Development of the Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics: Participatory Action Research

Piyarat Chaknum, Teeranut Harnirattisai, Chomchuen Somprasert, Li-Chi Chiang*

Abstract: In many cultures around the world, including those in Thailand, family caregivers have different views on caring for stroke survivors. These views affect the caring process, which tends to be a heavy burden for caregivers. This study used participatory action research to develop the Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics. Stroke survivors and their family caregivers were recruited via purposive sampling from two primary care units in Nonthaburi, Thailand. Fourteen caregivers participated in four cycles of activities for 16 weeks and they were divided into two groups of seven. Data were collected using family group discussions, observations, home visits, telephone, LINE application, and field notes, as well as a family demographic questionnaire. Participants in each group created caregiving strategies to balance family life tailored for stroke survivors' families. Individual and collective self-reflective cycles were used as a method that contained four steps: planning, acting, observing, and reflecting. Qualitative data were analyzed using the ATLAS.ti 8.0 program to develop data categorization and themes. The four major themes emerged and described the participatory process in caring stroke survivors: 1) Assessing problems and developing strategies; 2) Making collaboration for changing strategies; 3) Balancing the body and mind to empower themselves; and 4) Healthy family dynamics. This study demonstrated that there were five main phenomena affecting care: caregiver characteristics, family functions and relationships, assistant support, community resources, and community nurses. The model developed in this study can help direct nurses to promote healthy family dynamics in Thai stroke survivors, however, it is necessary to be further tested through research before being applied in practice.

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Introduction

Strokes remain the third-leading cause of death and disability, as 89.0% of disability-adjusted life years are lost worldwide.[1] More than 50% of all stroke survivors and caregivers are affected by at least one condition, such as a mental health or physically limiting condition, that leads to worse long-term

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outcomes.[2] The number of Thai stroke survivors has increased every year, especially for those >60 years, from 151,931 persons in 2017 to 232,338 in 2022.[3] Approximately 70% of survivors have long-term disabilities and nearly 40% experience a recurrent stroke within five years of the initial stroke.[4-5]

In Thailand, most care for stroke survivors begins at the hospital and continues to the home under the supervision of the primary healthcare system in the community. In the community, stroke survivors referred from hospitals receive home healthcare services. Healthcare teams provide healthcare services, such as community nurses, health volunteers, and other health providers (physiotherapists and family physicians). The recovery process continues after survivors return home. Following a stroke, some survivors will become dependent, with Barthel Scale/Index (BI) scores ranging from 0-79, requiring daily support and rehabilitation from others.[6] Stroke survivors and their families need time with various daily activities and adaptation to home environments.[7] These situations affect family interaction and relationships, leading to ineffective family dynamics. Family dynamics refers to the patterns of interactions among relatives, their roles and relationships, and the various factors that shape their interactions.[8] Because family members rely on each other for emotional, physical, and economic support, they are one of the primary sources of relationship security or stress.[8-10] If members have secure and supportive family relationships, they will provide love, advice, and care, whereas stressful family relationships are burdened with arguments, constant critical feedback, and conflict. Therefore, promoting healthy family dynamics is important in caring for stroke survivors to achieve healthy outcomes because it is a way to change caring to resolving problems. Caregivers are important for stroke survivors. However, if they are coping with stroke survivors' personality changes, they may find difficulties in caring for them; hence, they must learn effective strategies to manage complex and nuanced circumstances.[10-11]

In caring for stroke survivors in families, there are some differences between Eastern and Western countries in terms of compassion and respect and providing a sense of dignity.[12] In Thai culture, the young generally pay respect to their elders, and family caregivers have both positive and negative views.[13] While some families feel happy instead of burdened by caring for their parents, others feel burdened as they do not have sufficient support.[9] The way of caring for stroke survivors in families in each region may be different because of the social and cultural contexts.[9,13-14] A review of the literature found that many caregivers, especially those who feel they are not receiving enough help from other family members, have conflicted feelings when caring for stroke survivors with functional dependency.[8,11,15-16] As family members often have no experience or trained skills in caring for stroke survivors, they may face problematic situations, especially at the beginning phase of caregiving.[9,18]

Caring for stroke survivors can be a heavy burden for primary caregivers, particularly those providing long-term care that impacts lifestyle and well-being. Stroke survivors and their families come from different cultural, economic, and social backgrounds. These diverse backgrounds and experiences also affect families' spirituality and religion.[11,14,19] Experiences in providing care differ for each family. Family members and caregivers will often find problem-solving strategies to balance their lives.[19] Families of stroke survivors face challenges in daily life, roles, and responsibilities, resulting in individualized experiences that can involve heightened anxiety, depression, stress, and poor social adjustment.[15-20] Having a stroke survivor in the family can mean family members must consider long-term recovery plans, which also means developing and adjusting to new ways of life.

