Family Caregivers' Perceptions regarding Stroke Prevention for Family Members at Risk

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Abstract: This paper reports on the qualitative descriptive first phase of a participatory action research study, which aimed to develop a stroke prevention model for people at risk of stroke in a tertiary hospital. The study's purpose was to explore caregivers' perceptions of preventative behaviors for family members at risk of stroke. The qualitative data collection was conducted through semi-structured interviews held with 36 primary caregivers living for at least one year with family members at risk of stroke risk people. All informants were recruited through purposive sampling. The interviews were recorded, transcribed, and analyzed using content analysis.

The five emergent categories from the analysis were 1) struggle to modify behaviors, 2) lack of adequate knowledge about stroke prevention, 3) lack of awareness as being caregivers, 4) constraints of being caregivers, and 5) receiving unrealistic treatment regimens. These findings contribute to the need for interventions that enhance awareness and competency of the family caregiver, as well as promote the participation and collaboration of care among family caregivers and their family members, in addition, redesigning a stroke prevention service which appropriate with individual context.

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Introduction

Stroke is an important preventable cause of death and long-term disability worldwide. Preventing the first-ever stroke or primary stroke prevention can reduce about three-quarters of the global stroke burden.[1] Stroke prevention has generally focused on modifiable risk factors because more than 90% of stroke risk are modifiable factors, and about 74% are behavioral factors.[1] There are two approaches for primary stroke prevention including 1) lifestyle and behavioral modification, such as smoking cessation, adoption of healthy diets, moderation of alcohol consumption and adequate physical activity, and 2) identifying and treating people at risk which conditions such as hypertension, high cholesterol levels, diabetes mellitus, and atrial fibrillation.[2] Thus, healthcare providers should pay more attention to these two approaches among risk groups to provide effective stroke prevention.

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Recent studies showed that the patients who had a risk of a stroke particular in diabetes mellitus and hypertension had difficulties modifying and maintaining their behaviors and healthy lifestyle[3] because of poor awareness, lack of knowledge, and accurate information regarding the healthier behaviors.[3,4] They perceived adherence to their diet, recommended activities, and medication were multiple and cumbersome tasks,[3] as well as lacking family support.[5] However, although family caregivers have an important role in promoting a person's self-care and enabling them to modify their behaviors,[6-8] a few studies showed that the family members lacked support from their family about their diet, exercise, and medication resulting in being unable to change their healthy behaviors.[5,9]

Some qualitative studies address family caregivers' perceptions and experiences regarding caring for their family members who have diabetes mellitus, and/or hypertension. Most caregivers focus on providing care by preparing food, reminders about taking medication and exercise, accompanying them to hospital, and emotional support.[10-13] However, it is noteworthy that some family caregivers were not involved in care because they perceived that their family members were not sick,[10,14] did not regularly monitor in care for them,[13,15] regarded themselves external in the disease management process,[13,14] and did not share medical information.[13] These inadequate supports from family caregivers could result in insufficient modifying of risk behaviors. Little is known about perceptions of family caregivers in stroke prevention for people at risk. Therefore, it is necessary for the researchers to better understand how family caregivers perceived their roles regarding stroke prevention for their family members to develop an appropriate strategy to strengthen family involvement. This paper reports the findings of a qualitative phase of a participatory action research project (Development of a Stroke Prevention Model for People at Risk in a Tertiary Hospital). Data were collected to explore caregivers' perceptions of preventative behaviors for family members at risk of stroke.

Review of the Literature

Family caregivers' involvement has great potential to prevent illness in the family living in a close environment playing an essential role in caring for those at home. Caregivers are the significant in improving self-management and promoting healthy lifestyle modification by providing support, encouraging, facilitating, supervising, and reminding their affected relative regarding adherence to medication, healthy diet, regular exercise, and vigilance in monitoring at home.[6-8] They also can provide emotional support about problem-solving, and helping to solve emotional distress.[6,7] These studies are from a quantitative approach and focused on the support and involvement of family caregivers in caring for people with diabetes mellitus and hypertension. There are few qualitative studies which have explored the family caregivers' experiences in caring for their family members having diabetes mellitus and/or hypertension.

