Patient Preference and Adherence

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ORIGINAL RESEARCH

Implementing a Care Model for Bedridden Stroke Survivors: A Qualitative Study in Northeastern Thailand

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Background: Stroke remains a significant global health concern, including in Thailand, with high mortality rates. Despite investments in stroke prevention, inadequate support exists for severely disabled stroke survivors (SSs) and their caregivers, particularly in enhancing their quality of life.

Purpose: This research aimed to explore the experiences of SSs receiving home care, develop and implement a care model to enhance community volunteer caregivers' (CVCGs) capabilities, and evaluate the outcomes of this model for bedridden stroke survivors in Northeastern Thailand.

Methods: A research and development study was conducted in low-income, semi-urban communities in Northeastern Thailand, comprising three phases: 1) situation analysis, 2) development of a community care model, and 3) implementation and evaluation. Forty participants were purposively selected, including SSs, family caregivers (FCGs), CVCGs, and relevant community leaders (RCLs). Data collection involved focus group discussions, in-depth interviews, and participant observations, with content analysis used for data interpretation.

Results: Key themes emerged: SSs experienced "Feeling Isolation & Powerlessness" and "Hopelessness & Being Burden to Family", FCGs expressed "Sorrow & Gratitude", and CVCGs identified "Inadequate Capacity & Need for Training". These findings underscored the lack of sufficient support for all groups. The study proposed the KKU Bedridden Care Model, derived from the KKU Family Health Nursing Model, to strengthen families' and communities' caregiving capacities. After five months, the themes "Heartwarming" (SSs, FCGs) and "Being Proud of Capability" (CVCGs) highlighted improved outcomes.

Conclusion: The KKU Bedridden Care Model shows promise for long-term care in resource-limited settings. Its adoption by local administrative organizations could provide ongoing support, offering a scalable solution for improving the care of bedridden individuals both in Thailand and globally.

Keywords: the KKU Bedridden Care Model, community caregivers, family caregivers, stroke survivors, long-term care, Northeastern Thailand

Introduction

Stroke is becoming a critical global health problem with high prevalence and significant consequences. In 2021, there were 93.8 million prevalent cases and 11.9 million incident strokes worldwide. It was the third leading cause of death globally according to the Global Burden of Disease (GBD) 2021, following ischemic heart disease and COVID-19, and the fourth leading cause of disability-adjusted life-years (DALYs). This health issue is a major concern, particularly in developing countries, including Southeast Asia, East Asia, and Oceania, and countries with lower Socio-Demographic Index (SDI). In these regions, stroke incidence, mortality, prevalence, and DALY rates are increasing.[1] Worldwide, over

Received: 31 October 2024
Accepted: 1 February 2025
Published: 11 February 2025

143 million years of healthy life is lost each year due to stroke-related death and disability, and 6.5 million individuals pass away from stroke annually.[2] This indicates that stroke is now a leading cause of disability, leading to physical, mental, cognitive, and sensory decline. As the body's ability to function independently deteriorates, these individuals become increasingly reliant on others. Technological advancements aimed at extending the lives of those with permanent disabilities have also contributed to decreased independence, increasing the ratio of individuals who rely on others. This dependence is measured in terms of ability to perform activities of daily living (ADL), such as bathing, dressing, eating, and managing urinary and bowel functions. As a result, their quality of life and the standard of living they once had diminished.[3] Additionally, these individuals often suffer from a loss of dignity and social exclusion. Furthermore, social and community responsibilities place a significant burden on families who must provide care.[4]

