

# Situational Analysis: Community Care for Survivors of Stroke and Suggestions for Improving the Provision of Care

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**Abstract:** This descriptive qualitative study aimed to analyze the community care situation for survivors of stroke and provide suggestions for improving care. The study was conducted in a district of Chiang Mai Province. Purposive sampling was employed based on inclusion criteria to select 51 key informants comprised of 1) three health personnel, 2) 13 community leaders, 3) three local government officers, 4) 13 village health volunteers, and 5) 13 caregivers who took care of survivors of stroke. The data collection consisted of in-depth interviews and focus group discussions, based on the Expanded Chronic Care Model. Data were analyzed by content analysis.

The results revealed that community care for survivors of stroke is mainly provided by family members. As well, our analysis revealed for survivors: 1) inadequate personal skills among caregivers and volunteers; 2) inefficient health services; 3) the lack of support for a caring system; 4) incomplete clinical information system; 5) no healthy public policy; and 6) lack of a supportive environment. We suggest that, to improve the care available to survivors of stroke, there needs to be: 1) development of supportive policies at both national and local government levels; 2) development and provision of guidelines for the care; and 3) a supportive caring system that includes health personnel, caregivers, and rehabilitation facilities, as well as support for the home and community-based environment. These results and suggestions will be useful to community nurses and stakeholders who are responsible to design caring for survivors of stroke.

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## Introduction

Stroke is a major public health problem worldwide. In 2015, stroke death accounted for 11.8% of total death worldwide<sup>1</sup> and according to the Stroke Association, 6.24 million people worldwide died from strokes.<sup>2</sup> In 2015, stroke was the second leading cause of death with a mortality rate of 85 per 100,000 of population.<sup>3</sup> The leading cause is high blood pressure, which contributes to over 12.7 million cases of stroke

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worldwide.<sup>4</sup> It was estimated that, annually, 16.9 million strokes occur worldwide and 33.0 million prevalent stroke cases, 5.9 million stroke deaths.<sup>5</sup> In Thailand, the prevalence of stroke is estimated to be 1.88% among adults 45 years and older, with more than 250,000 new cases of stroke each year,<sup>6</sup> and around 80% of stroke patients were discharged into their homes. After discharge, most Thai patients return home and are taken care of by family members.<sup>6</sup>

The shift of care from the hospital to the home setting can impact both patients and caregivers. The survivors expressed loneliness, hopelessness, and a kind of world-weariness and withdrawal from social activities.<sup>7</sup> They reported cognitive impairment and psychological impairment such as depression and anxiety.<sup>8</sup> As well, returning home can be a traumatic experience for survivors of stroke if there is inadequate or insufficient support available<sup>7</sup> and increased stress and the feeling of being a burden.<sup>9</sup> These circumstances also have an adverse effect upon the psychological and physical well-being of caregivers who usually suffer a reduction of leisure time and social activities.<sup>9</sup> Another adverse effect of these stressful circumstances is the negative impact on, and consequential break down of, family relationships, often with the consequence of family members abandoning of the caring role.

In Thailand, the number of family members is now an average of 3.2 per family,<sup>10</sup> and, in the situation of having to care for a survivor of stroke, family members still go to work daily, leaving many survivors of stroke to stay alone, with the problems that this can cause. Most survivors of stroke identified the role of spouses, other family members, friends, a good social network and a caring relationship between family members and neighbors, being of great importance for their well-being.<sup>7</sup> However, both patients and their caregivers reported being inadequately informed regarding important aspects of stroke, such as its causes and prognosis, preventative measures, as well as statutory and informal support,<sup>9</sup>

To overcome those problems, the Chronic Care Model (CCM) was developed in the United States of America to improve the quality of patient care and health outcomes of people with long-term disabilities. It comprises six interrelated components: (1) community resources and policies; (2) health system organization; (3) self-management support; (4) decision support; (5) delivery system redesign; and (6) clinical information systems.<sup>11</sup> To include more of a public health perspective into the CCM, the Expanded Chronic Care Model (ECCM) was developed. ECCM integrates prevention and health promotion aspects into the CCM.<sup>12</sup> This Model can empower regional health authorities, primary-care providers, patients, non-governmental agencies and the government to work together for both preventive and treatment measures.<sup>12</sup> This benefits the community and improves its self-reliance and ability to take care of survivors of stroke.<sup>13</sup>