At present family caregivers encounter have an increasing need to support relatives at risk of stroke who need participation and support from their family members in maintaining a healthy lifestyle and preventing complications such as stroke. International and Thai studies about family caregivers' perception regarding stroke prevention has not been undertaken. Most relevant studies focused on the burden and quality of life of family caregiver taking care of a stroke survivor and studies have explored the experiences, caregiving behaviors, and feeling of family caregivers in caring those with diabetes mellitus and/or hypertension. The findings explained how family caregivers provided care for family members including giving instrumental support such as accompanying them to meet a physician or other appointments or driving and picking them up,[10-13] providing warnings of potential danger,[10] managing self-care, preparing healthy meals, encouraging exercise, promoting drug adherence,[10-12] assisting in activities for those with health limitations,[10] and taking care when they could not do anything.[11,15] Emotional support can occur by creating a calm atmosphere such as staying with their loved one, caring, being involved in daily activities, assuming a grateful mind,[10,11,15] and encouraging their loved one to accept the reality about illness.[10] Most family caregivers were the spouse or daughter being the main source of social support.[10,15] Some family caregivers had negative experiences regarding caring for their relative with diabetes mellitus because of lack of adherence to a regime of diet and activity, and family caregivers feared about the complications and felt helplessness while caring.[16] Some studies concluded that family caregivers did not involve in caring for family members because they perceived them as not sick, and considered self-care is self-responsibility.[10,12,14,15]

However, it is noteworthy that previous studies explored experiences from family caregivers in caring for the patient with diabetes mellitus and/or hypertension, not specific to perception regarding stroke prevention. Findings from this study would be beneficial for healthcare providers to develop a strategy or intervention regarding family caregivers' participation to prevent stroke among risk people.

Study Aim: This study aimed to explore family caregivers' perceptions regarding stroke prevention for people at risk of stroke in a Thai tertiary hospital.

Methods

Study design: This paper reports the finding of a qualitative approach which is part of a larger PAR project and followed the Consolidated criteria for reporting qualitative studies (COREQ).

Study setting and sample: This study was conducted from September 2019 to January 2020 and took place at the outpatient department of a tertiary hospital in northern Thailand. This hospital has a mission to provide advanced care in neurology and neurosurgery, covering the domains of promotion, prevention, treatment, and rehabilitation regarding stroke. Around 3,000 patients who are at risk of stroke per year utilize the service in the seven units of the outpatient department. The inclusion criteria included family caregivers who were 18 years or older and living with stroke risk people and caring for those risk people for at least one year. Purposive sampling was used through stroke risk people (gatekeepers) to get access to potential participants for the study. Patients with stroke risk utilizing services in the outpatient department were assessed by a co-researcher using a stroke risk scorecard[17] before approaching their family caregivers.

In keeping with the qualitative paradigm, the sample size was ultimately determined by the ability to obtain rich information to answer the research questions and to reach data saturation.

Ethical considerations: This study was approved by the Research Ethics Committee (REC), Faculty of Nursing, Chiang Mai, Thailand (Study code: 2019 – EXP019), and by Chiang Mai Neurological Hospital, Chiang Mai, Thailand (Study code: EC 009/63). All participants were informed verbally and in writing of the purpose of this study, methods, potential risks and benefits of participation, and study duration. It was explained that their participation was voluntary, and they could withdraw or refuse to answer any questions at any time without jeopardizing their health care. Before collecting data, participants were asked for permission to audio-record in each session. The information related to the participants was kept confidential by using pseudonyms instead of real names for tape transcriptions. The documents and tape recordings were kept under lock and key. Participant identities were not and will not be revealed in research reports or publications of this study.

Data collection: Data were collected by co-researchers facilitated by the principal researcher. Face to face, semi-structured interviews were applied to gain in-depth individual perspectives on the topic. Participants were voluntarily recruited by the researcher and the co-researchers at the outpatient department

(OPD). Semi-structured interviews were conducted in the meeting room of the OPD. Each interview lasted for approximately 60-90 minutes. Interview guides were used for the semi-structured interviews to explore the family caregivers' perceptions regarding stroke prevention among risk people. The main questions were "How do you perceive stroke prevention for the person at risk in your family?" and "Why?"

Data analysis: Qualitative data were analyzed following Stringer's method.[18] First, transcripts from semi-structured interviews were read repeatedly by the research team to become familiar with the data. Categorizing and coding were undertaken to identify the perceptions of family caregivers. The categories, sub-categories, and excerpts were identified by the primary author and subsequently verified by the second co-author. Finally, categories, sub-categories, and key findings were discussed and verified by the co-authors until consensus was reached.

