Care of stroke survivors in community: a case study of rural Thai community

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Abstract

Purpose – This study aims to describe survivors of stroke circumstances, issues with providing care for survivors of stroke and services expected by caregivers and survivors of stroke.

Design/methodology/approach – A qualitative research design was conducted in Singburi Province. Data collection methods included in-depth interviews, focus groups and participatory observations. Semi-structured in-depth interview guides, quality-of-life scale and depression scale were used to collect data from survivors of stroke, their caregivers, health personnel, local governors and village health volunteers. Naturalistic research tradition was used for qualitative data analysis and descriptive statistics for quantitative data analysis.

Findings – The majority of survivors of stroke had hemiplegic limb and severe deficits in their activities of daily living. Caregivers were family members, and they often developed depression. Issues with providing care to stroke survivors included lack of knowledge about stroke and home care, inadequacy and discontinuity of care and the shortage of stroke care personnel in the community. A stakeholder's expected stroke services included the provision of effective continuing care, community participation in care and enhancing the village health volunteer's capacity.

Originality/value – This study illustrated the stroke service systems in rural Thai communities. The study's findings could be applied when planning future research using community participation to test a model of care for stroke survivors to promote better outcomes and be responsive to the needs of stroke survivors, especially those who are disabled.

Keywords Cerebrovascular disease, Community stroke care, Stroke service system, Situation analysis, Thailand

Paper type Research paper

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Introduction

Stroke is a leading cause of death and impairment worldwide. It caused 3% of the world's disability burden in 1990, and the mortality rate from stroke is set to double in 2020, primarily among the elderly population [1]. In the past decades, low-middle-income countries (LMICs) have experienced a more serious stroke problem compared to high-income countries (HICs) [2]. There are current guidelines for the management of acute stroke, suggesting a course of treatment based on the diagnosis of ischemic stroke and hemorrhagic stroke. However, the challenges in managing these patients combined with inadequate rehabilitation services, lack of preventative measures and poor understanding of possible topical risk factors associated with stroke in LMICs may be the cause of domestic stroke burden [3]. The global epidemiology of stroke in 2015 was 6.33 million, while 80% were LMICs and nearly 10% (625,545) of those were of South-East Asian nationality [4]. The prevalence of stroke in Thailand in 2014 was 352.3 and the mortality rate equaled 44.84 per 100,000 populations. The mean age was 64.6 years old, with males recording a higher prevalence than females [5, 6]. Almost all new cases of stroke occur in people 50 years or older [7]. Research conducted in Thailand identified several risk factors of stroke; these included hypertension, dyslipidemia, diabetes mellitus and atrial fibrillation, which responded for 53, 30, 26 and 10% of stroke cases, respectively [8].

Of the two major types of stroke, namely, hemorrhagic and ischemic, ischemic stroke accounts for 70% of all strokes [9]. Approximately 50% of the stroke survivors aged 65 years and older had hemiparesis, and of that number, 30% could not walk without assistance, 19% had aphasia and 35% had depressive symptoms within six months [10]. Stroke is an important cause of Disability-Adjusted Life Year Loss (DALYL). Furthermore, the risk of recurrent stroke is high; one study indicated that approximately 7.1% of the stroke survivors may have a recurrent stroke within one year, 16.2% within five years and 24.5% within ten years [11].

Stroke victims and their family caregivers are often affected by depression, dissatisfaction with life, problems with family relationships, disruption to social and leisure activities and declining health [12]. A study by Nishio and colleagues revealed that caregivers also experience considerable burden; 69.4% reported experiencing distress or stress in everyday life [13].

Providing continuity of care can reduce hospitalization, shorten the length of stay, reduce bed-blocking and costs of care and reduce caregiver burden [14]. The important step in the continuum of care for stroke survivors is community care, whereby stroke survivors receive care while living at home [15]. Community-based stroke multidisciplinary teams, such as early support discharge teams, can provide better and potentially more cost-effective outcomes than exclusively hospital-based rehabilitation for stroke survivors who have moderate disabilities. However, only 36% of the hospitals in Thailand currently have such teams [16]. As a result, many stroke survivors do not receive timely treatment and rehabilitation, thus slowing down the chances of recovery.