The family is the primary unit and has a powerful influence in Thai society. Individuals have different beliefs, cultures, and contexts that establish each person's demands. Individual health outcomes are influenced by interaction and reciprocity, so living with stroke survivors usually affects the entire family unit.[7-8,21] Most studies emphasize promoting caregivers' knowledge and skills in caring for stroke survivors; the studies regarding the promotion of the family to function and adapt effectively for healthy family dynamics are limited.[10] Moreover, previous studies have focused on the physical health outcomes of persons, and there was limited intervention related to the families.[10,22] Therefore, the researchers in this study were interested in finding a model that encouraged family members to adjust their lifestyles to provide adequate care for stroke survivors and themselves, particularly in urban and semi-urban communities in Thailand.

Pragmatism, as a philosophical concept, emphasizes knowledge and truth, helping humans achieve a purpose and improve their practice in caring. However, pragmatism can change relative to each person's phenomena, context, and perception.[23] In this study, methods for changing practices can help families caring for stroke survivors adapt to healthier ways of life. The Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics (hereafter referred to as the FBCMSS) was developed to help stroke survivors' families form realistic and adjusted care experiences to achieve healthy goals.

Participatory action research (PAR) provides a collaborative commitment to improving communication among primary caregiver participants. Practice adjustment is a self-reflective PAR process resulting from investigating practices and involves studying the reality of participation by people in specific environments.[24-25] Thus PAR was used to develop a model that would promote healthier family dynamics for families of stroke survivors. Sample groups participated and created a care process to balance their lives to promote a healthy family dynamic. As researchers, we believe that this qualitative approach could improve nursing practice and help solve problems of the families of stroke survivors. These strategies will help healthcare professionals empower families with the confidence to adjust behaviors and relationships to maintain a functionally balanced lifestyle. Family members can contribute their subjective experiences to the family unit and encourage quality of well-being among other household members to maintain the health and happiness of the domestic environment.[17,26] Information about caring for stroke survivors must be communicated effectively to communities and primary healthcare services, which help in family support arrangements.[7,10,13] Thus, promoting a healthy family dynamic is necessary because it can help empower family members to maintain their dynamics as a healthy family unit and the communication of nurses and others as primary healthcare professionals.[7,10]

Study Aim

This study aimed to develop a caring model specific to stroke survivors to promote healthy family dynamics in a semi-urban community in Nonthaburi, Thailand.

Methods

The primary researcher (PI) employed the 32-item Checklist Guideline of Consolidated Criteria for Reporting Qualitative Studies (COREQ) to report the findings of this study in a transparent and unbiased way.[27]

Design: This qualitative study utilized focus group discussions in the PAR process as described by Kemmis and McTaggart.[24-25] The PAR process can be used to share the experiences and care problems of stroke survivors. Both participants and researchers can exchange and reflect on knowledge about the impact of care and needs in daily life and how they can achieve self-management strategies within their households. This study consisted of four cycles over 16 weeks. Primary caregivers were recruited and divided into two groups: group discussions and activities.

Sample and Settings: Fourteen family caregivers were selected using the purposive sampling method from an area under the service authority of primary care units in a semi-urban community in Nonthaburi province, in central Thailand. Once they had given research consent the caregivers were separated into two groups according to their residence area. Each group consisted of seven family caregivers who met the following criteria: (1) a Thai family member and primary caregiver of a stroke survivor, (2) at least 18 years of age, (3) provided at least four hours of healthcare daily, (4) had more than two members in the family, and (5) was willing to participate in the four-cycle PAR process, and (6) agreed to be audio-recorded while performing activities. The group activities were arranged at the participants' homes or places of convenience.

Data collection: In PAR studies, the researcher is considered the most significant research instrument.[28] The PI in this study developed both her research techniques and data collection skills. This included enrolling in a qualitative course, practicing interviewing and focus group interview skills with senior researchers and research project advisers, and learning how to use the ATLAS.ti 8.0 program (qualitative data software).

The other instruments included a family demographic questionnaire; a PAR guideline (**Table 1**) verified by three experts specialized in qualitative research, family health, and community health; an audio recorder; field notes a digital camera; and a manual on giving care to stroke survivors.