Rigor and trustworthiness: In order to ensure data trustworthiness, the principles of trustworthiness or Guba's criteria,[19] credibility, dependability, and confirmability were applied. In terms of credibility, the research information was verified by member checking using three family caregivers. Dependability was enhanced through the co-researchers analyzed the data independently, then compared and contrasted initial findings to achieve consensus including clarification of local context, and was approved by the advisory committee. Confirmability was enabled by using an audit trial derived from verbatim transcriptions and interpretations, and findings were verified by the research team.

Findings

There were 36 family caregivers of 36 people at risk of stroke. Most participants were female (n = 21). More than half were between 40-49 years old (mean = 46.89), had a bachelor's degree (n=24), and worked as a government official (n=18). About 53% was daughter or son (n=19), and 44% was wife (n=16). While most people at risk of stroke were male (n = 30), more than half of them were between 61-75 years old (mean 62.14). Two-thirds of them had no work and were retired. About 53% were the father (n=19), and 44% were the husband (n=16) of the family caregivers. Five categories emerged from the interviews reflecting family caregivers' perceptions and are described in **Table 1**.

Table 1 Categories and sub-categories arising from the data

Categories	Sub-categories
1. Struggle to Modify Behaviors	1.1 Unable to change accustomed behavioral diet
	1.2 Lack of experience with regular exercise routine
	1.3 Health issues which limit exercise
2. Lack of Adequate Knowledge about Stroke Prevention	2.1 Misconception of health status
	2.2 Misconception that labor replaces exercise
	2.3 Misunderstanding purpose of blood test
3. Lack of Awareness as Being Caregivers	3.1 Ignorance of important role of caregivers
	3.2 Misperception that patients can take care of themselves
4. Constraints of being Caregivers	4.1 Time constraints
	4.2 Inability to advise parents
5. Receiving Unrealistic Treatment Regimens	5.1 Inadequate assessment of risk factors relevant to individual patients
	5.2 Irrelevant nutritional education to dietary habits

The first category "Struggle to Modify Behaviors"

Family caregivers perceived that stroke risk people had faced difficulties to change their behaviors because they had grown accustomed to their usual diet. They also did not have a usual exercise routine and had limitations for doing exercises. This category had 3 sub-categories:

1.1 Unable to change accustomed behavioral diet: Family caregivers believed that changing eating behavior of their relative were difficult because of their eating habits. They had always ate a diet of oily, salty food, and sticky rice, as well as a heavy dinner for a long time:

> *"This taste of food; oily and salty food, she has eaten since she was young. It is behavior from being familiar; familiar with eating and the same taste of food."* (Fam_C8)

> *"It depends on the eating behavior in each family. He used to eat and live. For example, at my home, we have eaten sticky rice and Northern-style food from generation to generation. For dinner, we eat a big meal together with our family."* (Fam_C2)

> *"She is familiar with eating fried, or oily food, seafood, and in particular the food made from the internal organs of an animal. She likes eating these kinds of food. There is at least one dish like this in each meal."* (Fam_L2)

1.2 Lack of experience with regular exercise routine: Family caregivers mentioned that stroke risk people were not used to exercising regularly because they had never done it before nor had been encouraged to exercise and understood that exercising was not part of their routine habits.

> *"He doesn't like to exercise. He has never exercised since he was young. Going running every early morning is not his habit, he is not used to exercising."* (Fam_L3)

> *"In our context, most people feel that doing exercise every morning is not their lifestyle. They have never done this since they were young. So, it becomes like they never developed the habit to exercise."* (Fam_C2_Line68-75)

> *"He has never been taught to exercise. He does not have a habit of doing exercise. He is not familiar with waking up to go running in the morning."* (Fam_H11)

1.3 Health issues which limit exercise: Family caregivers stated that those at risk of stroke were unable to do exercise because of their health problems such as knee pain, back pain, or heart disease which caused increased pain and becoming easily tired.

