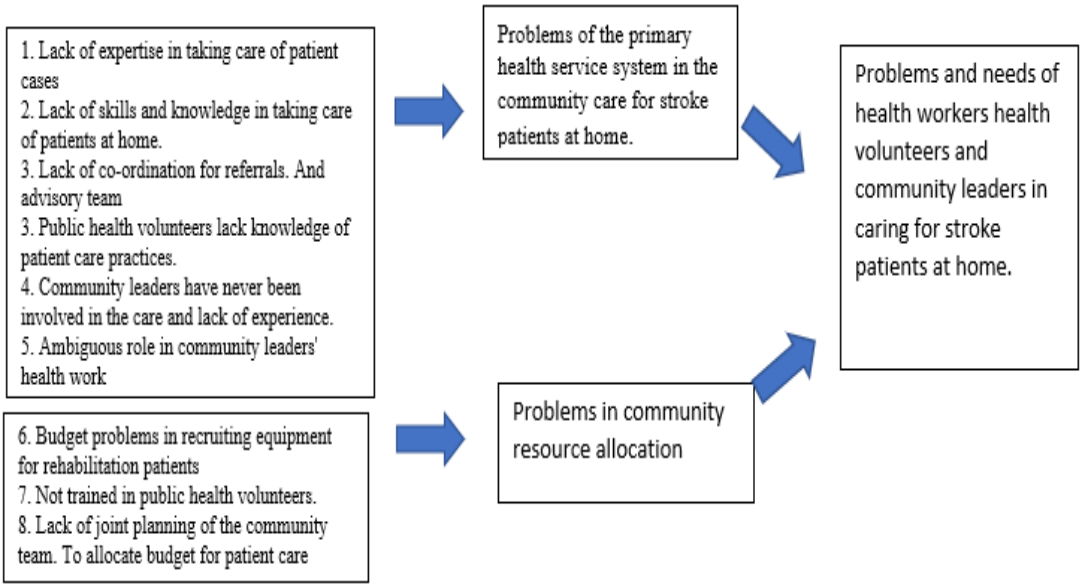
Health volunteers and community leaders want to increase their knowledge and skills about home care for stroke patients. including how to better support government policies [20]. Most community health workers need a team of professionals to provide individualized, integrated care for stroke patients [21]–[23]. Based on our research, we generated a summary of solutions for improving cerebrovascular care problems at community level. First, caregivers, public health volunteers and community leaders must have the knowledge of stroke and stroke care practice. Next, community health staff should provide a family-centered approach to identify the needs of stroke patients and to support home stroke patients have better health. In addition, public health workers need to ensure the cooperation of health volunteers and community leaders to support and help caregivers [24]–[27].

Guidelines for home care for stroke patients at the district level are unclear. This is because most patients will continue to use this form of home care [28], [29]. Therefore, it is important to focus on family members as the primary caregivers. We had trouble coordinating help and advice for caregivers and patients when patients had health problems at home. We found little or no service for stroke patients in the community from the interview data this is our recommendation to establish a patient care guideline by a district-level medical team to coordinate with community nurses and health workers at the community level. That require specific knowledge and skills to care for stroke patients at home [30]. It is including physiotherapists who play a role in teaching patient rehabilitation skills to caregivers and public health volunteers so that they have the ability to practice rehabilitation [31] with a mental health professional to help in the beginning. As anxious and stressed patients and their relatives, as well as audience leaders, play a role in coordinating assistance among community health teams to support appropriate resources. Working together at different levels, this joint team can keep patients safe improve results and reduced hospitalization in stroke patients at home [32]–[34].

The study faced two significant limitations: i) a sample of stroke patients was recruited from a single hospital. The limited scope limits the generalize ability of our findings to community leaders, health volunteers, and public health workers in other communities that are different from the one in our study; ii) the sample size we used in our quantitative assessment was relatively small.



(a)



(b)

Figure 1. Summary of focus group discussion and interview of problems and needs when caring for stroke patients at their homes: a) the problems and needs stroke patients and caregivers of stroke patients at home; b) the problems and needs of community leaders public health volunteers and health professionals to care for stroke patients at home

4. CONCLUSION

The stroke patient care in community was the challenge for health care team to reduce disabilities and recurrence of cerebrovascular disease including mental health and socio-economic problems. Health care team requested to address many problems, firstly, health worker in community at the sub-district level would like to be supported from the medical team from hospital. They would like to understand and solve the health

and the physical problems of individual patients. Secondly, health volunteers and health workers in community should coordinate to follow up the doctor's appointments, and the stress psychological anxiety of caregivers. Finally, community leaders should coordinate with government agencies to support environmental stewardship and equipment for patients. Besides, to find strategies for supporting and increasing the income in households through government policies.

The information about the stroke patient transferring from the hospital to the center community hospital and the public health agencies in the community was very importance to care for stroke patients. Public health workers in the community and public health volunteers should be supported the training, the knowledge and the practice for caring stroke patients at home by good practice guideline. In addition, government policies should support fund and resources to improve the health care service system for stroke patients as a national healthcare policy. For the further research, we need to continue research on appropriate intervention. It aims to provide the effectiveness of health care service for stroke patients, cost-effective transitional care and the needs of caregivers and patients by a focus group to improve health care service. It is also to reduce disability problems and unnecessary medical costs for stroke treatment.

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