Information from the literature, particularly in Thailand, had determined policy data, as well as an enormous amount of caretaking systems.[4–8] The Thai government initiates Intermediate Care Service Plan that aiming to reduce the gaps of health service system between acute care and communities. This service plan provides seamless care between all levels of hospitals and communities as well as related networks. After the patients survive from acute illness, they will be assessed and screened for intermediate care. The care includes variety of services to meet the needs by a multidisciplinary team. In case of the patients still unable to perform their self-care within 6 months, they will be linked to long-term care system.[9] LTC is defined as a comprehensive care that covers social, health, economic and environmental dimensions for individuals who are partially able or totally unable to perform routine daily life by own self. Long-Term Care (LTC) program has been initiated by the National Health Security Office (NHSO) to encourage multi-sectoral collaboration for community-based care targeting dependent elderly persons and ones living with disabilities and chronic diseases. LTC can be provided formally by personnel or informally by family members, friends, and neighbours. LTC settings can be in the family, community or institution.[10] Caregivers and care managers are crucial in long-term care, where care managers make strategic plan and lead caregivers in providing care within their communities, while caregivers who are mainly recruited from the village health volunteers then added up skills and knowledge to being able to perform basic health services.[11] In addition, the stroke service system has also been developed in the study Health Zone, which comprise 1) the 7th Health Care Stroke Network that designed to allow patients in all areas can access the stroke fast track service and receive the same standard treatment throughout the health zone with fast and efficient service. The stroke fast system included creation of people awareness, alert of stroke signs/ symptoms and access of the stroke fast track in the community, develop the stroke fast track service system within the hospital; and 2) referral network that also emphasizes the necessary of home visit after stroke.[12] Nevertheless, SSs still received inadequate supported when they went back home with disabled condition and depend on caregivers for ADL, which were their downstream fate. They should be prepared and promoted to live as independence as possible as well as be treated with dignity and enhanced quality of life within physical, psychological, sociological and economical constraints. Caring for these permanently disabled, vulnerable, and bedridden individuals currently in Thailand rely on their families, which were affected with an increase of healthcare costs and financial burden,[13,14] and are in need of assistance.[15,16] Promoting capabilities of family caregivers is crucial. The research team therefore carried out a research and development study, aiming at understanding the experiences of SSs receiving care at home, developing and implementing the care model to enhance CVCG capabilities, and evaluating the outcomes of the developed care model for bedridden stroke survivors in Northeastern Thailand.

Study Context

Currently, it has been observed that chronic diseases and severe strokes are becoming increasingly prevalent in Thailand. This trend has contributed to a significant number of individuals across the country suffering from permanent disabilities. Stroke risk increases with age[1] and the proportion of elderly individuals (aged 60 and over) in Thailand has been steadily increasing, with 16.73% of the population being elderly in 2019, and reaching 14 million in 2025, which accounts for 21.62% of the total population.[17] In addition, number of Thai individuals aged 65 and over was 9.6 million, accounting for 14.56% of the total population[17] In comparison, Singapore elderly population aged 65 and over has also increased from 11.7% in 2013 to 19.1% in 2023, and predicted to be 24.1% by 2030.[18] This increase in the aging population, combined with the rise in age-related chronic diseases such as stroke, is likely to result in a higher number of homebound and bedridden individuals, placing a greater burden on families to manage their daily living activities.

Significant risk factors for stroke were high systolic blood pressure, smoking, high LDL cholesterol, household air pollution, diet high in sodium, high fasting plasma glucose, kidney dysfunction, diet low in fruits, high alcohol use, high BMI, second-hand smoking, low physical activity, and diet low in vegetables.[1] In Thailand, the prevalence of these factors has been steadily increasing. In 2018, 331,086 Thai individuals were hospitalized due to ischemic stroke, reflecting a rate of 506.20 per 100,000 population.[19] Stroke is characterized by a sudden neurological event resulting from disrupted blood flow to the brain. Blood supply to the brain is regulated by a network of four major arteries: two internal carotid arteries in the front and two vertebral arteries in the back, forming the circle of Willis. Ischemic stroke occurs when blood and oxygen flow to the brain is insufficient. When blood flow is inadequate, cells experience extreme stress, resulting in necrosis, or untimely cell death. In contrast, hemorrhagic stroke results from bleeding or leakage within the brain's blood vessels. Brain tissue stress and internal injury cause blood vessel rupture, leading to vascular toxicity and subsequent infarction.[20] These conditions lead to impairments.