> *"He has a problem with his weight. It's difficult for him to exercise. He gets tired easily. Also, he has issues with bad knee joints, pain, and degeneration. So, it's hard for him to do exercise that requires walking or using the knees or something like that."* (Fam_H2)

> *"He has health problems. Old people of his age have either knee pain, back pain, or heart disease. So, he doesn't exercise because he has pain or easily gets tired."* (Fam_H3)

> *"He has gout, so he cannot do any exercise. Even though he walks for regular exercise, he is always in pain."* (Fam_C10)

The second category "Lack of Adequate Knowledge about Stroke Prevention"

Family caregivers perceived that stroke risk people misunderstood issues regarding their health status since they perceived themselves to be healthy, as well as stroke prevention practices such as assuming that labor done at their jobs can replace regular exercise. They also misunderstood the purpose of a blood test by preparing for a normal result by limiting their intake of salty and oily foods the week before taking the blood test. This category had 3 sub-categories:

2.1 Misconception of health status: Family caregivers perceived that stroke risk people had a misperception which they were healthy because they did not have any abnormal signs or symptoms and they still work and live a normal life.

> *"She doesn't care about her high blood pressure. If there are no abnormal signs and symptoms, she always thinks that she is fine and healthy. She still can work and live as usual."* (Fam_L1)

> *"She does not control her diet, she has diabetes, but she always eats cake, and sweet fruit, particularly durian. She thinks that she is healthy because she has no abnormal signs and symptoms, and she can function as usual"* (Fam_H10)

> *"She thinks that she doesn't have a health problem because she does not have abnormal symptoms. So, since she feels healthy, she behaves as usual. Then she can eat oily, sweet, or salty food as much as she wants."* (Fam_H11)

2.2 Misconception that work replaces exercise: Family caregivers perceived that that their relative at risk of stroke had a mistaken belief about doing exercise. They perceived that doing physical labor at their job or doing housework was exercise because it caused them to sweat and feel tired.

> *"She has a misunderstanding about exercise, she says that she does a lot of work all day until she is tired and sweating. So, she understands that working is equal to exercise"* (Fam_L1)

> *"He thinks that working or doing housework is a kind of exercise because when he works, he will get tired like he exercises too."* (Fam_H1)

> *"Exercise in her meaning is doing housework, housekeeping, or walking to the market every day. So, she thinks that she already did exercise."* (Fam_L6)

2.3 Misunderstanding of purpose of blood test: Family caregivers viewed that people at risk of stroke misunderstood the reason for having a regular blood test. Some people at risk strictly avoid oily and salty food for about a week before having a blood test. When the results are reported as normal, they assume they no longer have a health problem, so they resume their previous unhealthy diet.

> *"If she has an appointment for a blood test, she will strictly control her eating especially for oily, sweet, and salty food. She does this for about one week, then after her blood tests are normal, she will return to eating everything she wants without any concern."* (Fam_H9)

> *"He strictly controls his eating around one week before seeing the doctor for a blood test. He avoids eating oily or fried foods. When the blood tests are normal, he thinks that he is fine so he can go back to eating everything as usual."* (Fam_C1)

> *"Before the appointment date for a blood test, she will tell everyone that she will not eat oily and fried food, especially seafood. She tries to strictly control her eating, but after coming back home, she will return to eat like usual."* (Fam_L2_Line436-446)

The third category "Lack of Awareness as being Caregivers"

Family caregivers did not recognize their important role as being caregivers, so they were not involved in discussions about the treatment regimen with the those at risk of stroke and healthcare providers. They perceived that they could take self-responsibility for their health condition. This category had 2 sub-categories:

3.1 Ignorance of important role of caregivers: Family caregivers perceived that they were not necessary to play a vital role as caregivers for their family members with stroke risk. They understood that visiting a physician at the hospital was a routine follow-up for receiving treatment as usual. In addition, they experienced that healthcare providers did not recognize their role as family caregivers.

> *"I think going to the hospital is just for a blood test or picking up the same prescription. I just drop him off to the hospital but don't come in to discuss the problem or symptoms with the doctor."* (Fam_L9)

> *"I used to be involved but the doctor only speaks to my grandmother. The doctor only talks with her and asks about her symptoms, and she can answer by herself. The doctor doesn't give any instructions on how family members can be involved in patient care at home."* (Fam_L5)

> *"I go together with him in the examination room, but I don't do anything, I only listen to the doctor talking with him. The doctor does not talk or tell me anything. So, I don't think I need to come to the examination room with him. I just let him talk with the doctor alone."* (Fam_L3)

3.2 Misperception by family members that patients can take care of themselves: Family caregivers perceived their relative with stroke risk as being a normal people, not bedridden patients, so they can perform their own daily life activities. They recognized that they had enough knowledge to manage and take care of themselves.