Table 1. PAR guideline

Process	Researcher activities
Process planning	1. To engage with 14 family caregivers selected based on the criteria and who agree to participate 2. To select participants from the list of stroke survivors of two sub-district health promoting hospitals, Nonthaburi using purposive sampling 3. To divide participants into two groups according to their residence area 4. To conduct family group discussion for four times a month per cycle 5. To follow four stages of PAR process: planning, acting, observing, and reflecting
PAR process	1. To inform participants regarding the study's objectives, procedures, and expected outcomes to give the written permission 2. To ask for permission to record field notes, photos, and audio recordings during research activities 3. To introduce the discussion topics and perform as a facilitator and supporter to encourage the participants 4. To encourage participants to address their obstacles, targets and outcomes in each group, and encourage them to design their own activities 5. To conduct four stages of each cycle as follows: Planning: to promote participants in setting goals and designing caring strategies Acting and observing: to encourage participants to apply the strategies acquired from the group discussions and observe their activities Reflecting: to promote participants working together to conclude the strategies and evaluate the activity results before replanning the strategies in the next cycle

Data were collected using family group discussions, observations, home visits, telephone calls, LINE follow-ups, and field notes. The PI built friendly relationships with the participants before the commencement of the activities. Discussions in small groups were more convenient for the arrangement of activities, so the participants were observed, interviewed, and participated in group discussions. The PI conducted all of these discussions, providing information regarding the four cycles of the PAR process. Each cycle applied a spiral process involving four steps: planning, acting, observing, and reflecting.[24-25,29] In the planning steps, the group participants worked together for 90-120 minutes to develop suitable caring strategies and goal achievements in the family context. Then, in the acting and observing steps, the participants applied the planned strategy to their own families and observed how it either worked or did work. Subsequently, in the reflecting steps, the participants discussed in groups about their problems and experiences and revised or developed new strategies. The participants were required to participate in the activities every week for four months, and the PAR process was undertaken from October 2020 to January 2021. The participants in each group discussed and created caregiving strategies to balance family life tailored to the families of stroke survivors. They then observed problems and obstacles as feedback for discussions and group adjustments each week toward their goals. Individual and collective self-reflective cycles were used as methods consisting of four steps: planning, acting, observing, and reflecting.

Ethical Considerations: The Human Research Ethics Committee of Thammasat University (Science) approved the study (project no. 138/2562). Permission was granted by the Governor of Nonthaburi Province to conduct the study within the community before collecting data. The participants were informed of their research rights, research objectives, data collection procedures, duration of data collection, and possible benefits prior to signing a consent form and subsequent participation in the study. The PI kept informing the participants of the change process during the study, as well as informing them of their rights. This included their rights to reject questions or withdraw from any activity at any time if they expressed discomfort or unwillingness to continue.

Data Analysis: Qualitative data analysis was used to interpret and define the meaning of the data content, which involved coding techniques, grouping, and organizing themes gathered from the participants' information. Qualitative data were analyzed using five general approaches of analysis using the following method: (1) managing and organizing the data for analysis; (2) reading and rereading the data; (3) describing and classifying applied codes into themes; (4) assessing the interpretation to understand and explain how the situation happened in the within-case and cross-case analysis; and (5) representing and visualizing the data with a map or diagram.[30] The PI simultaneously collected data and then analyzed this with the support of the ATLAS.ti 8.0 software package.

Trustworthiness: According to Lincoln and Guba, data needs to be verified for its trustworthiness to ensure its accuracy and truthful information based on four criteria: credibility, dependability, transferability, and confirmability.[30] For credibility, steps undertaken included a constant comparative method of data collection and analysis; data triangulation of different data sources and methods; prolonged involvement with participants, member checking, and peer debriefing with participants. The caregivers gave information that ensured the accuracy of the concepts presented in the study until their satisfaction was met during the research activities, along with coding and categorizing processes. For the criterion of dependability, an inquiry technique was employed to inspect the theoretical consistency, clarity of the study question, and language suitability of inquiry by three experts as mentioned above. For transferability, the PI used a descriptive technique to explain caring for stroke survivors and used three techniques including peer debriefings, theoretical triangulation, and member checking to build confirmability.

Findings

The participants consisted of 13 females and one male, aged 30–76 years, with a mean age of 58. They provided care for stroke survivors who were two females and 12 males, aged 56–87 years, with a mean age of 70. Stroke duration ranged from one month to 17 years, with a mean of five years. Fifty percent of stroke survivors were independent in activities of daily living (Barthel Index (BI) score 80–100), some needed help (BI score 20–79), and only three were dependent (BI score <20).[6] Participants lived with three to ten family members, with an average of five people per household. Each family had lived in the community for at least 20 years. Activities that family members often engaged in together were talking, eating, traveling, staying, and attending important events. The important problems proposed by the family caregiver participants were a lack of caring knowledge, family relationships and conflict, no time to take care of themselves and relaxation, and no support from others. Most conflicts in the family came from dissatisfaction with family members, impulsiveness, and differing opinions and views. The general information of the families participating in the research on family activities and conflicts is shown in **Table 2.**

Table 2. General information of caregivers, stroke survivors, and families (N = 14)

General information	Lowest	Highest	Average
Age of caregiver	30	76	58
Age of stroke survivors	56	87	70
Duration of stroke care (months)	1	204	61
Number of family members	3	10	5
Period of stay in the community (years)	20	40	29
Family activities and conflicts			
Daily activities	Talking (4), eating (3), no activity (7)		
Activities on important occasions	Traveling (4), making merits (3), eating (6), no activity (3)		
Activities on important days	Making merits (3), staying with all members (3), eating (8), no activity (1)		
Conflicts	Displeasing conversations (6), impatience/annoyance/scolding (7), misunderstandings/disagreements (6), money (1), caregiving (1), disobedience (1)		

To develop a caring model specific for stroke survivors aimed at promoting healthy family dynamics, the model was created using four cycles of PAR as the following themes and subthemes (**Table 3**).