Both the original and expanded versions of the Model have been widely adopted. The CCM was successfully used for patients with diabetes mellitus<sup>14</sup>, chronic obstructive pulmonary disease (COPD)<sup>15</sup> and mental disorders such as depression.<sup>16</sup> Applying two components of CCM, decision support and clinical information systems, also moderately improved care for people living with HIV.<sup>17</sup> A systematic literature review reported that self-management support and delivery system design were the most commonly used elements of a CCM.<sup>14</sup>

Reports of success of using the ECCM in Thailand are not available. With its unique social, culture and public health service system, development of stroke survivor care policies and programs in Thailand are crucially needed. As an initial step for the development of a stroke survivor care model, our study's objectives were to identify and describe the situation of stroke survivor care in a district of Chiang Mai Province, which is a well-defined area in northern Thailand.

This district is located in the central northern region of Thailand. At present, there are no caring systems that have been designed for survivors of stroke available. In other situations of chronic diseases, caregivers usually receive training by health care personnel on caring for patients before returning home. The services available in the community include home visits by a community nurse once every 2 weeks, or once a week for patients with a serious condition. During the visit, the nurse provides health education to caregivers and assesses the competency of the caregivers in providing care, rehabilitation, and giving medication to the patient. In addition, village health volunteers (VHVs) visit the patients, measure blood pressure, dress wounds, and observe any unusual conditions. Our intention is that this study will be used to improve care for survivors of stroke in the community by the provision of home-care services already available to patients with other conditions, as discussed.

## **Review of the Literature**

### **Community care for survivors of stroke**

Community care for survivors of stroke is the transition from specialized medically-based stroke services usually administered to in-patients at hospitals, to care services available within the community where the survivor lives, works, and socializes. The evidence that is available indicates that family caregivers do not receive adequate recognition or support during the discharge process from health care professionals.<sup>18</sup> Many survivors of stroke experience a poor transition of care from hospital to home. Our contention is that in-patient and early supported discharge or community-based stroke teams must work collaboratively to ensure that the patient and caregivers are fully informed of what services are provided post discharge.<sup>19</sup>

Community care for survivors of stroke involves several groups of people:<sup>19</sup>

*Community health nurses* often mobilize several resources in order to effectively and appropriately meet health care needs. They have a key role in managing and supporting patients and caregivers following a stroke.

*Caregivers* are people who provide direct care or assist survivors of stroke. These can be either formal or volunteer caregivers, such as spouse, family members, relatives, or close friends

*Local government* has a supporting role for caring service system. It can create and sustain winning coalitions to ensure the long-term viability of organizations, policies, plans, and money.

Community volunteers are those who work to improve community services and conditions in communities in which they live. These include neighborhood groups, church groups, and community groups.

In a health care system, community and public health nurses can act as caregivers, case manager, coordinator, advocator, educator, counselor, collaborator, and information broker. In Thailand, in the community care team, nurses play various roles including: support patients and caregivers at home, and arrange for disposal items and equipment. In addition to care practice, nurses can involve in planning and administration.<sup>20</sup>

## **The Chronic Care Model**

The Chronic Care Model (CCM) is a widely adopted approach for long-term care. The CCM is a framework that re-orientes healthcare services to effectively deal with the needs and concerns of individuals and population with chronic disease.<sup>21-22</sup> The model focuses on linking informed, active people with long-term conditions with pro-active teams of professionals.<sup>11</sup> CCM was developed based on a review of interventions to improve care for various chronically ill population and evaluation revealed that improving of health outcomes can be done through changing of 6 components as mentioned above.<sup>12, 22</sup>

To introduce a more public health perspective into the CCM, the ECCM was developed. The ECCM attempts to expand the relationship between health system and the community. With cooperation from local authorities, health promoting hospitals, and the civil community, people in the community can share in the planning, implementation, monitoring, and evaluation of the project. By changing and modifying some of the CCM, the ECCM now contains the following 7 components:<sup>12</sup>

1. Self-management and self-development of personal skills: refers the provision of support not only to cope with a disease but also to enable the development of personal skills for health and wellness.