> *"He has the ability to take medicine or eat food. He does not need my help to prepare his medicine or food. I let him manage it himself and he is always responsible for himself, I do not interfere."* (Fam_L3)

> *"I believe that people living with hypertension or diabetes mellitus can manage and solve their own health problems. They know well about how to take their medicine so we don't need to remind them."* (Fam_H11)

> *"I think since he can still do everything by himself, having hypertension or dyslipidemia doesn't mean he has to stay in bed. He is like a normal person who can do things without any help, so he should be responsible for himself."* (Fam_C6)

The fourth category was "Constraints of being Caregivers"

Family caregivers stated that they were limited because they had time constraints and some family caregivers could not give any restricting advice to their parents who had a risk of stroke due to the hierarchical culture of the family. This category had 2 sub-categories:

4.1 Time constraints: Family caregivers explained that they had to work outside to support their families, do housework, and childrearing so they had a tight schedule and were unable to spend much time with the family member with risk of stroke.

> *"I go out for work in the early morning and come back home in the late evening every day. I don't have time. When I am back home, I feel very tired, and I want to rest so I don't want to talk or ask my mother about taking medicine or eating food."* (Fam_H6)

> *"I work every day and sometimes neglect to take care of my mother. I have to bring my children to school in the early morning, and then, take them back home in the evening. So, I don't have much time to take care of her."* (Fam_L4)

4.2 Inability to advise parents: Family caregivers perceived that since they were son or daughter, like children, so they could not guide their parents because of the hierarchical culture of the family. The parents could not accept their children's recommendations and would become angry.

> *"I cannot give him suggestions, because he is the father, the head of the family. He thinks that a child cannot teach the parents. If I tell him about eating, he will not believe me and will be easily angry."* (Fam_H5)

> *"Because they are my father and my mother, they always think that I am their daughter. I am a child who was taught by them, then they will feel strange if I tell them how to eat. They will not believe me because a daughter cannot advise her parents"* (Fam_H10)

> *"He does not believe me, because I am a daughter. Based on our culture, older people or parents seldom listen to their children, moreover, a child or son or daughter cannot tell them something or make suggestions, they don't believe them."* (Fam_C2)

The fifth category "Receiving Unrealistic Treatment Regimen"

Family caregivers viewed that their relative received a treatment plan which was not relevant to their underlying risk factors because of having inadequate assessments and limited time in visits to physicians. Also, the suggestions based on the nutritional education were not relevant to their dietary habit. This category had 2 sub-categories:

5.1 Inadequate Assessment of Risk Factors Relevant to Individual Patients Family caregivers mentioned that their relative with stroke risk were inadequately assessed by healthcare providers for the real causes and other risk factors which promoted a poor outcome of treatment.

> *"The doctor talks only about the problem of the patient which he found that day. He does not explore the causes or other factors which promote the progression of the disease. Patients are not investigated for other reasons of why they are still sick."* (Fam_L1)

> *"There is no additional history talking about the daily life of the patient which may be relevant to the disease and promote a poor outcome of the treatment. All patients should be investigated, particularly long-term patients on why they cannot control their blood pressure or blood sugar."* (Fam_H6)

5.2 Irrelevant Nutritional Education to Dietary Habit: Family caregivers explained that those with risk of stroke were advised how to eat healthier in a manner that was not relevant to their Northern Thai dishes. Then it became difficult to adjust their eating habits by cooking with non-local vegetables or Western food.

> *"Staff teach about how to choose useful food, pesticide-safe vegetables, organic vegetables, use sesame oil or olive oil, avoid or reduce sugar, salt, or fish sauce; or use sugar institute, stevia, or low-sodium fish sauce. People don't know about these things. Even though they know, it's difficult to implement because these recommendations are not consistent with their current eating pattern."* (Fam_C2)

> *"They teach only theory, but in our context, we don't know what is in Thai pounded jackfruit salad (Tum Ka-Noon). We don't know if people with hypertension and diabetes can eat it, or how much they can eat it. I want them to focus on this instead of focusing on eating clean food and high-protein food, reducing fat, eating three or five colors of vegetables, or something like that. No more talking about this. It's no use teaching this. It cannot be practical."* (Fam_H9)

Discussion

This study reported on family caregivers' perceptions regarding stroke prevention for at risk people in their families. Family caregivers perceived that being accustomed to an unhealthy diet, lacking experience with a regular exercise routine, and having health issues that limit exercise caused struggles in modifying the health behaviours of their relative at risk of stroke. They explained that these relatives were accustomed to unhealthy eating habits, especially oily and salty food, sticky rice as well as a big heavy dinner.