Table 3. PAR findings

Themes	Subthemes
Assessing problems and developing strategies	Knowing problems Setting goals Strategies for problem-solving
Making collaboration for changing strategies	Sharing caring experiences Cooperation in care within the family Assistant support and community resources Mental health support
Balancing the body and mind to empowering themselves	Positive thoughts and providing care with love Promoting physical health and improving mental health
Healthy family dynamics	Perceived happiness Physical and mental health Financial balance Family relationship and interaction

Theme 1: Assessing problems and developing strategies

From Cycle 1 of the PAR process, participants were arranged into small groups and freely discussed caring problems, which influenced family dynamics. Then they discussed setting goals for taking care of stroke survivors and developing their ways of solving the caring problems. Three sub-themes arose from analysis:

Sub-theme 1. Knowing problems: After the assessment, the participants recognized and understood the causes and factors related to the problems. These related factors included a lack of knowledge regarding symptoms and illness conditions, inability to access healthcare services for rehabilitation, stroke survivors' ignorance of their self-care, unstable relationships and conflict within the family, and the mental and physical health issues of family caregivers, as indicated by the examples below:

> *"Having a stroke needs to do lots of exercise and rehabilitation but my sister said he's old already. She asked why I have to hurt him, what if his arms or legs were broken?"* (G1_902)

> *"I don't understand why stroke survivor is always frustrated and aggressive."* (G1_905)

Sub-theme 2. Setting goals: All participants shared their caring experiences and carefully considered goals to help their family member recover their independence, as exemplified by:

> *"I will take care of him until the end of his life. I will go travel with him and find good nutrition for him."* (G1_906)

> *"I do bed bath, feeding, and changing position but not the wound dressing. My sister will do dressings after she gets home in the afternoon."* (G2_910)

Sub-theme 3. Strategies for problem-solving: The participants discussed problems and methods suitable for individuals and families to solve those problems. One participant suggested talking as a strategy to solve relationship problems:

> *"Have you ever had a general talk with her? Maybe you can try talking about general topics with her, such as 'You look so fresh this morning,' 'You look so good,' so that she can feel that you did not ignore her and help her feel better."* (G2_908)

Theme 2: Making collaboration for changing strategies

After participants acted on the strategies, they helped other group members adjust their strategies and care practices, leading to adequate rehabilitation and health for stroke survivors and overall family dynamics. They created ideas for visiting the home of other group members to assess the actual situation and adjust to the appropriate care to fit the family context in Cycle 2 of the PAR process. The activity helped promote health and well-being to the caregivers and helped them adjust their environments to provide effective rehabilitation for stroke-affected family dynamics, as explained below.

Sub-theme 1. Sharing caring experiences: The participants discussed and shared experiences after home visits, such as encouraging patients to perform activities, relieving muscle pain, finding benefit resources, adapting, and identifying successful outcomes from using caring strategies suitable for their own families:

> *"I use the water from washing the rice and massage his fingers with it. It helps to prevent joint adhesion. I do this for him every day. We also can do [this] with his feet."* (G1_902)

> *"The patient at home needs to eat ivy gourd leaves. I sometimes make it as soup or stir-fried with eggs for him. He doesn't like eating other veggies. Now, his constipation problem is much better."* (G1_905)

Sub-theme 2. Cooperation in care within the family: The group conversations helped the participants improve their knowledge and instilled in them the confidence to provide adequate care for stroke survivors. Participants were closely acquainted and helped each other create strategies, such as care assessment, home environment modification, rehabilitation techniques, stress management, and family relationship building:

> *"I think the bathroom is not big. If you add the handrail on both sides, it would help to support him to walk himself so that you won't have to carry him to the bathroom and don't have to be worried that he will fall down as well. Also, what if both of you fall? Having handrails would be very useful for both of you."* (G1_902)

> *"This bed has dents. The urine can get stuck in those dents when he urinate [sic]. It might cause pressure sores later."* (G1_913)

Sub-theme 3. Assistant support and community resources: Support provided by other families and the community was one of the key factors needed by families caring for stroke survivors. It included support from other family members or external resources, such as assistive devices, financial and health services, and other conveniences:

> *"My sister bought all the things for the house, such as foods and other necessities. If I want something, then I will ask her. Before, no one gave me any supports [sic]. So, I had to be a merchant and sell lots of things. When I stop selling, my sister helps and the need for support is met."* (G1_905)

> *"Money is very important. At least in one month, we have money to buy foods [sic]. Month after month is better. Don't be in the needy [sic]. If we are in need, we will mentally suffer. Money is the number one factor and a priority for each family."* (G2_909)

Sub-theme 4. Mental health support: Participants showed empathy for each other while participating in group activities. They provided each other with positive energy, encouragement, and support through verbal persuasion, especially regarding mental health support, which helped the participants relax. The participants adopted the ideas they shared in the group sessions and implemented them with their own families, including providing help and support, showing empathy, and building self-confidence for the patient.

