Original Articles

Caring for Older Adults with Stroke During Hospitalization: Thai Family Caregivers' Experience

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Abstract

This study aimed to describe the difficulties in caring for older adults with stroke during hospitalization as experienced by Thai family caregivers. Twenty-six participants who met the inclusion criteria, such as experienced in providing care for older adult stroke survivors within the past 12 months were recruited by using purposive sampling. The data were collected between November 2013 and October 2014. In-depth interviews were performed. Content analysis was used to analyze the data. Trustworthiness was established by following Lincoln and Guba's criteria. Five themes were revealed describing in the experience of caring for older adult stroke patients during hospitalization. These included 1) facing a crisis; 2) difficulty in making decisions about the treatment options; 3) being incompetent in providing care and relying on healthcare staff, 4) difficulty in accessing help from healthcare staff; and 5) difficulty in learning care skills. The findings of this study suggested that caring for older adult patients during hospitalization was a highly stressful experience. Family caregivers need encouragement and support from both family members and healthcare providers in order to provide compassionate care to patients. Knowledge gained from this study is applicable for healthcare providers, particularly clinical nurses in order to develop the appropriate intervention to promote family caregivers proficiency in caring for older adult patients during hospitalization.

Keywords: caring; caregivers; experience; older adults; stroke

Introduction

Recently, a society of aged people has been noted worldwide, including in Thailand, where the proportion of older adults aged ≥ 60 is 14.9%.[1] This is expected to increase to 15.9% of the total population by 2020,[2] resulting in an increase of chronic diseases, especially strokes, in this group of the population.[3] The incidence rate of stroke in older adults increased from 795.56: 100,000 in 2004 to 1,013.7: 100,000 in 2009.[4] The occurrence of stroke is usually sudden and unexpected and causes acute physical and cognitive dysfunction. Most stroke victims are then hospitalized as a result of this acute condition of illness. This situation causes anxiety and distress for family members.[5] The period of hospitalization was identified as the most difficult time for American family caregivers.[6] However, this study did not clearly identify what difficulties were experienced by those family caregivers during this period.

Unlike Western countries, being involved in caring for a family member during illness is part of Thai culture. Based on the strong value of katunyu katavedi, Thai family members are expected to take care of their older relatives especially when they get sick or are admitted to hospital.[7] Additionally, a shortage of manpower in hospitals requires a dependency on the family to take care of the patients during hospitalization. Family members are also required to learn and be involved in providing care for the patient in this period.[8] Furthermore, care transition for the stroke survivors in the Thai healthcare context is different from Western countries. Rather than being moved from acute care to a rehabilitation unit and then to home,[5] Thai stroke survivors and their family are moved directly from acute care in hospital to home.[9] As a result, family caregivers have little time to learn and adapt to their new role due to the short length of stay in hospital. Therefore, Thai family caregivers may experience different difficulties than caregivers in Western countries.

However, previous research on stroke caregivers in Thailand focused on family caregiving following hospital discharge.[10-12] In order to support family caregivers in adjusting to their stressful situation and to provide effective caregiving role, it is important to understand the difficulties they experienced in caring for older adult stroke survivors. This study aims to explore the difficulties experienced by family caregivers during the period when they must take care of their older relatives who are in hospital recovering from stroke.

Purpose of the Study

The purpose of this study was to describe the experience of family caregivers in caring for older adults with stroke during hospitalization.

Methods

Design of the study

This study used a descriptive qualitative design to understand the experience of family caregivers (FCGs) in caring for older adult patients with stroke during hospitalization. It was a part of a larger study using grounded theory approach to explore how FCGs overcome difficulties in caring for older adult stroke patients transitioning from hospital to home.