This is consistent with previous studies, where family caregivers mentioned that patients with diabetes did not follow the dietary advice because they stuck with their preferable foods.[16] This is congruent with the perception of people with hypertension consuming high fat and high sodium foods who were used to eat unhealthy diets since they were young.[20] In the same manner, healthcare providers' perceived that diabetic self-care was difficult, getting patients with diabetes to change certain eating habits, as they always had sweet foods throughout their lives.[21] They had developed a taste familiarity and had difficulty to follow recommendations that required them to avoid or reduce the quantity or frequency of consuming such foods.[21] Moreover, in this study, people at risk of stroke were used to eating sticky rice and a heavy dinner. By culture, Northern Thai people have been eating sticky rice since childhood. This was in line with patients with diabetes who always ate sticky rice, and without sticky rice, felt as if they were not eating rice.[22] In addition, having dinner is very important in Thai culture. People eat a heavy meal and a variety of food because they have much time for preparation. At the dinner time, all family members can eat a lot of food and enjoy eating together.[23]

In our findings, family caregivers perceived that their relative at risk of stroke lacked experience with a regular exercise routine because they had not been motivated or encouraged enough from childhood onwards. They did not have that mindset to take care of their health by doing exercise, and exercise was not a priority in their daily life.[24] This finding is congruent with the perception of patients with non-communicable diseases including diabetes, hypertension, and coronary artery disease. They did not undertake regular exercise since they had never done it before and perceived that regular exercise was not important and was not part of their lifestyle.[25] Family caregivers expressed that their relative at risk of stroke had health issues such as knee arthritis, back pain, and obesity, causing them to be unable or limited to do regular exercise. Our finding is in line with healthcare providers who stated that patients with diabetes mellitus were unable to do exercise because of their current chronic conditions such as arthritis.[10,21] As well as patients living with diabetes, hypertension, and obesity expressed that they did not do regular exercise because of their chronic conditions such as obesity, knee and leg pain.[25,26] These health issues significantly decreased their ability to exercise effectively and led to poor exercise adherence.

Family caregivers stated that the people with risk of stroke lacked adequate knowledge about stroke prevention because they had a misconception of their health status. As disclosed by the family, those with risk of stroke perceived themselves to be healthy and understood that they were not sick because they could still work and live a normal life without any symptoms. Stroke risks, particularly hypertension and dyslipidemia, are often called the 'silent killer' because most sufferers have no obvious signs, symptoms, or serious complications in their early stages, and seem to be healthy and have good functioning.[27] This is congruent with previous studies where patients with hypertension mentioned that hypertension was not a disease; it did not hurt and they often had no severe symptoms, and this misunderstanding resulted in a lack of attention to the disease and poor adherence to treatment.[28] Some participants stated that they were not sick, so they did not need any special care or did not adhere to their treatments such as diet, exercise, medication or they skipped medical check-ups.[29]

Moreover, family caregivers perceived that their relative at risk of stroke had a misconception that work replaced exercise, so they did not do regular physical exercise. Although it is acknowledged that doing any activity is better than none, there is a danger that those undertaking household chores may assume that this activity is similar to doing exercise and therefore it can be counted as exercise. However, exercise differs from other activities in that exercise is planned, structured, and repetitive and has as a final or an intermediate objective for improvement or maintenance of physical fitness, whereas others are not[30]. Our finding is in line with previous studies, in that family caregivers mentioned that patients with diabetes mellitus did not do regular exercise because they understood that they were active working.[10,16] While the patients with diabetes mellitus and hypertension stated that they did not do regular exercise because they thought that they did regular work, everyday activities such as housework, gardening, or walking during shopping, and getting sweaty and tired which were enough and perceived as sufficient replacement for exercise, so additional exercise was unnecessary.[24,31,32]