2. Delivery system design/re-orient health services: involves encouraging those in the healthcare sector to move beyond the provision of clinical and curative services to support individuals and communities in a more holistic way.

3. Decision support: defined as having 3 sub-compartments including, building healthy public policy, create supportive environments and strengthen community action.

4. Information systems: include the creation of broadly based information systems to include community data beyond the health care system

5. Building healthy public policies: which aims to improve the general health of the population and include the promotion of a more equitable society including equity in the provision of services and maintenance of the environment, and safer and healthier goods.

6. Create supportive environment: refers to living conditions in the community, work place safety and an enjoyable lifestyle, by creating supportive environments that will have a significant impact on public health and quality of life.

7. Strengthen community action: aims to support people in finding their own ways of managing the health of their community by enabling individuals and communities to take more control over health

determinants. Community actions involve working with community groups to set priorities and goals to enhance community health.

## **Study Aims**

1. To describe the situation of community care for survivors of stroke in a sub-district of Northern Thailand.

2. To suggest improvements for care of survivors of stroke

## **Methods**

### **Design**

This was a qualitative descriptive study. Sandelowski<sup>23</sup> defines a qualitative descriptive study as being appropriate where the researcher is conducting qualitative research to enable them to properly and fully describe the situation and circumstances observed in the study.

### **Informants and setting**

The study was conducted in a district of Chiang Mai Province, northern Thailand, with a population of 10,152 people. It is a semi-urban community with a high incidence rate of strokes (177.30 per 100,000 population).<sup>24</sup>

The inclusion criteria for informants in the study were: survivors of stroke had been discharged from hospital, lived in the study setting, and were willing to participate in this study. Other informants, due to their position in the community, included the local government officers, the director of district hospital, nurse, health personnel who responsible for caring of survivors of stroke, and other community leaders and VHV's who provide care for survivors of stroke and caregivers.

### **Data collection**

An in-depth interview guide and a focus group discussion guide were developed by principal investigator (PI) based on the ECCM framework.

Data were collected from September 2014 to May 2015. The PI was also considered to be a research instrument by virtue of her long experience over 7 years as a community health nurse, who had gained experience in chronic care through home visits and as a teacher of nursing students. The PI also was knowledgeable of qualitative methods in nursing research acquired during her studies and by attending seminars. Additionally, she gained her professional experience in this field, working instructors who were experts in qualitative research.

#### **Focus group discussion**

Focus group discussions were conducted with two groups of VHV's and two groups of community leaders. In each session, a group of 6–7 people were interviewed for about 80–100 minutes, with the interviews conducted according to the focus group guide. Open-ended questions were used to facilitate key informants' recounting of experiences and expressions of opinion. The interviews started with general question, "Did the health promoting hospital have health service system for survivors of stroke?", which was then followed by more specific questioning such as "How did you conduct home visits?", and "Please give me more some examples", and "Who was involved?" The PI took the role of moderator in all four discussions with the aid of a note-taker and a digital recorder.

#### **In-depth interviews**

In-depth interviews were conducted after establishing a rapport with the participant, and were conducted with 3 health personnel, 3 local government officers, 3 VHV's, 3 community leaders, and 19 stroke caregivers. Before the interviews took place, the key informants were requested to confirm their informed consent, and provide this confirmation in writing. Each interview ranged from 60–90 minutes. The interviews started with open-ended broad questions, with further probing questions as needed to explore and clarify the situation. For example, an interview with stroke caregivers would begin with the general question, "Was the community involved in planning for the care of survivors of stroke?" followed by

specific/probing questions, "Who were involved in planning for the care of survivors of stroke?", "How did the community get involved?", "What information was in the plans on and how to care for survivors of stroke?". The information gained during the interviews was recorded using field notes. The interviews continued until no new data emerged.

#### **Data analysis**

The data collected in the focus groups and in-depth interviews were analyzed using content analysis as suggested by Graneheim and Lundman<sup>25</sup>. First, all interviews and the content of digital recordings were transcribed verbatim. Coding of the data took place to identify the categories and themes and sub-themes. This was done comprehensively by the researcher until no new data was identified to support the existing themes. The themes were then discussed for relevance with the thesis advisor.