Most stroke research focused on acute and post-acute care, with less attention paid to the more chronic recovery phases where most patients face functional impairment that impacts their daily lives. Thus, successful recovery after hospital discharge starts with discharge planning for all stages of post-stroke rehabilitation and care. The chronic phases of recovery focus on improving the survivor's performance of functional activities and support to facilitate community integration, including participation in vocational and avocational rehabilitation [17]. This study aimed to describe stroke survivors' circumstances, issues with providing care for stroke survivors and expectations for services of caregivers and stroke survivors. Understanding the needs of stroke survivors helps to develop appropriate community care services that would then decrease the overall cost of care, support quality of life among survivors of stroke and reduce caregiver burden.

Methods

A qualitative research method was used to describe the status of stroke care in Tar-Ngam, Inburi, in the Singburi province of Thailand. Data collection from 87 participants included individual interviews with survivors of stroke and their families to assess their perceptions about the stroke care received and what they had expected (Table 1). Focus group discussions of village health volunteers (VHVs) and village headmen were used to describe environment and community participation in stroke care services. Participatory observation of home visits was used to obtain qualitative information about the survivors' care problems and needs. Attendance at meetings with community members to maximize the range of community stakeholder's perspectives captured information about policies, resources mobilization, practice guidelines and coordination of projects. Documentaries from the sub-district health-promoting hospital (SDHPH) and district hospital (DH) were also used to study the condition of survivors. Survivors' functional ability and caregiver depression status were used to understand the nature of the burden and consequence of care provision.

Key informants

Groups	Participants and codes	*N*
Survivors and families of caregivers	Survivors of stroke (PT)	22
	Family caregiver (CG)	20
	Employee caregiver (CG)	4
Healthcare personnel	Medical doctor (PH)	1
	Pharmacist (PH)	1
	Physical therapist (PH)	1
	Nurse (PH)	1
	SDHPH nurse (PH)	1
Community partners	Sub-district administration organization officer (CP)	3
	Village headmen (CP)	11
	VHVs (CP)	22
Total		87

Table 1. Number of participants and codes

Instruments

There were four instruments. First, a semi-structured in-depth interview guide was developed by the first author using the innovative care for chronic conditions (ICCC) framework assessment [18]. This interview guide was detailed as community resources mobilization, environment and participation of the community in the provision of care for stroke survivors. It was validated for both content and validity by three experts. Second, focus group discussion was used to identify stroke health issues, the caregiver situation and building a vision for stroke health care by community stakeholders. Third, an observational guideline was developed using health information obtained directly from stroke survivors and caregivers. Fourth, health documentaries from SDHPH and DH were used to collect baseline data regarding each patient. Fifth, to measure the physical functional ability of stroke survivors, the modified Barthel index (MBI) was used [19]. The Thai version was translated by Loharjun *et al.* [20]. Sixth, the Thai version of the Center for Epidemiologic Studies Depression (CES-D) scale [21] was used to measure caregivers' depression. Cronbach's alpha coefficient reliability for the MBI and Thai version of the CES-D scale was 0.80 and 0.90, respectively.

Procedure

Ethical approval was obtained from the Faculty of Public Health, Mahidol University, and COA. No. MUPH 2014-123, date of approval was May 30, 2014. Participants who met the study criteria were provided with details about the study's purpose and methods. All who agreed were required to provide written informed consent to participate in the research.

Data analysis

Qualitative data were collected and analyzed simultaneously using a thematic analysis approach [22, 23]. The characteristics of the participants were analyzed by using descriptive statistics. The trustworthiness of the data was identified by using the criteria proposed by Lincoln and Guba [24]. The researcher conducted member checking by sharing and discussing the interview summaries with five stakeholders to evaluate the credibility of the data collected through the focus group discussions, in-depth interviews and the researcher's transcribed field notes.

Results

Characteristics of stroke survivors

Of the 27 stroke survivors recruited into the study, 12 were men and 15 were women. Hypertension was the main co-existing condition. In the overall sample, 40.7% were in years 1–5 of post-stroke stage, 77.8% had a hemiplegic limb disability and 37% were dependent on physical functional ability (MBI). Most caregivers were family members, and 25.9% suffered from clinical depression (Table 2).

Theme 1: stroke care issues

The findings found three sub-themes of stroke care issues.