Participants

A total of 26 participants comprised the FCGs who provided care for 16 older adult stroke patients were purposively selected to participate in the study, based on the inclusion criteria 1) age 18 years or older, 2) defining themselves as a member of the nuclear family, 3) providing care for older adults with first-time stroke within the past 12 months. Participants were recruited from one regional hospital and one provincial hospital in Southern Thailand. FCGs were recruited for interviews until data saturation was achieved and no new categories could be identified from the analysis.[13]

Data collection

Data collection was conducted from November 2013 to October 2014 by using in-depth interviews. The interviews took place in the participants' homes and were recorded using a digital audiotape recorder after obtaining the participant's permission. The first interview was approximately 60–90 minutes. The second interview was about 45 minutes. Interview guide questions included probes on experiences and difficulties in providing care during hospital stay such as, "Tell me what have happened to you and your family since……. had a stroke?", "How did you feel and think when you were first told that……had a stroke and had to be admitted to hospital?" The examples of probe questions included "Did you experience any difficulties in taking care for……once he/she was admitted to hospital?", "What were The second interview required the participants to clarify and validate some points from the previous interview data. Following each interview, tape-recorded data were transcribed verbatim in Thai.

Data analysis

Data analysis was done concurrently with data collection. All transcribed data were checked for accuracy by the researcher. Content analysis was used to examine the transcribed interview. The analysis was performed in several steps.[14] First, the transcriptions were read through several times in order to get a sense of the text as a whole. Then the whole text was re-read and highlighting of meaningful statements were done. All meaningful text units relevant to the research objectives were determined and coded. Subsequently, the codes were related to each other and grouped into categories depending on similarities and differences, and given a description of their manifest content. Sub-themes were then formulated, sorted and abstracted into one theme. All transcripts were coded by the first author. The research team met monthly to discuss ongoing data analysis and interpretation. Queries and disagreements were reconsidered by returning to the transcripts. Validating the interview findings by returning to four FCGs to ask that they confirm the descriptions of their experiences.

Ethical considerations

Ethics approval was obtained from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University No. 0521.1.05/0432 The data collection started when the hospital granted authority. Agreement to participate in the study was obtained from all participants by both verbal and informed consent. The participants were informed of the voluntary nature of their participation in the study. They were also assured that their personal data would be kept confidentialy and their anonymity strictly protected. They had the right to withdraw from the study at any time for any reason without penalty.

Trustworthiness of qualitative study

Trustworthiness of this study was addressed in four scientific criteria: creditability, transferability, dependability, and confirmability as proposed by Lincoln and Guba.[15] The researcher made one to three visits to interview the participants in their homes. Each interview took from 60-90 minutes. The transcription and interpretations were reviewed with the participants for data validation. A peer debriefing with the advisory committee and the scholars was done to enhance the credibility of this study. To ensure transferability, the detail description of the characteristics of the participants, contexts, and settings in the study was described clearly. The verbatim transcriptions of the audiotape records and memos were kept for an audit trail. Confirmability was achieved by using a variety of participants, member checking, and peer review.

Findings

The caregiver participants consisted of 16 primary caregivers (the participant who provided main activities of caregiving roles) and 10 secondary caregivers (the participant who provide partially of caregiving activities) who provided care for 16 older adult stroke survivors. Most of the participants were females (n = 17) Buddhist (n = 22) and had finished high school (n = 10). The mean age of the participants was 53.7 years ranging from 21 to 82 years old. They were patients' children (n = 16), spouse (n = 6) daughter in law (n = 1), sibling (n = 2), and grandchild (n = 1). Half of the participants lived with the older adult stroke survivors, others were living nearby. One third of the participants' family had insufficient economic status. Five themes were revealed from the descriptions of the FCGs while they took care of the older adult patients with stroke during their stay in hospital. These themes were: facing a crisis, difficulty in making decisions about the treatment options, being incompetent in providing care and relying on healthcare staff, difficulty in accessing help from healthcare staff, and difficulty in learning care skills.

Facing a crisis

At the beginning when the older adults were diagnosed with a stroke and admitted to hospital, the FCGs experienced a crisis. This is because of the unexpectedness of the situation. Some FCGs were informed that their older relatives had a severe condition that needed brain surgery and had been admitted into the intensive care unit. As a result, they were concerned about their survival and recovery. This caused them to feel highly stressed, frightened, frustrated and fearful of loss. Some quotations reflecting this theme are presented as follows:

> *I was very frightened. I thought she (her mom) had only fainted. I never thought it was a stroke, never thought about it. I didn't expect that she would be in a serious condition like that (stroke). (CG10a)*

> *All of us (the patient's children) went to look after mom at the hospital, all day and night. Everyone was unable to work because we were concerned about our mom...We did not know whether our mom would survive or die, we were not sure if she would pass this crisis (on ventilator). Then all of us came to look after her because we were concerned for our mother. (CG06a)*