#### **Trustworthiness**

Trustworthiness of the data was identified by using the criteria proposed by Lincoln and Guba.<sup>26</sup> The researcher conducted member checking by sharing and discussing the interview summaries with five stakeholders to prove the credibility of the data gained in the focus group discussions, in-depth interviews, and the transcribed field notes. To enhance the credibility of the results, peer debriefing was conducted independently by three experts in qualitative research, and the content analysis process was reviewed by the advisory committee and a group of experts.

#### **Ethical considerations**

The study methodology was reviewed by the Human Subjects Review Board of the Faculty of Nursing, Chiang Mai University (Approval number 059/2014) prior to the study. A summary of the project was proposed to all the key informants, including full disclosure of their rights, and the risks and benefits of participation. Those who agreed to participate in the study were asked to sign an informed consent form to ensure that their participation was on

an informed, voluntary basis. While the key informants' names and addresses were recorded, these were kept confidential, as was all other information.

#### **Data reflection and recommended suggestion for improving the care**

The results of the study were summarized and presented to stakeholders at a forum attended by 30 key informants, including 2 health personnel, 1 local government officer, 7 community leaders, 13 VHV, and 7 caregivers. A community forum was also attempted to elicit suggestions for improving the care for survivors of stroke.

### **Findings**

The 51 key informants in total purposively selected including 3 health personnel, 13 community leaders, 3 local government officers, 13 VHV, and 19 caregivers.

Of the 19 survivors of stroke participating in the study, 10 were women, 9 men. Among them, 2 had paralysis, 5 had hemiparesis, and another 12 cases had difficulty in talking and swallowing. All of them needed caring assistance, the majority of which was provided by their caregivers and VHV. Most of the caregivers were females aged between 40–70 years. Nine of the caregivers of survivors of stroke were husbands, 4 were wives, 5 were married daughters and one was an unmarried daughter. Seventeen had finished primary school and 2 had no school education. Fifteen were employed, 2 were housewives and 2 were househusbands. Monthly income for 11 of the families was between 1000 and 5000 Baht (US\$31.87 and US\$159.34), 4 had income of 500 baht/month (US\$15.93), and another 4 were without a fixed monthly income. The duration that they have been functioning as caregivers was 1–20 years. All of ten VHV were female, married, and had working experience of 2–15 years.

Findings are presented here as six major themes: 1) inadequate personal skills among VHV and caregivers; 2) inefficient health services; 3) lack of support for a caring system; 4) incomplete clinical information system; 5) no healthy public policy; and 6) lack of supportive environment.

#### **Theme 1: Inadequate personal skills among caregivers and VHV**

Physicians and nurses at community hospitals provide knowledge and skills in caring for survivors of stroke to VHV and caregivers. However, the information content provided by those health professionals during the training is considered an overload given the limited time allowed, and few VHV were properly trained. As a result, caregivers and VHV lacked confidence in providing proper care for survivors of stroke at home because they did not receive a complete and continuous program of personal skills development. They received some knowledge from nurses but it was soon forgotten. VHV only measured blood pressure, and some caregivers had no confidence dressing pressure sores.

*Previously I had some knowledge from a nurse who did home visits, and during hospital stay. But it's been somewhat forgotten. I would like them to teach again, and give new information. (ID-Caregiver12)*

*When I do home visits, I can only measure blood pressure. I did not do other support because of having no confidence. Want to have training on rehabilitation activities so I can teach others. (FG1-VHV1)*

Key informants stated that frequency and the duration of the training is important for developing personal skills. Some training programs for diabetes mellitus and hypertension had been provided by nurses, but not for stroke. It was reported that the training for taking care of survivors of stroke was only available for a short period (one day) and not on a regular basis, for example:



*We train VHV's annually, but focus on diabetes mellitus and hypertension.*

*For stroke, the program is operated only about once in 2-3 years. (ID-Nurse1)*

*Each session in only one day, probably less. (ID-Nurse1)*

A caregiver stated that the methods used to develop skills have no variety. If there was a variety of training methods, they would allow learners to learn and use those skills more effectively. The opinion from the caregiver was shown as follows:

*Teaching us the knowledge and letting us practice in the afternoon by practicing each 15-20 minutes per session. There are no other methods than this. (ID-caregiver1)*

#### **Theme 2: Inefficient health services**

Key informants stated that the management system for caring for survivors of stroke showed that the health services were inefficient for survivors of stroke. The health care team, consisting of doctors and nurses, planned the care for existing cases, new cases, and patients with complex problems, but VHV's did not participate in the planning, monitoring or evaluation. It was also found that the number of volunteers is inadequate. There was no continuity of follow-up by health care team

Key informants mentioned that health care team follows up the survivors of stroke for old cases, new cases, and some cases with complex problems. The health personnel planned for home visits together with doctors. VHV's also joined the health care team for home visits. Health care team was not continued of follow-up in some cases.

*A doctor said, Our home visits for patients with stroke in normal cases is every three weeks, for complicated cases will visit every week. (ID-Doctor)*

This accorded with the statement by a nurse: *Home visits are planned with doctors for old cases, new cases, and those with complex problems. (ID-Nurse 1, ID-Nurse 2)*

Another concern under this theme was that there appeared to be no community involvement in planning and evaluating of caring for survivors of stroke. Key informants stated that the community members did not participate in planning and evaluation of caring for survivors of stroke.

*A VHV said that We're not involved in planning of caring for survivors of stroke. (FG1-VHV2)*

*Similarly, a community leader said Did not plan or evaluate anything. Go to talk to encourage only. (FG1-CL3)*

#### **Theme 3: Lack of support for caring system**

Key informants mentioned that the health promoting hospital has no guidelines, inadequate number of VHV's, limited budget for caring for survivors of stroke, and they had only an outdated rehabilitation manual. Also there was an inadequate number of VHV's for taking care of survivors of stroke.

Health personnel had practice guidelines for patients with chronic diseases such as diabetes mellitus and hypertension, but there were no practice guidelines for survivors of stroke. When VHV's visited a patient's home, they had no manual or practice guidelines in providing care for survivors of stroke. Informants wanted guidelines and to know how to use them correctly. This would increase confidence and give more suggestions for care. Comments from health professionals included:

*Practice guidelines are not made for survivors of stroke particularly, no practice guideline in caring for survivors of stroke, caring patients in calm and relapsing conditions. (ID-Nurse1)*

VHV's expressed their opinions as follows:

*I want to have guidelines. So when taking care, it will be continuous. It helps to inform what to do. (FG1-VHV7)*

In addition, hospitals received a health promotion budget from local government for caring for patients with all types of chronic diseases, but the budget for equipment procurement in caring for survivors of stroke was limited.

*Budget for physical therapy equipment is limited. Reserved drugs are not enough. (ID-Doctor)*

#### **Theme 4: Incomplete clinical information system**

Key informants stated that incomplete clinical information system is an important problem. It was found that no specific record form for survivors of stroke existed and no detailed data about caring for survivors of stroke was kept, leading to a lack of important information. The only specific recording forms available were the form for patients with diabetes mellitus and hypertension. For VHVs, it was found that they usually record care provided on their personal notebook.

*We do not have specific record form designed for survivors of stroke. We have only the form for diabetes mellitus and hypertension. (ID-Nurse1)*

*There is no recording form on caring for survivors of stroke during home visits. We use our notebook, but do not know what to write. (FG1-VHV1).*

Additionally, there appeared no detailed data about caring for survivors of stroke. Scrutiny of existing records showed that only general information is recorded, but not the details of patient care, due to lack of time. It was found that the health promoting hospital has a data storage system for survivors of stroke, and data on every home visits and walk-in patient is recorded in the family folder and in the computer database by nursing staff assigned for

managing the system. However, detailed information of the survivors of stroke was missing because there is no specific record form for survivors of stroke.