This research was obtained in the northeastern region of Thailand, commonly known as "Isan", which is characterized by unique cultural beliefs and practices that have been passed down through generations. The people of *Isan* shared cultural similarities with those in other regions of the Mekong River Basin, such as Lao PDR, including a deep respect for supernatural powers and a strong connection to Buddhism. The culture places significant importance on making merit to ensure good fortune in the future, as well as on family unity. In *Isan* Buddhist culture, caring for others is deeply rooted in the belief of "making merit", contributing to positive karma. This, combined with a strong sense of community where even non-blood relatives are considered family, fosters a robust system of care. Within families, respect for elders and the enduring nature of familial bonds, even in challenging relationships, are highly valued. These cultural strengths align with the World Health Organization's concept of community-based care, providing a strong foundation for supporting bedridden individuals and their families.[21]

Project and Setting

The study has been conducted in two concurrent areas, community A and B: improving community self-health care services to enhance the capabilities of CVCGs in caring for homebound and bedridden individuals at home, and thereby supporting FCGs in managing long-term health conditions and well-being. The key goal of the project was to address these needs. Before starting this project, a survey was conducted to assess the situations of patients and their families, identify problems, and understand health needs in the area, including community engagement. The main research question was, "What is a viable community-based support model for SSs and their families for long-term care at home?" This qualitative article focuses on the results identified by CVCGs, FCGs, and SSs based on the proposed model.

All participants in the present study lived in the same village community within two semi-urban, low-income areas in Khon Kaen province, located in the central part of Northeastern Thailand. The population of these two village communities totaled 17,930 individuals: 8888 males and 9042 females, residing in 2445 households.[22] The primary occupations of most community volunteers were laboring and farming. Additionally, farming mainly involved growing crops such as sugar cane, corn, cassava, and rice.

Materials and Methods

The research questions of this research and development study were: 1. What were experiences of SSs receiving care at home? 2. What was an appropriate care model to enhance CVCG capabilities? 3. What were the outcomes of the developed care model for bedridden stroke survivors in Northeastern Thailand? It was conducted in three phases. The situation analysis phase aimed at understanding the experiences of bedridden patients (SSs) receiving care at home. The phase of care model development aimed at developing a care model for improving SSs and FCGs, and the phase of implementation and evaluation of a care model for SSs living at home. The final phase aimed to describe the effects of such a developed care model. The study involved 40 participants, comprising 9 SSs, 9 family caregivers (FCGs), 9 community volunteer caregivers (CVCGs), and 13 relevant community leaders (RCLs). Participants were recruited through purposive sampling based on specific criteria. SSs were included if they were conscious and able to communicate, either verbally or non-verbally. FCGs were selected family members designated as primary caregivers for SSs, with the ability to communicate and understand Thai or the Isan dialect. CVCGs were community health volunteers responsible for SSs in their community, with prior experience in home health care training and the ability to communicate in Thai or the *Isan* dialect. RCLs were individuals serving as community leaders. All participants volunteered to participate in the project from the first through the third phase of study.

The situation analysis phase, to generate an understanding of the experiences and needs of SSs receiving care at home. Qualitative data were collected through focus group discussions, in-depth interviews, and field notes. Six focus group discussions were conducted CVCGs from two initial groups: Community A and Community B. Following this, two focus group discussions were held with RCLs, and finally, two mixed focus group discussions included both CVCGs and RCL participants for member checking. In each focus group discussion, two authors were assigned specific roles: one acted as the facilitator, while the other served as the note-taker. For the CVCG discussions, the first author facilitated the group, and the second author took notes. In the RCL group discussions, the third author facilitated, while the fourth author took notes. For the mixed group discussions, the fifth author acted as the facilitator, with the sixth author responsible for note-taking. Additionally, in-depth interviews were conducted with individual SSs and FCGs participants. Each participant from these categories was interviewed by the first and seventh author. All interviews were audio-recorded with consent to ensure the accuracy of data collection. During the data collection process, detailed field notes were documented, reviewed, and reflected upon. These notes were subsequently discussed and interpreted collaboratively with the research team, forming part of an iterative process of reflection and meaning making to enhance the depth and rigor of the analysis.[23]