FCGs indentified they needed emotional support particularly from family members when they faced with a crisis. However, Some FCGs lived only with their spouses who were stroke sufferers. They had nobody to share the feeling or to give advice and support. As a result, they experienced more stress, as one participant stated:

> *When the doctor told me that he (her husband) needed to have a surgery, I was badly frightened. I didn't know how he would be after the surgery. On the day of his surgery, I was alone. I had no relative with me in the hospital. There was no one around me. I felt afraid if something happens to him. I did not have anyone to consult or talked to. I was afraid. (CG01)*

Difficulty in making decisions about the treatment options

Some FCGs were asked to make decisions related to life-changing treatment for their older adult family members, such as brain surgery, and tracheostomy. They experienced difficulty in making such decisions. While FCGs wanted their older relatives to survive and recover, they were informed by a doctor that their family member was in a critical condition and needed intensive care, and/or needed an operation which had a "fifty-fifty" chance of survival. They were also concerned that their decision might make their loved one suffer pain. As a result, they felt uneasy and uncomfortable in making a decision, as shown in the following statements:

> *I wanted her to get a recover, but the doctor said that she had a fifty percent of chance to surviving, I thought if she hadbrain surgery, she had a 20% chance of shock and a 20% chance of an increase inblood pressure. So, I rejected the operation. (CG08b)*

> *The doctor said she needed to have a tracheostomy. I asked why she needed to have it. He said that if she had an endotracheal tube for fourteen days, she may get an infection. I told the doctor to wait until the last moment.*

> *The next day, a doctor asked about the tracheostomy again. My oldest brother agreed with the doctor. I was the youngest child so I couldn't oppose it. I had to agree to let her have the tracheostomy, but I couldn't accept it. I thought mom would be in pain and suffer so I didn't want her to have a tracheostomy. (CG08a)*

> *After she had been in hospital for two weeks, the doctors told us that she (her mother) had to have a tracheostomy, otherwise she might get infection because of the prolonged endotracheal intubation. Initially, I rejected that and wished to take herhome because she was too old and we (family members) didn't want to make her suffer. With her condition, we thought that she would not survive ...But on that day, the nurses didn't take out the endotracheal tube. They said if we wished to take her home, we would have to take it out by ourselves. So, we had to let her stay in the hospital and let her have a tracheostomy. (CG11)*

Being incompetent in providing care and relying on healthcare staff

After the older adults had survived the stroke or passed the critical period, they were moved to the general ward. FCGs perceived that their older adult family members needed care provided by others, due to impairment of their cognitive and physical functions. However, they had no idea how to provide care for their older adult stroke survivors especially for the complex tasks such as suctioning, or personal care for the bed ridden/unconsciousness persons. They were faced with the new difficulty of being unable to provide care. As a result they relied on nurses or nurse's assistants to help them perform care skills and provide care for their older adult stroke survivor. The following quotes of FCGs describe how they perceived their incompetence and powerlessness in managing the caregiving situations.

> *At that time, I didn't know how to suction. I could not do it. My father had a secretion, so I asked the nurse to do the suction. (CG02)*

> *When she defecated and her diaper was full, I couldn't change the diaper for her. I had to wait for a nurse because I couldn't do it by myself. My mom is big and fat so it is hard to move her. I didn't know how to move her. I needed to do it but I had to wait for the nurse. (CG10a)*

Difficulty in accessing help from healthcare staff

While FCGs needed help from health care staff, they had difficulties in accessing to help. For instance, at times they did not receive help promptly as they needed it and sometimes they did not needed it and sometimes they did not get any response from the nurses as they had expected. FCGs identified the delays in receiving help and needed to manage the care by themselves, but they could not due to a lack of care skills and inexperience in providing care for their older relatives. Some quotes that reflected this are given below:

> *When my father had a secretion sound, I asked her (nurse) for help again. She said that the patient with tracheostomy would be like this... until nearly 4 a.m. on the next day, my dad had a lot of productive coughing, it was liked he had secretion in the throat. I decided to ask the nurse to suction my dad one more time. She nodded, but she didn't come. (CG02)*