Knowledge and passive attitude of stroke. Survivors and their caregivers had a lack of knowledge about stroke. They did not know what causes a stroke, and many thought a stroke was caused by a fall or "karma," which cannot be prevented and corrected. Unfortunately, survivors of stroke experienced loss of follow up regarding their condition:

> I didn't know he had a stroke, I thought he became disabled because of a fall. After he first fell, he could walk by himself. I always reminded him to be aware of falling again but it happened (CG7).

> I thought all sickness resulted from one's past deeds. We couldn't negate it all (PT4).

> I believed it was from a past experience that I had drowned in a gas tank and inhaled the vapor amount of gas, (thus causing this present condition) (PT9).

Stroke caused survivors to isolate themselves from social activities, especially the survivors who had severe disabilities such as a hemiplegic limb, cognitive dysfunction and speech impairment. They lived as a burden to their families:

> I couldn't go out since I fell. My everyday life for the past 8 years is spent in this wooden cradle until my leg joints couldn't work (PT17).

> I ate the same with others so I could not choose which one (food item) is good (for my condition) which one is not. I didn't want to make any problem for others. My blood sugar and blood pressure were not reduced as I expected (PT3).

> When he had the first fall, he could walk, and I could provide care by myself. After the second fall, I could not handle it alone. So, my son had to leave his work in a big city and live close to home where he earns less money (CG2).

One consequence of caring for survivors of stroke was depression, with 25.9% of caregivers experiencing depressive symptoms. Besides, 58.3% of the caregivers had restless sleep, 25% felt depressed and 45.8% had trouble keeping their minds on what they were doing. Survivors with severe or persistent disabilities caused severe depression for the caregiver:

> Since he was a stroke patient, I was the only one who provided care. I had to quit a steady job to take care of my father. Don't ask me if I suffer from depression, but rather, how depressed I am (CG1).

Characteristics of survivors of stroke	Frequency	%
Gender		
Male	12	44.4
Female	15	55.6
Age (years) mean = 75.5 years		
30–40	1	3.7
51–60	3	11.1
>60	23	85.2
Marital status		
Single	3	11.1
Married	9	33.3
Widowed	15	55.6
Years of stroke experience (years)		
< 6 months	1	3.7
1–5	11	40.7
5–10	7	25.9
>10	8	29.6
Co-existing conditions		
Hypertension	22	81.5
Diabetes mellitus	4	14.8
Hyperlipidemia	6	22.2
Heart disease	3	11.1
Other diseases	3	11.1
Stroke impact		
Hemiplegic limb	21	77.8
Cognitive problem	3	11.1
Non-impact/full recover	3	11.1
Physical functional ability (MBI)		
Total dependence	10	37.0
Severe dependence	2	7.4
Moderate dependence	1	3.7
Slight dependence	5	18.5
Independent	9	33.3
Caregiver		
Family caregiver	20	74.1
Employed caregiver	4	14.8
None caregiver	3	11.1
*Caregiver depression (CES-D >16)**		
Depressed	7	25.9
Non-depressed	20	74.1

Note(s): *The CES-D scale is a brief self-report scale designed to measure self-reported symptoms associated with depression experienced in the past week. The items of the scale are symptoms associated with depression, which CES-D scale equal to 16 or greater aid in identifying individuals at risk for clinical depression

Table 2.
Characteristics of survivors of stroke ($n = 27$)

While knowledge of self-care and rehabilitation among survivors and families was very important, the perceptions about stroke were also crucial because these perceptions helped to promote the accuracy and appropriateness of self-care. Unfortunately, many survivors did not realize they had diseases, due to cognitive dysfunction from the pathology of the brain, belief in karmic laws and disability caused by accidental and orthopedic conditions:

> She lost her memory. She could not remember the activities she had performed. Sometimes she was angry that she did not eat when in fact she had eaten. I am sometimes bored and wanted to leave home when she taunts me with profanities (CG16).