Following the exploration of experiences and support needs among SSs receiving home-based care, as well as their relevance within the community context, the study progressed to its second phase. This phase focused on developing a care model for bedridden individuals and enhancing the capabilities of CVCGs. The development was guided by the KKU Family Health Nursing Model, originally designed to prevent noncommunicable diseases through qualitative content analysis of interviews and focus groups with nurses. The KKU Family Health Nursing Model integrates a conceptual framework, a family nursing process, and key action strategies. The framework emphasizes four levels of care: health promotion, early detection, direct care, and rehabilitation. It leverages community social capital and promotes participatory action tailored to local contexts, ensuring both effectiveness and sustainability.[24] At the conclusion of this phase, a comprehensive home care model for bedridden individuals, along with strategies for enhancing the capabilities of CVCGs was proposed, namely "the KKU Bedridden Care Model" (Figure 1).

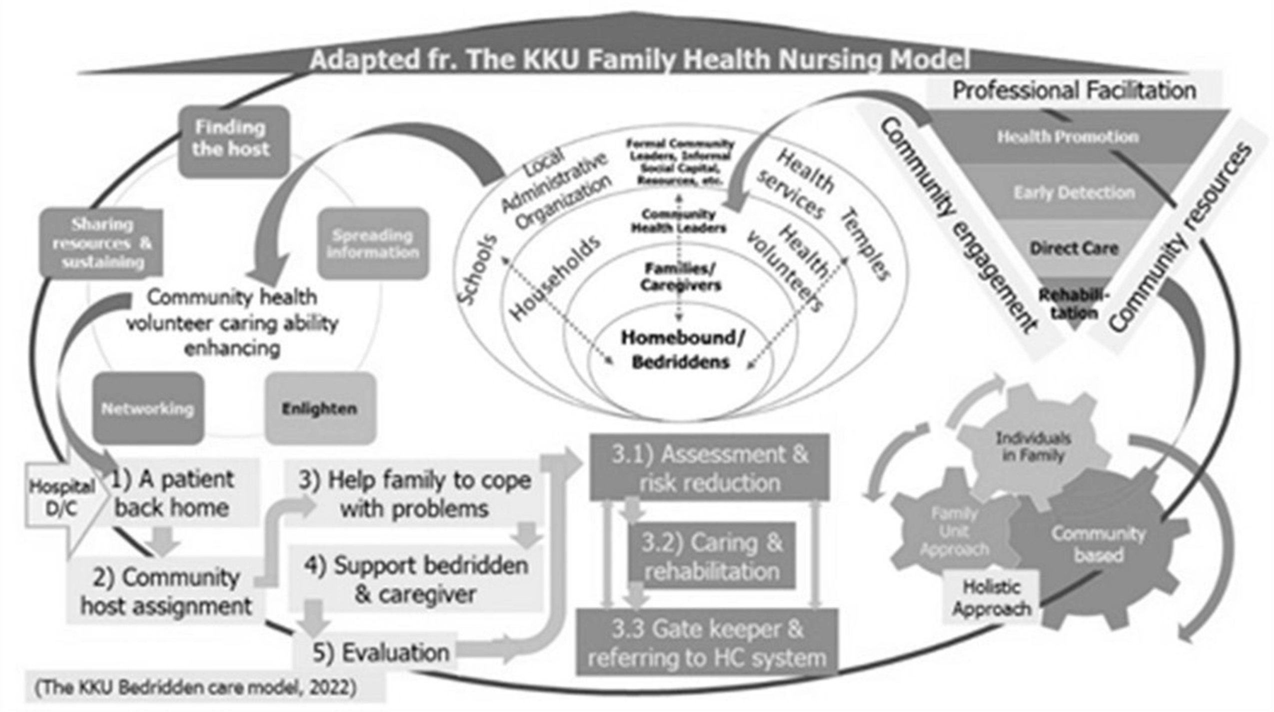

Figure 1 The KKU Bedridden Care Model.