> *My mom had many assisted devices while she was in the hospital. There were so many lines in her body. The problem was that every time my mom defecated, I couldn't take care of her by myself. I needed some help from a nurse and that was a difficulty. I needed to wait until they (nurses) were available. (CG10a)*

> *Relatives of the patients were unsure whether some symptoms of patients are abnormal or not. When the relatives say that there are abnormal symptoms, why don't you (a nurse) come to see? At least you could come to encourage us. When we are frustrated, we need you for a little help. You should tell us whether you're able to come or not. Come to advise us. I noticed that both patients and relatives are relieved when the nurse just shows up. Suffering and stress disappear or are reduced. (CG06b)*

Some FCGs described that they felt reluctant (kreng jai) to ask for help from healthcare staff, particularly nurses. They also mentioned they were worry for having a conflict with healthcare staff. As a result, they avoided in asking questions or expressing their opinion related to care of the older adult stroke survivors. These characteristics in Thai FCGs blocked them to access the available support, as some participants stated:

> *At the beginning in hospital, I felt stressed, I thought that I could not do anything (care-giving tasks), I felt kreng jai (reluctant) if I asked them (nurses) often. (CG11)*

> *Everybody (patient' relatives) who was taking care of patients in the hospital was scared of the nurses, it meant that the nurses had a lot of power. We couldn't offer any opinion or any argument. If we had an argument, we would get a problem. But we didn't want to have a problem because we needed to rely on their care. (CG10)*

Difficulty in learning care skills

Before discharge, FCGs are usually prepared with knowledge, basic skills for taking care of stroke survivors at home. Care skills that they learned include bathing and changing diapers and clothes. Some FCGs have to learn complex care skills such as NG feeding, wound care, and suction. Most participants experienced problems in learning care skills because of fear and concern over patient safety. They were scared to perform care skills in the beginning. This included fear of making a mistake, fear of being blamed by nurses, and fear of causing danger for the patient. These feelings caused them stress as expressed by feelings of being anxious and nervous when practicing care skills.

> *My first time practicing, when I fed my dad, my hand was shaking. At that moment, my dad had a cough with secretions. I panicked. I'd no idea what I should do...I was shaky. (CG02)*

> *I was afraid to make mistakes, I felt very fearful. When I fed my mom, I was afraid that I'll would make her aspirate. They (nurses) told me to draw out the stomach content to check. I was so scared and didn't want to do it...I did not dare to look at it, I did not dare to draw it out because I was afraid that it may be dangerous to my mom. (CG05a)*

> *At the beginning, I was afraid that a nurse would blame me if I couldn't do something properly. For example, I was very nervous when I was wearing gloves. I was pretty slow because it was wet. (CG12)*

This difficulty was due to a number of factors, including unfamiliarity with the care environment, patient condition, and lack of knowledge and experience. Nearly all FCGs stated they lacked of confident and afraid to do care because lack of knowledge and experience. While the others expressed hardship in performing care related to the older adult stroke survivors' condition, as one FCG stated:

> *At the hospital, my mom had many assist-devices. There were so many lines in her body. The problem is that every time my mom defecated, I couldn't take care of her by myself. (CG10)*

FCGs also indicated time limitations in learning care skills at hospital negatively affected their learning process. Most participants reported that the nurse generally taught them only one or two times and never assessed their understanding. As a result some of them felt they received inadequate information to practice care skills. They also had insufficient time to practice the required care skills which led to the feeling of lack of confidence to provide care and this caused participants' emotional stress. Some participants expressed this as follows:

> *When they taught, they taught briefly because they needed to take care of the other patients too. I had to watch and remember it quickly because they had to go on to others. (CG11a)*

> *Sometimes the staff think that I understand but I don't understand. They teach me how to do many things, but it is not easy to me. They have done that a thousand times but I have just done it for the first time. I'm not sure that I will do it right which makes me feel unconfident, because I have never do that, and the staff don't give me enough information. (CG06b)*

Discussion

The findings of the study revealed that at the beginning of acute care in the hospital, FCGs experienced a crisis. It was expressed in various forms of emotional stress including being frightened, fear of loss, and frustration. This might be because of the occurrence of stroke event was usually sudden and caused of unexpected admission to the hospital for the victims. In addition, half of the older adults in this study were in a serious condition and needed an operation and intensive care. That also, might cause a high concern for FCGs and other family members. These findings were in line with some previous studies[5-6] which found that during the period the stroke patients were hospitalized and under acute care, FCGs experienced stress, confusion, fear, and loss of control. This reaction was obviously expressed in the participants who perceived that their older adult relatives were in a critical condition and survival was uncertain. These participants' responses could be explained by the cognitive theory of stress and coping,[16] where by people appraised the environmental situation that they encountered as a stressful event that exceeded their resources and threatened potential harm/loss of their well-being. This appraisal is characterized by negative emotions.