Family caregivers mentioned that their relative misunderstood the purpose of a blood test by strictly controlling their intake before taking a blood test for having a normal result. And they resumed their previous unhealthy diet when the results are normal. This temporary eating behavior changes only a short period prior to a blood test is inappropriate behavior for stroke prevention and does not match with the aim of a blood test. Blood testing helps to evaluate and monitor the treatment effectiveness in order to appropriately adjust the medication or other treatment selection. Moreover, since these tests aim to measure blood sugar, or cholesterol and other blood lipid levels, their results may indicate the need for diet modification, increased physical activity, and/or pharmaceutical intervention to reduce risks and avoid serious, even fatal, complications of their disease.[33]

In this study, some family caregivers ignored the importance of caregiver roles because they did not recognize their important role as caregivers. They perceived that monthly or bimonthly visiting physicians at the hospital was a routine and common practice for their family members. In addition, healthcare providers did not request them to participate in discussions about treatment regimens. Thus, they perceived that they were not necessary and important to be a part of caring for people at risk of stroke. It is widely known that family caregivers play an important role in promoting healthy lifestyle modification and improving the health outcomes of the patient in their family by providing necessary support such as encouraging, facilitating, supervising, and reminding the patients regarding self-management, as well as giving emotional support.[6-8,34] Therefore, when family caregivers lack awareness of their role as caregivers, the receipient of care lacks necessary support from family, resulting in unhealthy behaviors. This finding is consistent with previous studies which showed that family caregivers did not provide necessary care to their family members. Some family caregivers explained that they often dropped them off at the hospital because they understood that patients would only sit and receive the same medicines.[10,13] In addition, some family caregivers accompanied the patient in the examination room, but they had never been asked or communicated with by a physician about how to facilitate medication taking at home.[13,15]

Moreover, our findings presented that family caregivers had a misperception that those with stroke risk could take care of themselves since they seemed healthy without any abnormal symptoms, and it was their responsibility to manage their health. Consequently, family caregivers did not take action as caregivers properly. This finding is consistent with a previous study that family caregivers of people with diabetes did not participate in caring, mentioning that they did not have any complications, and could underake normal daily activity.[15] Family caregivers also considered self-care as self-responsibility so, they only watched their self-management as outsiders, and wanted to respect the integrity of their relative by not undertaking the role of the controller.[14]

Family caregivers perceived that they had time constraints to participate in caring as they had tight work schedules such as taking care of children, current work, and household. Family caregivers for those with diabetes and hypertension had similar difficulty participating in care because of tight work schedules, childrearing, and working outside the home.[12] In another study, patients with diabetes mentioned the absence of support from family members because their caregivers were too busy, then, they were unable to exercise together, or prepare healthier meals.[35]

Lastly, family caregivers expressed an inability to guide their parents in self-care due to the hierarchical culture in Thailand. Their parents could not accept recommendations from them, and they would be angry because they were sons or daughters. In Thai culture, parents are the head of the family and have the responsibility of taking care of, teaching their children, and making a decision in the family.[36] Children must respect older people or their parents, obey, and follow their recommendations.[37] This finding is consistent with previous studies in which family caregivers could not suggest self-care to their parents because of cultural factors as the parent's position is highest, so, they were fearful about the tense relationships among family.[11,16]

Family caregivers perceived that their relatives at risk of stroke received unrealistic treatment regimens from healthcare providers, and they were inadequately assessed for any individual risk factors. Health assessment and risk screening are vital to foundation of effective care; an appropriate, and comprehensive assessment provides complete information for making an appropriate decision quickly and accurately, resulting in improved patient safety.[38] If assessment or investigation does not cover all dimensions of a patient's problems, they may receive inappropriate treatment. Previous studies indicate that health professionals lacked time to conduct health assessments that cover all aspects of the patient, and poses difficulties during regular encounters with many patients.[5]

In our study, family caregivers stated that their relative with risk of stroke often received irrelevant nutritional education to their dietary habits. The recommendations received were impractical in their daily life and the content was irrelevant to the patient's context. This is consistent with previous studies where some family caregivers mentioned that patients were unable to follow healthcare provider's recommendations due to a lack of understanding about nutritional needs for their disease because they received unsuitable and impractical health education.[39] To promote knowledge and skills for adapting to patients' health conditions and performing self-care behaviors, health education should be relevant to the context of each person and so it is necessary to assess requirements, the context and level of education given individually.[40]

Limitations

More than half of the participants had a high education level, and most were female, so their perceptions regarding stroke prevention for people at risk may be different to the general population of caregivers.