The KKU Bedridden Care Model is structured around four key components, designed to ensure comprehensive and sustainable care:

Health Support

This component integrates health promotion, early detection, direct care, and rehabilitation, emphasizing a collaborative approach. It highlights the coordinated efforts of healthcare professionals, the utilization of community resources, and active engagement of community members to comprehensively address the diverse needs of patients.

Holistic Approach

The model adopts a holistic approach to care that spans all levels—individual, family, and community. This approach ensures the comprehensive integration of physical, emotional, social, and environmental dimensions of health in addressing patients' needs.

Patient-Family Care

At the heart of the care model is the central role of the patient and their family. This approach underscores the necessity of tailoring healthcare interventions to align with the specific needs, preferences, and circumstances of both the patient and their family. By prioritizing their involvement, the model empowers patients and families to take an active role in the care process, fostering collaboration and enhancing care outcomes.

Capacity Building and Strategic Role Development for CVCG

The model focuses on enhancing the capabilities of CVCGs. Training programs are designed to strengthen their knowledge and skills, while strategic plans are developed to clearly define their roles in providing effective support and care for patients within their communities. According to Capacity Building for CVCGs, A one-day capacity-building workshop was conducted by a team of health professionals to enhance the competency of CVCGs in providing care for SSs. Following the workshop, CVCGs engaged in two weeks of skill review and practice under the guidance of health professionals to build confidence in their abilities. When the SSs were discharged from hospital to home, the strategic role development for CVCGs comprising of:

1. When a patient comes back home: The patients' information should be communicated to community health support.
2. Community host assignment: A community-driven process was facilitated to assign CVCG responsibility for supporting SSs and FCGs within their respective neighborhoods.
3. Help families to cope with a problem: CVCG developed plans for regular, goal-oriented home visits to SSs. These visits encompassed the following activities: 1) Assessing health problems, needs, and potential risks. 2) Providing general healthcare support and facilitating physical rehabilitation and, 3) Being as a gatekeeper: offering counseling services and acting as intermediaries for referrals to formal healthcare services.
4. Support bedridden and care giver: Ongoing process, CVCGs provided direct support to FCGs to enhance their caregiving skills in managing SSs.
5. Evaluation of Collaborative Care Practices: The outcomes of the collaborative care practices among CVCGs, SSs, and FCGs were evaluated. This included assessing the effectiveness of joint efforts in addressing health needs, providing support, and improving overall caregiving outcomes.

This model integrates professional expertise with community strengths to create a robust system for delivering home-based healthcare. It prioritizes collaboration, inclusivity, and sustainability to improve the quality of life for patients and their families. The model was presented to community leaders and stakeholders, who reviewed and endorsed it, granting approval for its implementation and testing.

The implementation phase and evaluation of the KKU Bedridden Care Model and enhancing the capabilities of CVCGs. The implementation of the model was carried out over a five-month period. Data collected involved in-depth interviews with SSs and FCGs. Interviews were conducted until data saturation was reached, which was determined through an iterative process of data collection and analysis. Therefore, each participant was interviewed approximately 2 to 3 times, resulting in a total of 42 in-depth interview sessions. The first author conducted interviews for the SSs, while the second author conducted them for the FCGs. All interviews were audio-recorded with consent to ensure the accuracy of data collection. These interviews explored participants' experiences to address the following key questions: "What lessons were learned, and what effective strategies did the team develop and adopt to promote the health and well-being of SSs and their FCGs?" Additionally, two focus groups—one for each of the CVCGs and RCLs—were conducted for member checking. In each focus group discussion, two authors were assigned distinct roles: one served as the facilitator, and the other as the note-taker. The third and fourth authors facilitated the discussion for the first group, while the sixth and seventh authors facilitated the discussion for the second group. Prior to data collection, a team meeting was performed to ensure the specific research question and method. Participant observations were conducted throughout the project, including during an ongoing period of field and family visits.[25]