> *"How about you? I deeply understand you. I'm here to support you. Keep going."* (G1_913)

> *"I understand how you feel but you have to let it go. Don't care about others' issue and what they said. Like my family. Don't care [sic] other people's business. It's their business, not ours. Also do not blame others, [sic] just be us."* (G2_908)

Theme 3: Balancing the body and mind to empower themselves

According to Cycle 3 of the PAR process, the participants could share their opinions with others' care plans. Participants adjusted their care strategies and practiced dharma (the teaching of Buddhism), which encouraged them to care happily. They helped each other create positive energy and shift their perspectives. The activity provided stroke survivors and their families with a chance to cooperate in the caring process to achieve their goals. The results were as follows.

Sub-theme 1. Positive thoughts and providing care with love: The participants suggested changing their mindsets by practicing emotional control and developing a perspective that helps them provide care with happiness. They altered their care plans from the first two cycles. These new plans resulted in better physical and mental health. They became more optimistic, reflected on themselves while providing care, and were kind to others:

> *"I will continue doing good thing [sic] unconditionally."* (G1_903)

> *"I'm good at being greedy. I also know fascination. It means being credulous."* (G2_909)

Sub-theme 2. Promoting physical health and improving mental health: The participants were concerned with developing strengthened mental health that could improve their family dynamics and help them provide more effective care. A specialist used meditation to strengthen the participants' mental health. They practiced daily until they could control their feelings and know how to let something go. Meditation retreats helped them control emotions, be more reasonable, and use wisdom to solve problems; for example, controlling negative emotions, understanding the reality of the situation, and praying and making merit. Moreover, participants set aside their own time by exercising 30 minutes daily for at least three days a week. Each family had a different exercise style depending on the family context:

> *"It makes me sleep better. I have never prayed before until I joined this group activity. I usually have difficulty in sleeping, not sure if it's because I'm getting older."* (G1_902)

> *"There is a playground in front of our house. When I take him out for exercise, I'll do it too. So that we will be healthy together. He is sick and I am not that healthy. So, I have to take care of myself as well."* (G2_911)

Theme 4: Healthy family dynamics

Caring for the family as a unit, many factors promote healthy families for stroke survivors, such as quality of care from caregivers, family member interaction relationships, social support, and the healthcare system. These factors directly affect the achievement of the care goal. Based on the three cycles of PAR, the participants applied strategies within the family and observed, reflected on, and revised activities to achieve the goals until obtaining the final strategies as a caring achievement that fit their family contexts. In Cycle 4 of the PAR process, the participants summarized all their findings about activities and three sub-themes arose from data analysis that performed as follows.

Sub-theme 1. Perceived happiness: Happiness is evaluated through the resulting satisfaction reflected after collaborative activities and can be discerned through acceptance, forgiveness, and reasonable thought. The resulting feelings of happiness and better quality of care were reflected in the statements provided by the participating caregivers, for example:

> *"I'm so happy that my family is being like this. Do not have any arguments. At first, we couldn't accept this. But now, we have talked and that made us feel better. If we couldn't accept the fact, we won't be happy like this."* (G2_909)

> *"It's much better. I'm happy and got lots of knowledge. I forgive him about behaviors and personality changes as I understand that it's because of the sickness."* (G2_912)

> *"I moved all his Buddha amulets to his room so that when he sees his collection, he will be happy. He was so happy when he saw them yesterday. Had had a huge smile. I asked if he liked it, and he said, 'Yes, yes, yes, of course! I have been collecting them my entire life.' I'm happy if he's happy."* (G1_913)

Sub-theme 2. Physical and mental health: To be healthy in families include both physical and mental health. The physical and mental health of all family members is important, as is the rehabilitation of stroke survivors. The good physical health of family members has been achieved after changing behaviors, such as exercise, diet control, and having enough rest. When the people are in the independent stage, Moreover, the physical health of stroke survivors can be assessed through cooperative rehabilitation until they can perform activities themselves or independently. Being independent makes the person happier and more empowered in daily living, as explained in the following statements:

> *"I also do exercise. I do exercise with my husband* (stroke survivor). *When I take him out for a walk, I also walk with him. I sometimes use exercise equipment and ride a bike there too."* (G2_911)

> *"My dad can look after himself well. It helps my mom lots. It's not much different for me as I didn't help a lot in the beginning. But for my mom, it was different. She's less tired and less grumpy than before."* (G2_912)

> *"He is getting better. He speaks more and keeps getting better. I have been taking care of him since he was bedridden until he can walk and do activities himself."* (G1_913)

Sub-theme 3. Financial balance: The feelings of family members, if they feel like they can afford personal living expenses and medical expenses, and rehabilitation for stroke survivors. They can receive support from other family members or nearby community organizations. The following are some statements from the participants:

> *"There are canes, wheelchairs, and stretchers at the health-promoting hospital. We can borrow from there. People who don't use them anymore donate to the hospital. We don't have to spend money."* (G2_908)

> *"I had lots of debt before but now the situation is better. I opened up a noodle restaurant. I'll treat you someday. There are many customers every day. Always sold out. I plan to have a day off. The business is going well. I get profits and have some left for saving."* (G2_911)

Sub-theme 4. Family relationships and interactions: The relationships and interactions among family members can be assessed from the gestures and behaviors they express to each other. It can also be evaluated through how they help and support each other and form healthy relationships within the family, bringing peace and harmony to the household:

> *"I have been looking after my dad until I do not have time for my boyfriend. My boyfriend told his mom, 'I love her lots. I feel pity for her. I can't leave her alone.' I started crying when I heard that."* (G1_913)

> *"I'm happy my family is being like this. They do not have arguments. At first, we couldn't accept this. But now, communication has made us feel better. If we didn't do this, we wouldn't be happy now."* (G2_909)

According to the PAR process, the researcher synthesized data to develop the Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics. The development of the model for stroke survivor care specified five main affecting care: caregiver characteristics (knowledge and skills), family functions and relationships, assistant support (assistive devices), community resources (rehabilitation center, healthcare workers, volunteers, and organizations), and community nurses. Community nurses were important persons in the caring model to help family caregivers in operating the process of care to achieve healthy family dynamics. Community nurses took the roles of health educators, providers, counselors, and coordinators between organizations and health professionals in the community. (**Figure 1**)

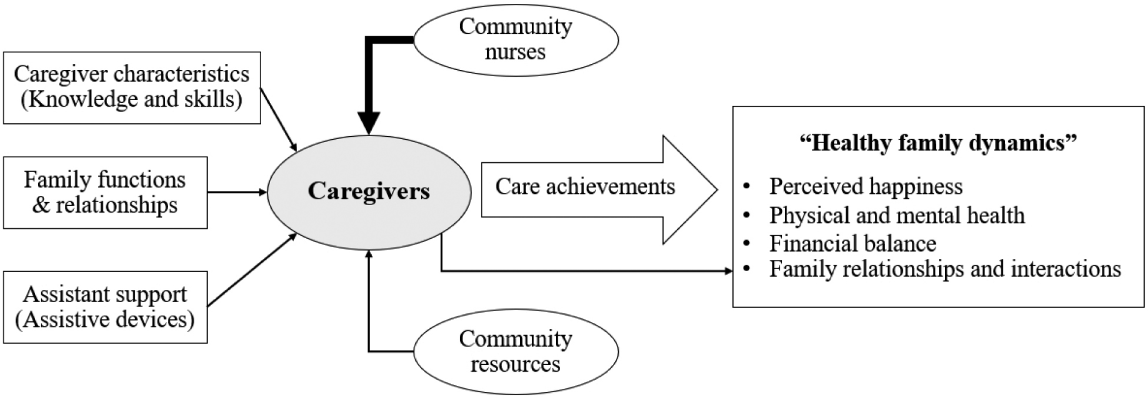

Figure 1. The Family–Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics

Discussion and Recommendations

The development of the Family–Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics in this study came from the desire to strengthen the health of stroke survivors, caregivers, and their families. This model explained that caregivers were directly affected by five main affecting care: caregiver characteristics, family functions and relationships, assistant support, community resources, and community nurses. The PAR process was used to provide empirical knowledge regarding the caring experience of the participants in the family with stroke survivors. Because of this process, the caregivers became more knowledgeable, understanding, and capable of caring for stroke survivors better.[24–25,30] In the Thai context, most caregivers of stroke survivors were family members who had responsibilities to provide unconditional care, learn practical skills, improve their performance to care for the stroke survivor and help them with continuous rehabilitative therapy.[31] According to previous literature, encouraging stroke survivors to undertake activities of daily living will help them recover and return to living independently faster.[8,10,22] Thai caregivers, together with families, need to be responsible for caring for stroke survivors, resulting in successful planning and better quality of care.[32]