Improper care and discontinuity of care. While the researcher was collecting data, the multidisciplinary team that was hired by the sub-district administration organization (SAO) had canceled home care activities as a result of a physician shortage. The family care team (FCT) [25] responsibilities remained unclear and needed more preparation from both healthcare personnel and VHVs. There was a lack of continuous care, due to canceled care caused by a physician shortage during the study, especially for survivors of stroke who were bedridden. This cancelation of care resulted in dissatisfaction, diminished the quality of care and increased the level of stress among caregivers:

What can I do if he couldn't see the doctor at home again? How are we to take him to the hospital in his bedridden condition? (CG9)

Preparing survivors and their family caregivers to provide the level of care that was given during hospitalization was problematic. Unfortunately, survivors and their caregivers did not receive proper training or support, especially for survivors who had cognitive impairments and caregivers who did not have enough knowledge to provide continuous care and rehabilitation. As a result, survivors did not continue medical care and did not receive suitable care at home:

> I have a medical appointment every two months, but they did not say anything about complications. Just say what I have to do and what I do not (PT5).

> We have learned only how to prevent stiff joint when the patient was hospitalized but we do not know how to restore him further after discharge (CG1).

Clinical practice guidelines existed for co-existing conditions, such as diabetes mellitus or hypertension, but none was specific for stroke preparedness. When survivors underwent continuous treatment, both survivors and their caregivers attended a group health education class to receive hypertension and diabetic care education again. Thus, they missed the full range of recovery care for survivors of stroke:

> Now we have no specific disease and stroke care guidelines. Post-stroke care focuses more on physical care and co-existing conditions that cause a recurrent stroke (PH5).

> Nurses told us how to control blood pressure, how to release stress, how to prevent complications but they did not mention much about stroke (PT18).

Most survivors and caregivers were not informed about their diagnosis or specific stroke care information from healthcare personnel during the discharge process. Community partners and community caregivers also had limited knowledge and skills to provide stroke care, but all were responsible for providing full support to the survivors of stroke in the community:

> Information by public health care volunteers did not meet the patient's needs because they had insufficient knowledge of stroke care, so they lacked the confidence to transfer knowledge as well (PH5).

Stroke motivation of public health agencies in the community focused on providing services rather than on motivating community participation in the care of survivors of stroke. This resulted in resource limitations and their workload:

> Generally, the VHVs would help to carry out house care responsibilities for patients. However, public health care volunteers had limitations in providing sophisticated knowledge, especially stroke care. Health authorities did not motivate or spread the knowledge to the community or the patient's home (PH5).

The findings showed that stroke survivors had unequal access to rehabilitation services. Out of 27 survivors, two were trained by a physical therapist to rehabilitate themselves while they were still in the hospital. In total, 11 survivors who were bedridden enrolled in a collaboration of community partners' caring project of the survivors trained by a physical therapist at home. For those survivors who had not been admitted to the hospital or were not in the project and could not follow up, they had no opportunity to receive rehabilitation. As a result, they became discouraged thinking that they would be permanently disabled:

> I had trained how to rehabilitate at home, and I had many materials provided from my son but I did not do anything at all because I didn't think it could improve my function (PT2).
>
> I had so many conditions in myself. I used to shop around with my illness, modern or traditional medicine like a massage. Not only it didn't help me get better, but it also seemed like I got worse. Therefore, I stopped thinking about recovery (PT7).

Shortage of stroke care personnel. Inadequate levels of healthcare personnel strongly hindered survivors' health outcomes and satisfaction. Despite these obstacles, VHVs took responsibility for each survivor, but these VHVs lacked stroke care training and confidence:

> Occasional home visiting by staff made us feel that we were left to take care of ourselves haphazardly (CG1).
>
> We are neighbors who are close to the patient and that may affect the trust of care. (CP4).
>
> How can I be confident that the medicines I get are correct and proper for me? (PT8)

Theme 2: expected stroke services in the community

The findings found two sub-themes of expected stroke services in the community.

Specific caring. Stroke-specific care did not exist in the study setting; therefore, survivors received the standard of care for co-existing chronic conditions. They were integrated into the general population of survivors and received the same types of medical services. Three survivors of stroke (11.1%) followed up at an SDHPH out of personal convenience. Despite the basic care they received, SDHPH care is not equivalent to that provided in the hospital. Survivors with complex care needs were sent to DH for appropriate care:

> We still have no stroke clinic right now, but we start to gather a group of hemiplegic patients to provide health education when they come to continuous treatment (PH4).
>
> It will be good to have more specific care, but we cannot because of the lack of physicians and personnel to perform such activities (PH1).
>
> Previously, we focused on diseases such as diabetes and hypertension as those are the risks of stroke and it was common community policy anyway (PH5).