This research project was approved by the Ethics Committee for Human Research, Khon Kaen University (HE642108), and conducted in accordance with the principles outlined in the Helsinki Declaration. Prior to the commencement of the study, researchers provided a detailed explanation of the study's purpose, data collection procedures, and the rights of participants. Participants were informed that their involvement was voluntary, with the option to withdraw at any time without consequence. Confidentiality measures and the intended use of the data were thoroughly communicated, and written informed consent was obtained. Additionally, participants explicitly consented to the publication of anonymized data and direct quotes. No identifiable information was included in the publication, ensuring the anonymity of participants.

Data Analysis

Descriptive statistics were used to summarize demographic characteristics of participants. Qualitative data analysis, we performed a manual approach to content analysis and theme development, the analysis was both systematic and grounded in the participants' perspectives. Data from the focus group discussions were transcribed, followed by the defining of a coding scheme, data coding, analyzing the data, and interpreting the findings.[26] For the interview data, verbatim transcription was carried out. The author responsible thoroughly read and re-read the transcripts to identify key terms and phrases, generating initial codes related to the research questions. Potential themes were built, reviewed, defined, and named to provide a comprehensive explanation of the findings. The process involved generating themes that emerged from the data through iterative coding and categorization, in line with the principles outlined by Braun and Clarke (2006) for thematic analysis.[27] A synthesis of the findings was conducted, drawing common conclusions based on the participants' shared experiences and perspectives. Saturation was defined as the point at which no new themes, subthemes, or insights emerged from the data, despite conducting and analyzing additional interviews. Researchers met regularly to review and compare coded data, ensuring consistency in determining saturation.

To ensure the credibility of the qualitative data, Triangulation technique was applied to ensure the credibility of the study. Data Source Triangulation, data was collected from multiple sources, including focus group discussions and in-depth interviews to obtain diverse perspectives on the research topic. Additionally, participant observations were also carried out. By comparing the findings from these data sources, any inconsistencies or convergences in the results were identified, providing a more comprehensive understanding of the phenomenon under study. Method triangulation, the use of different methods, allows for the cross-checking of results to ensure that the findings are not method-specific but reflect the broader patterns emerging from the participants' experiences. This helped in verifying the consistency and depth of the data. Investigator Triangulation, multiple researchers independently analyzed the data using their unique perspective and expertise. Then, each researcher brought their analysis results to discuss in the meetings, and summarized the agreed-upon themes. This approach helps to minimize individual biases and ensures that the interpretation of the data was not shaped by a single perspective. Through these triangulation methods, the study ensured that the data collected were credible, accurate, and reflective of the participants' authentic experiences and perspectives, enhancing the trustworthiness of the qualitative findings.[28,29]

Results

A total of 40 participants were involved in the project, categorized into four distinct groups. The first group comprised nine bedridden individuals (SSs), with an age range of 49 to 84 years and a mean age of 71.67 years. Among these, six were male, and three were female (Table 1). The second group included nine family caregivers (FGCs), consisting of four wives and five daughters. Their ages ranged from 46 to 70 years, with a mean age of 55.4 years.

The third group comprised nine Community Volunteer Caregivers (CVCGs) whose ages ranged from 45 to 76 years, with a mean age of 54.4 years. The final group consisted of 13 Responsible Community Leaders (RCLs), with an age range of 42 to 82 years and a mean age of 57.9 years. Detailed demographic information for each group is presented in Table 2.