The study showed that FCGs faced difficulties in making decisions regarding treatment options. This might be due to the fact that the illness of their older adults was sudden and critical, and the decisions were often related to life-changing and concerned the survival of or suffering of their loved ones. In addition, the amount of time that the patient and caregiver had to face this crisis and make life-changing decisions was often very short.[5] This argument was supported by the study of Kongsuwan and Matchim[17] who reported that the duration of time in making decision and unexpected or sudden illness could have influenced the decision making of family members to withhold or withdraw treatment for their loved ones in the end of life. In addition, it seemed that the difficulty in decision making of some FCGs related to their authority within the family. This phenomenon appeared when the primary caregiver was the younger or youngest children of older adult stroke parents.

The findings highlighted that the FCGs' need for help and support when they faced with difficulty especially during the crisis time. This was congruent with the study by Bakas and colleagues[18] who reported that when caregivers perceived that someone was available to discuss issues and provide guidance during difficult times, it greatly reduced anxiety and loneliness. In contrast, lack of help and support either from family or from external sources such as the community and health care professionals could make FCGs experienced more difficulties and stress.[6,19-20]

The findings also showed that fear was a potential factor which inhibited FCGs to learn and practice care. This was because they lacked experience in care and were unfamiliar with the care environment and/or the older adults' condition. They were also concerned about their older adults' safety. Interestingly, female caregivers tended to verbally express more fear than male caregivers. Although the participants desired to learn care skills, fear could induce anxiety and interrupt the learner's readiness to learn.[21] In addition, the participants' concern about blamed by healthcare staff seemed to enhance their fear.

The study's finding also showed the impact of Thai culture, namely, *kreng jai* and the hierarchy of relationships between healthcare professionals and FCGs, on the learning and caregiving of FCGs, since the participants described feeling reluctant to ask healthcare staff for information regarding health care skills. They preferred to ask for such information from other caregivers who had experience in taking care of patients with similar conditions. They also tried to ovoid arguments with healthcare staff. This might be because most relationships among Thais are linked to status or role, wealth, education, professional rank and age.[22] The interpersonal interaction between family caregivers and health care professionals is more likely to be subordinate which might create a communication barrier. The hesitation in asking crucial questions from healthcare staff may cause misunderstanding of the requirements of the caregiving role.[23]

In addition, there were some factors involving health professionals reported as contributing to the difficulties in learning care skills by FCGs in his study. These included the limited time for teaching and learning of care, and inadequate information being provided. This might be due to the work overload of nurses. Since nurse-to-patient staffing ratios in Thai government hospitals were reported as an average of 1:10,[24] which is higher than the recommended ratio from the Thailand Nursing and Midwifery Council (TNC) which is 1:4-5,[25] this work pressure could affect the amount and quality of time staff had to interact with relatives.[26]

Conclusions and Implications

This study provides an insight into FCGs experience difficulties in caring for older adult stroke survivors during hospitalization with the aim of better understanding their views in order to facilitate them to overcome those difficulties. Knowledge gained from this study will help nurses and other health professionals to design appropriate interventions to support FCGs to overcome the difficulties and enable them to succeed in transitioning to the new role. In particular, health professionals need to address FCGs' needs for information on all aspects of stroke to enable to make appropriate decision during the crisis time. Establishing friendly interactions to reduce the gap of communication by offering appropriate skills training are needed for nurses to enable FCGs to effectively cope with the difficulties and to feel encouragement to learn their new role. While this study focused on FCGs perceptions, future studies should incorporate the perceptions of nurses about their experience in dealing with the needs of FCGs during they take care of hospitalized older adult stroke sufferers.

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