Family dynamics is an essential concept that can be modified depending on the environmental context and situation,[26] and refers to the patterns of interactions among family members, their roles and relationships.[7–10,14] This study explained that if the family has positive experiences in care, they can improve the family function to support the altered life of stroke survivors.[18–19,21] This finding was consistent with a previous study in Thailand finding that negative experiences resulted in a lack of trust and affected family dynamics and future encounters.[14]

Although our study focused on family caregivers, the family as a unit of care made it different. When a family member suffers a stroke, the entire family is affected.[8,14,17] Thus, healthcare in the future will depend more heavily on family supports, including spouses, family members, and others in the social network.[33] In addition, getting support from others can relieve conflict and burden on families with stroke–affected family members.[8–9,13–14] Caring at home, assistant support and community resources facilitated family caregivers to have the quality of care.[9–11,13] Healthcare systems in Thailand have resources to support stroke survivor caregivers, including rehabilitation centers, assistive devices such as hospital beds, canes, wheelchairs, fitness equipment, or assistive equipment for rehabilitation, and personal resources such as health volunteers, healthcare workers, and occupational therapists. Caregivers of stroke survivors need assistance and the collaboration of family members, and a coordinator of community health workers to plan for stroke recovery from the hospital to the home setting so they will achieve transition of care to the home.[7-10] All supporters need to encourage stroke survivors to have self-management and assist caregivers to provide care objectively.[8,21] Financial support for medical and living expenses from family members can alleviate the stroke survivor's economic burdens.[34] Health insurance and healthcare service support can help families access medical services and the basic medical insurance system of Thailand's Universal Coverage Scheme that can provide treatment and rehabilitation, giving the family members better health and stability.[35] Moreover, support from environmental factors can help caregivers have time for themselves, be more relaxed, and reduce the burden.[10,13]

Community nurses and community resources propel strategy and care achievements, directly affecting the caregiver and promoting healthy family dynamics.[7,33] In Thailand, community nurses have an essential role as "chief commander" to support caregivers and families to provide care confidently.[32] Among post-stroke rehabilitation professionals, community nurses serve as coordinators of care and offer direct delivery of a range of interventions in the home and community setting. Patient-centered care is currently the most powerful emphasis in healthcare. Community nurses have to realize how important taking care of families is, and they cannot ignore the family needs.[9-10,32-33] They provide care information, conduct follow-ups, assess care, coordinate and organize activities, empathy and support families in each context, helping the families understand the condition more and reducing the knowledge gap.[9-10] Community nurses need to carefully assess the family status and continuously provide care and information, contributing emotional support to reduce the caregiver's burden.[36] Similarly, community nurses or healthcare teams should provide strengthened health education and encourage family members to be proactive, enabling families to provide continuous independent care.[30] This finding is consistent with a previous study, which found that community nurses need to be close to the family to assess the family's strengths and resources, as well as provide support and information specifically for each family to create improved outcomes.[7,10,33,37]

Healthy family dynamics explored through participants in this study included perceived happiness, physical and mental health, financial balance, and family relationships and interactions. Perceived happiness was assessed through the satisfaction expressed by family members after participating in activities together, including knowing how to move on, understanding their thoughts, living with reality, and accepting the imperfections.[38] These will help reduce negative perceptions of problems, such as the perception of sickness, limitation, and disability, acceptance of self-efficacy, forgiveness of others, and acceptance of reasonability.[14,16-17,22,39] The family needs to accept the situation, understand the symptoms and the condition, share their experiences, and find helpful resources in the family and community to address the problems and live positively with illness.[7,13,18-19,40] The physical and mental health of caregivers and other family members need to be assessed when caregiving is involved. Family finance needs to be planned and managed appropriately, and families may need support with this. The relationship and interactions within families can be strengthened to be helpful and treat each other with love and kindness. This improvement will lead to an adequate quality of care, happiness, and peace of mind for caregivers and families of stroke survivors. The findings of this study were consistent with existing literature that support from both within the family and community can enhance families with stroke survivors to have the quality of care and family health.[16,18,32]

Limitations

Using the PAR process, a specific study was conducted with caregivers of stroke survivors in semi-urban communities. These qualitative findings referred to the families of caregivers and stroke survivors in the Thai context. Moreover, studying in a semi-urban community limited participation time and place for some groups of people that have high privacy, which made access difficult. It also took a long time for the researcher to establish trust.

Conclusion and Implications for Nursing Practice

This study used a PAR process to develop the Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics. The PAR process is an optional way to help participants gain knowledge, be understanding of themselves and stroke survivors, and be capable of doing things in the right way. This model has five main affecting care: caregiver characteristics, family functions and relationships, assistant support, community resources, and community nurses. Community nurses take the roles of health educator, health provider, counsellor, and coordinator in enhancing family caregivers in caring for stroke survivors to regain their function and to promote healthy family dynamics. Since the Family-Based Care Model for Stroke Survivors to Promote Healthy Family Dynamics was developed after one study in a specific location and with a relatively small sample, it needs to be tested elsewhere before being applied in practice in the community family care system for chronic illness. Nursing personnel working in the community can provide accurate information and advice for people within the community so they can adjust according to the contexts and culture of each family.