Conclusions and Implications for Nursing Practice

Our findings provide information about family caregivers' perceptions regarding stroke prevention for people at risk. Family caregivers perceived that their relative with stroke risk faced struggles to modify their health behaviors and had inadequate knowledge about stroke prevention. They were not aware of their family caregiver roles and encountered time constraints. Other family caregivers described they lacked awareness in their role as caregivers, and had constraints having to honor their parents through obedience. Moreover, they pointed out there were issues about treatment regimens that were not realistic or relevant to actual needs.

Even though stroke can be treated, its treatment was limited in this study, and the results can be so devastating. Prevention among those at risk of stroke through risk management and modification is essential to decrease morbidity and mortality. Moreover, actions which promote maintenance of health might be easier and more effective than reversing existing damage, as well as changes in health practices are likely to have the greatest impact or benefit early in life, before having the disease. In addition, it is widely known that family caregivers play an important role in improving health outcomes of the patient in their family, therefore, these findings could help healthcare providers, particularly nurses to develop effective and comprehensive interventions for family caregivers to enhance their awareness and competency, as well as promote the participation and collaboration of care among family caregivers and their family member at risk of stroke. In addition, our findings can help healthcare providers to redesign a stroke prevention service that is appropriate with individual context and can help inform future research to develop a model for enhancing the family caregivers' participation in preventing stroke for risk people that is appropriate to the local context.

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การรับรู้ของผู้ดูแลในครอบครัวเกี่ยวกับการป้องกันการเกิดโรคหลอดเลือดสมองสำหรับผู้ที่มีภาวะเสี่ยง

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บทคัดย่อ: การศึกษาครั้งนี้เป็นส่วนหนึ่งของการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมที่มีวัตถุประสงค์เพื่อพัฒนารูปแบบการป้องกันการเกิดโรคหลอดเลือดสมองสำหรับผู้ที่มีภาวะเสี่ยงในโรงพยาบาลตติยภูมิ วัตถุประสงค์ของการศึกษาเชิงคุณภาพนี้ เพื่อศึกษาการรับรู้ของผู้ดูแลในครอบครัวเกี่ยวกับการป้องกันการเกิดโรคหลอดเลือดสมองสำหรับผู้ที่มีภาวะเสี่ยงในครอบครัว ดำเนินการเก็บรวบรวมข้อมูลโดยใช้วิธีการสัมภาษณ์กึ่งโครงสร้างในผู้ดูแลในครอบครัว จำนวน 36 ราย ที่อาศัยอยู่กับผู้ที่มีภาวะเสี่ยงต่อการเกิดโรคหลอดเลือดสมองอย่างน้อยหนึ่งปี โดยเลือกอย่างจำเพาะเจาะจง การวิเคราะห์ข้อมูลใช้วิธีวิเคราะห์เชิงเนื้อหา

ผลการศึกษาสามารถจัดกลุ่มได้เป็น 5 ประเด็นหลัก ดังนี้ 1) มีความยากลำบากในการปรับเปลี่ยนพฤติกรรม 2) ขาดความรู้ที่เพียงพอเกี่ยวกับการป้องกันโรคหลอดเลือดสมอง 3) ขาดความตระหนักในการเป็นผู้ดูแล 4) มีข้อจำกัดในการเป็นผู้ดูแล และ 5) ได้รับแผนการรักษาไม่ตรงกับความเป็นจริง ผลการศึกษาครั้งนี้ช่วยสนับสนุนถึงความจำเป็นในการจัดกิจกรรมเพื่อสร้างความตระหนัก และสมรรถนะของผู้ดูแลในครอบครัว ตลอดจนส่งเสริมการมีส่วนร่วม และความร่วมมือในการดูแลระหว่างผู้ดูแลและสมาชิกในครอบครัว นอกจากนี้ ควรมีการปรับการให้บริการป้องกันโรคหลอดเลือดสมองที่เหมาะสมกับบริบทของแต่ละบุคคล

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คำสำคัญ: ผู้ดูแลในครอบครัว การรับรู้ การศึกษาเชิงคุณภาพ การป้องกันโรคหลอดเลือดสมอง ผู้ที่มีภาวะเสี่ยงต่อการเกิดโรคหลอดเลือดสมอง

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