The opinions from nurses are as follows:

*We record the patient information every time we do a home visit or when the patient comes to the hospital. Data is recorded on the family folder first and then into a computer by the staff. (ID-Nurse1)*

*We record only the general information such as temperature, blood pressure but do not record anything about the provided care since we do not have time. (ID-Nurse2)*

#### **Theme 5: No healthy public policy**

Key informants stated that there had been no local legislation or specific budget allocation in caring for survivors. The community has no healthy public policy for survivors of stroke because of no community forum for people in the community to assess problems and needs among survivors of stroke:

*Our health promoting hospital has never conducted a specific community forum to know the problems and needs of caring for survivors of stroke. (ID-Nurse2).*

*As far as I know, there is no forum regarding survivors of stroke. (FG2-CL5).*

Local government does not have direct policies and budgets. Most budgets are spent on chronic diseases. This is supported in a comment from a local government officer:

*The municipality does not have policies and budgets directly for caring for stroke victims. It is integrated with chronic diseases. It is not separate. (ID-LC1, 2).*

*The budget has not been specifically allocated for stroke. (ID-Nurse1)*



**Theme 6: Lack of supportive environment**

It was found that there was a lack of a supportive environment to facilitate care for survivors of stroke, due to both the caregivers and VHVs lacking knowledge about a proper and safe home environment. The local government provided inadequate budgets for rehabilitation equipment in the home. This resulted in a lack of training for VHVs and caregivers to have adequate knowledge to give advice about the home environment to those who survived a stroke, and therefore they do not dare to give advice to patients and relatives, for example:

*We do not have the training for VHVs and caregivers who care about the environment to prevent accidents or what complications it provokes. (ID-Nurse1)*

*Does not have knowledge about the home environment for these patients, does not dare to give advice. (FG1-VHV2)*

Rehabilitation facilities are provided at the health promoting hospital, but there are too few physical therapists and there is not enough rehabilitation equipment due to the lack of budget or a dedicated space for this. The municipality provides an area for exercise which does not have equipment for the rehabilitation.

*Community leaders said: The municipality provides an area for exercise, but there is no place for these patients. (FG1-CL3, 8)*

*Similarly, a local government officer said: We have no budget to buy equipment specifically for physical therapy. (ID-LC1.)*

**Suggestions for improving the care**

The community forum suggested that improving the care for survivors of stroke should be included in future community care policies and programs. Key informants agreed that a direct policy for supporting survivors of stroke is needed to improve the care offered to survivors of stroke. The local authority,

local government, should have a budget for managing care for survivors of stroke, rehabilitation tools and equipment, such as wheelchairs and diapers. The key informants agreed to have a “community forum for stroke survivor care” for community members to exchange experience in caring survivors of stroke. This forum could increase caregivers’ knowledge, raise public awareness, and support public health policies for survivors of stroke.

Most of the caregivers and VHVs agreed that they needed training and guidelines by professional health personnel for taking care of survivors of stroke, especially on the topics of food consumption, types of food they can or cannot eat, and basic health care. The guidelines would also be helpful to increase their confidence in their caring role.

The forum identified that there needed to be a supportive caring system including health personnel, caregivers, and rehabilitation facilities as well as supportive home and community environment. Members recommended a multidisciplinary team for home visits to survivors of stroke. Under a coordinated program including the health promoting hospital, professional health staff and VHVs would be able to work together for taking care of the survivors of stroke.

Key informants agreed that a form for recording stroke victim information was essential for recording the health conditions and personal details specifically of stroke patients. This information is important for knowing patient histories and preparing for the next visit.

VHVs need to know about safe home environment for survivors of stroke. The information can be used for advisory caregivers to manage their home environment to support survivor of stroke’s activities and prevent accidents.

**Discussion**

**Community care for survivors of stroke**

It was found that community care for survivors of stroke in a district of Chiang Mai Province was

inadequate when assessed using the ECCM as a framework. The problems were categorized into 6 themes, including (1) insufficient knowledge and skill; (2) insufficient health services; (3) lack of support for stroke caring system; (4) incomplete clinical information system; (5) no healthy public policy; and (6) lack of supportive environment. This is not surprising as the concept of the ECCM and recognition and acknowledgement of the problems of stroke survivor care is rather new in Thai society.<sup>27</sup>

It was found that caregivers still need more skills to taking care of survivors of stroke. Lack of knowledge and skills made them have less confident to do the job. This result is consistent with the study of Rungpoth and Jitbantad<sup>28</sup> who found that the majority of VHV's had only primary school education, and had knowledge on how to taking care of the disabled only at a moderate level. Copley et al.<sup>9</sup> also reported that caregivers received poor information regarding the extent of support available after discharge. In Uganda, as an example, the lack of information about the illness and how to handle it meant that most caretakers just employed 'trial and error' methods in the care of the patient.<sup>29</sup> However, education and knowledge support will depend on the stroke survivor's condition; and the needs and concerns of caregivers.