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การพัฒนาแบบจำลองการดูแลเป็นโรคหลอดเลือดสมองโดยใช้ครอบครัวเป็นฐานเพื่อส่งเสริมพลวัตของครอบครัวให้มีสุขภาพดี: การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม

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บทคัดย่อ: ผู้ดูแลในแต่ละครอบครัวมีมุมมองที่แตกต่างกันในการดูแลผู้เป็นโรคหลอดเลือดสมองซึ่งส่งผลต่อกระบวนการดูแลซึ่งมีแนวโน้มที่จะเป็นภาระหนักสำหรับผู้ดูแลและครอบครัวในหลายวัฒนธรรมทั่วโลก รวมทั้งในประเทศไทย การศึกษานี้ใช้การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมเพื่อพัฒนารูปแบบการดูแลโดยครอบครัวที่ดูแลสมาชิกที่เป็นโรคหลอดเลือดสมองในการช่วยส่งเสริมครอบครัวให้มีสุขภาพที่ดี ผู้ดูแลได้รับการคัดเลือกโดยการสุ่มตัวอย่างแบบเจาะจงจากหน่วยบริการปฐมภูมิสองแห่งในจังหวัดนนทบุรี ประเทศไทย ผู้เข้าร่วมการศึกษาเป็นผู้ดูแล 14 คนแบ่งออกเป็นสองกลุ่ม ๆ ละ 7 คน มีส่วนร่วมในกิจกรรม 4 วงรอบเป็นเวลา 16 สัปดาห์ เก็บข้อมูลโดยใช้การสนทนากลุ่มครอบครัว การสังเกต การเยี่ยมบ้าน การโทรศัพท์ การใช้แอปพลิเคชัน LINE การบันทึกภาคสนาม รวมทั้งการใช้แบบสอบถามข้อมูลพื้นฐานของครอบครัว ผู้เข้าร่วมในแต่ละกลุ่มสร้างกลยุทธ์การดูแลเพื่อสร้างสมดุลชีวิตครอบครัวที่เหมาะสำหรับสมาชิกที่เป็นโรคหลอดเลือดสมองและสมาชิกคนอื่น ๆ ในครอบครัว ด้วยวิธีการสะท้อนตนเองทั้งแบบรายบุคคลและแบบภาพรวม ซึ่งแต่ละวงรอบของการวิจัยประกอบด้วยขั้นตอนสี่ขั้นตอน ได้แก่ การวางแผน การปฏิบัติ การสังเกต และการสะท้อนคิด ใช้วิธีการวิเคราะห์ข้อมูลเชิงคุณภาพโดยใช้โปรแกรม ATLAS.ti 8.0 ในการจัดประเภทข้อมูลและประเด็นสำคัญ จากข้อมูลเชิงคุณภาพที่ได้รับจากการมีส่วนร่วมในการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมอง สรุปออกมาเป็นประเด็นสำคัญสี่ประการ: 1) การประเมินปัญหาและการพัฒนากลยุทธ์ 2) การทำงานร่วมกันเพื่อปรับเปลี่ยนกลยุทธ์ 3) ปรับสมดุลร่างกายและจิตใจเพื่อสร้างพลังให้ตนเอง และ 4) พลวัตของครอบครัวที่มีสุขภาพดี

การศึกษานี้แสดงให้เห็นว่ามีปรากฏการณ์หลัก 5 ประการที่ส่งผลต่อการดูแล ได้แก่ 1) ลักษณะของผู้ดูแล 2) หน้าที่และสัมพันธภาพภายในครอบครัว 3) สิ่งสนับสนุนการช่วยเหลือ 4) ทรัพยากรและแหล่งประโยชน์ภายในชุมชน และ 5) พยาบาลชุมชน ซึ่งแบบจำลองที่พัฒนาขึ้นในการศึกษานี้สามารถช่วยพยาบาลโดยตรงในการส่งเสริมพลวัตของครอบครัวที่ดูแลผู้เป็นโรคหลอดเลือดสมองให้มีสุขภาพดี อย่างไรก็ตาม แบบจำลองนี้จำเป็นต้องมีการทดสอบเพิ่มเติมโดยการวิจัยก่อนที่จะนำไปใช้ในทางปฏิบัติ

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คำสำคัญ: การดูแลโดยครอบครัว ผู้ดูแลของครอบครัว พลวัตของครอบครัว การพัฒนารูปแบบการดูแล การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม ผู้รอดชีวิตจากโรคหลอดเลือดสมอง

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