Family and community support. Encouragement or close supervision contributed greatly to self-care and continued home rehabilitation. Furthermore, family connections and relationships greatly contributed to the quality of care. The most motivational factor in encouraging survivors to perform self-care, as well as a continued physical rehabilitation and medical treatment, was not the presence of public healthcare personnel but family members and the strength of the patient himself. Survivors who did not receive encouragement from their families or lived alone lacked adequate self-care:

> My daughter encourages me to go on. If I ignore it, it will lock out. Keep fighting; volition was important (PT4).

> My father lived alone here, but I often came to visit. I had no idea how long he had been without medicine or how he had to be rehabilitated, as he was able to use the rest of his body to live without ever asking for help but then we found him dead at home at the age of 51 (CG6).

The mission of community partners in the implementation of public health care in the community is to promote all aspects of people's well-being in terms of coordination with local health authorities, including the SAO, village headmen, VHVs and other related agencies, such as provincial social development and human security officers to allocate budgets and resources mobilization. However, specific care has not been given to stroke survivors, nor was there any information on stroke prevention among those at high risk of stroke:

> Chronic condition patients who can receive treatments at the SDHPH will be treated by a doctor who was hired by SAO twice a month. Thus, all those patients will get necessary treatments such as laboratory testing and medicine (PH5).

> We raise awareness about the disease and promote self-care focusing on changing the risk behavior of chronic diseases. We prepared people who are approaching old age by providing health screening and information. About stroke, we supported the budget in terms of caring activities but may not meet all dimensions of the patient's needs (CP3).

> For example, we coordinated with the provincial development office to help in a modified house and environment that is suitable for stroke survivors. As (name of patients,) we have contact with Social Development and Human Security agencies to help him renovate a room suitable for disability after it had flooded (CP2).

Discussion

This research found healthcare services for survivors of stroke experienced a gap in continuing care between hospital- and community-based care. Preparedness, information and motivation were lacking for specific diseases, thus complicating efforts to prevent recurrent strokes and provide rehabilitation practices. The shortage of medical personnel in the community led to survivors having to receive care at the hospital and changes in the community healthcare policy. Besides, there was a lack of clarity about a new national health policy that was in its early stages. As a result, most survivors lost continuous treatment. Not recognizing the importance of continuing treatment leads to poor-quality outcomes [26]. Some caregivers and family members of a dependent survivor of stroke reported depression, consistent with a prior report that stroke caregivers observed significantly higher mean depression scores than survivors of stroke [27].

Although the care of stroke survivors is well supported by community stakeholders, changes in community health policies due to the lack of healthcare personnel resulted in unsatisfactory delivery of patient services. Furthermore, some survivors were hospitalized, but still received limited information about their illness and aftercare support and advice. Additionally, advising relatives of survivors was not always beneficial as some lacked understanding of the situation. Consequently, those family caregivers were frequently unprepared and lacking in knowledge and skills and admitted to a lack of confidence in caring for survivors [28].

Very few survivors (14.8%) knew that stroke could recur and with increased severity; this finding is consistent with that of Saengsuwan *et al.* [29]. Yaowapanon *et al.* [30] suggested that the preparation of specific interventions for survivors of stroke, care information, including caregiver knowledge, improved caring competencies and promoting caregiver mental health that will improve the sense of well-being for the caregiver are very important.

Conclusion

Stroke causes disability and creates a great burden on family members and communities. Appropriate stroke prevention, specific treatments and suitable rehabilitation facilitate a better quality of life for survivors of stroke. Therefore, specific stroke care guidelines and adequate healthcare personnel are a necessity. Further research investigating the development of a care model for stroke survivors by community participation is needed to improve the quality of life for both survivors of stroke and their family caregivers.

Limitations

There are two limitations to this study. First, at the conclusion of the activities in this study, a new Ministry of Public Health policy was implemented. Qualitative data was needed for re-assessment by using the newly developed national health policies to get an up-to-date viewpoint. Second, community health policy in the study area may be different from other communities, which could affect different context of care for patients with stroke in community.

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