Both VHV's and caregivers wanted guidelines for caring for survivors of stroke. The availability of a practice manual would definitely help them to better perform their role in stroke patient care, and have more confidence in performing that role. Kusun<sup>30</sup> found that knowledge about strokes and survivors of stroke' needs, among caregivers, was significantly improved after a guide for patient care was provided. As well, a brief educational handout describing the risks of obstructive sleep apnea (OSA) and its link to stroke improved both patient knowledge and intention to discuss OSA screening.<sup>31</sup> In addition, a study on the availability and use of guidelines for stroke patient rehabilitation showed that the ability of doing daily living activities among caregivers was raised from low to moderate level.<sup>32</sup>

Health information systems regarding survivors of stroke still need to be improved.

Applying modern information and communications technology infrastructure, including developing computerized processes for collecting, recording, accessing and reporting on health system data, and providing information on survivors of stroke, would play a significant role in providing effective and efficient primary health care services.<sup>33</sup>

For policy support, although there was the budget for chronic diseases, local authorities do not specifically allocate funds for stroke care; budgets are applied to other diseases which are more prevalent, such as diabetes or hypertension. This situation was also clearly identified in a study of care for survivors of stroke in Khon Kaen Province.<sup>27</sup>

There was no community forum regarding the care for survivors of stroke. Therefore problem and need evaluation was limited, notwithstanding that community participation is the core issue for success of public health programs. A recent study on stroke survivor care in Khon Kaen also found that the community at large and VHV's were not much involved in stroke care.<sup>27</sup>

The lack of a supportive environment for survivors of stroke is an ongoing problem, even though studies have shown that a supportive environment can significantly improve the physical condition, level of activity, and general behavior of survivors of stroke, and their general health outcomes.<sup>34</sup>

#### **Suggestions for improving care**

The Ottawa Charter incorporates five key action areas to improving care are to build healthy public policy, create supportive environments for health, strengthen community action for health, develop personal skills, and re-orient health services.<sup>35</sup>

Based on the results of the study, we strongly support the Ottawa Charter, and the suggestions for actions are: 1) develop and promulgate supportive policies for the care of survivors of stroke at both the national and local government levels; 2) provide

guidelines on the care of survivors of stroke, especially to inform caregivers and VHVs; and 3) develop a supportive care system that includes professional health personnel, caregivers, and rehabilitation facilities, together with a supportive home and community environment.

Supportive policies in caring for survivors of stroke from country level and local government. Consistent with the study of Phinyo et al.<sup>27</sup> it is suggested that local government, community leaders, and professional health care providers, should have policies for cooperation in caring for survivors of stroke. We also suggest the development of care policies and activities for survivors of stroke with broad community participation, encouraging competencies in health care and continuing care. Ruangmee and Khuphantawee<sup>36</sup> suggested the need for budgetary and policy support for patient care that focus on survivors of stroke.

Providing guidelines to care for survivors of stroke is important. Our findings were similar to those of Pitthayapong et al.<sup>37</sup> who found that family members needed a handbook covering essential knowledge on stroke care. Guidelines specifically for survivors of stroke included education and information of stroke, recovery, and secondary prevention are key components of skill development.<sup>38</sup>

A supportive caring system including health personnel, caregivers, and rehabilitation facilities as well as supportive home and community environment should be established. Chaiyawata and Kulkantrakornb<sup>39</sup> also suggested that family caregivers require training to provide care relevant to patient's problems and needs including feeding techniques, aspiration prevention, and wound care. Social support such as compassion, advice, and equipment for patient care and rehabilitation from family members, health care providers, and the community are also needed. Petchrong et al.<sup>40</sup> also found that family caregivers need knowledge regarding how to manage and prevent complications after stroke, supporting a patient's activities daily living, and

access to rehabilitation services, and information of available community services. Included in the overall process of stroke survivor care are activities during the home visit and equipment for patient care and support, such as a canes, walkers, and wheelchairs. Patients also need to receive further support from health care providers in the community.<sup>37</sup>

## **Limitations**

The study was conducted in a district of Chiang Mai Province, which is representative of only a mid-town community with the northern culture of Thailand. Since social and cultural factors play an important role in our caring model, the results of the study might only be transferable to settings which have similar context of study.

## **Conclusions and Implications for Nursing Practice**

Community nurses can reflect on our findings to develop models or interventions aimed to strengthen the community capacity to care for survivors of stroke at home. Nurses and other health personnel should develop practice guidelines for survivors of stroke and develop a specific process for recording stroke survivor information during home visits. As well, nurses can play an important role in coordinating with other stakeholders to create a healthy environment and public health policies as well. The community at large, too, needs to be involved in planning and evaluating a community care framework for caring for survivors of stroke.

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*Situation Analysis: Community Care for Survivors of Stroke*

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## การวิเคราะห์สถานการณ์: การดูแลผู้ที่รอดชีวิตจากโรคหลอดเลือดสมอง โดยชุมชนและข้อเสนอแนะเพื่อพัฒนาการดูแล

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**บทคัดย่อ:** การศึกษาเชิงคุณภาพนี้มีวัตถุประสงค์เพื่อวิเคราะห์สถานการณ์การดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมองโดยชุมชนและข้อเสนอแนะเพื่อพัฒนาการดูแล ดำเนินการศึกษาในอำเภอแห่งหนึ่งของจังหวัดเชียงใหม่ คัดเลือกผู้ให้ข้อมูลหลักแบบเจาะจงตามเกณฑ์ จำนวน 51 คน ประกอบด้วย 1) บุคลากรทางสุขภาพ 3 คน 2) ผู้นำชุมชน 13 คน 3) เจ้าหน้าที่องค์กรปกครองส่วนท้องถิ่น 3 คน 4) อาสาสมัครสาธารณสุขประจำหมู่บ้าน (อสม.) 13 คน และ 5) ผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง 19 คน เครื่องมือในการวิจัยประกอบด้วยแนวสัมภาษณ์เชิงลึกและแนวสนทนากลุ่มโดยใช้แนวคิดต้นแบบการดูแลโรคเรื้อรังภาคขยาย วิเคราะห์ข้อมูลโดยการวิเคราะห์เนื้อหา

ผลการศึกษาพบว่า การดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมองในชุมชนส่วนใหญ่ได้รับการดูแลจากสมาชิกในครอบครัว และสถานการณ์การดูแลโดยชุมชนคือ 1) ทักษะส่วนบุคคลของผู้ดูแล และ อสม. ยังมีไม่เพียงพอ 2) การบริการทางสุขภาพสำหรับผู้รอดชีวิตจากโรคหลอดเลือดสมองไม่มีประสิทธิภาพ 3) ขาดการสนับสนุนระบบการดูแลผู้ป่วย 4) ระบบข้อมูลสารสนเทศทางคลินิกไม่สมบูรณ์ 5) ไม่มีนโยบายสาธารณะที่เอื้อต่อการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมอง 6) ขาดการสนับสนุนด้านสภาพแวดล้อมที่เอื้อต่อสุขภาพ ข้อเสนอแนะสำหรับการพัฒนาการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมองประกอบด้วย 1) มีนโยบายที่เอื้อต่อการดูแลทั้งในระดับชาติและระดับท้องถิ่น 2) มีการจัดทำแนวปฏิบัติในการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมอง 3) มีระบบสนับสนุนการดูแล ทั้งด้าน บุคลากรทางสุขภาพ ผู้ดูแล อุปกรณ์การฟื้นฟูสภาพรวมถึง สิ่งแวดล้อมที่เอื้อต่อการดูแลที่บ้านและชุมชน ผลการศึกษาในครั้งนี้เป็นประโยชน์ต่อพยาบาลและผู้มีส่วนเกี่ยวข้องในการดูแลเพื่อนำไปออกแบบการดูแล

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