This article aims to present the outcomes of the implementation of the developed care model, highlighting a clear comparison of conditions before and after its application. The findings encompass insights from a situational analysis to understand the experiences and needs of bedridden individuals (SSs) receiving care at home. The results revealed critical issues and care requirements of both bedridden patients and their families. Additionally, the findings shed light on the experiences and needs of Community Volunteer Caregivers (CVCGs). The findings are presented as emerging themes as follows:

Table 1 Characteristics of SSs (n=9)

Characteristics	Frequency	Percentage
Gender		
Male	6	66.67
Female	3	33.33
Education		
Primary school	7	77.78
Secondary school	1	11.11
Other	1	11.11
Marital status		
Single	4	44.44
Couple	5	55.56
Occupation prior to illness		
Agriculture	4	44.45
Employee	3	33.33
Unemployed	2	22.22
Financial support		
Elderly welfare	1	11.11
Disability welfare	1	11.11
Elderly-Disability welfare	6	66.67
Have no resource	1	11.11
Family occupation		
Agriculture	2	22.20
Employee	5	55.60
Unemployed	2	22.20
Family income monthly		
< 5000 Thai Bath	5	55.60
5000–10,000	3	33.30
Thai Bath		
10,001–20,000 Thai Bath	0	0
>20,000 Thai Bath	1	11.10
Supportive resource		
Family	5	55.60
Government	3	33.30
Other	1	11.10

Table 2 Characteristics of FCGs, CVCGs, and RCLs

Characteristics	FCGs (n=9)		CVCGs (n=9)		RCLs (n=13)	
	Frequency	%	Frequency	%	Frequency	%
Age						
Average (std.)	55.4 (8.58)	–	54.40(8.82)	–	57.95(10.31)	–
Min -Max	46–70	-	45–76	-	42–82	-
Gender						
Male	9	100	1	11.11	7	53.85
Female	0	0	8	88.89	6	46.15
Education						
Primary school	8	88.89	3	33.33	2	15.38
Junior high school	1	11.11	2	22.23	5	38.46
Senior high school	0	0	4	44.44	4	30.78
Bachelor	0	0	0	0	2	15.38
Marital status						
Single	0	0	2	22.23	2	15.38
Couple	9	100	4	44.44	8	61.55
Separated /divorce	0	0	3	33.33	3	23.07
Occupation						
Agriculture	6	66.67	6	66.67	11	84.62
Employee	3	33.33	3	33.33	2	15.38
Monthly income						
< 5000 Thai Bath	7	77.77	2	22.23	2	15.38
5000–10,000Thai Bath	2	22.23	5	55.55	8	61.55
Uncertain	0	0	2	22.22	3	23.07
Health status						
Healthy	7	77.77	9	100	10	76.93
Sick	2	22.23	0	0	3	23.07

Before Model Implementation

Feeling Isolation and Powerlessness

The theme “Feeling Isolation and Powerlessness” encapsulates the profound psychological and emotional challenges experienced by bedridden patients. These individuals often face extended periods of physical immobility and social disconnection, leading to feelings of exclusion and helplessness. When stroke survivors (SSs) were discharged from the hospital, they often experienced a sense of societal abandonment, feeling isolated even when surrounded by family members providing care.

> I have always felt strong and have never felt sick before. However, I currently don’t have any energy and realize being no one in the community cared about me. (SSs01)

> I love to assist people regarding community activities at the temple. When I was ill, no one cared about me. In the beginning, there were just a few people that visited me. However, they no longer visit me now and act like strangers towards me. (SSs02)

> After I was sick, no one was there to take care of me. Consequently, I had to take care of myself. (SSs07)

This theme highlights the critical need for healthcare systems to prioritize the psychological and emotional dimensions of care for SSs patients, ensuring their dignity, self-worth, and quality of life are preserved despite physical limitations.

Hopelessness & Being Burdened to Family

The theme “Hopelessness and Being Burdened to Family” captures the complex emotional challenges experienced by SSs patients receiving care at home. This theme encompasses profound feelings of despair, a loss of purpose, and a perceived sense of burden imposed on their families. Many SSs patients, upon transitioning to home care, report a pervasive sense of hopelessness regarding their recovery, often believing that complete healing is unattainable. Furthermore, the perception of their illness as a significant burden on their families exacerbates their emotional distress, intensifying feelings of despair and, in some cases, fostering a sense of resignation or a diminished will to continue living.

> My first thought would be, if I had a gun, I would shoot myself. (SSs01)

> After I came back from the hospital, I was confused about my life. I don't know how to take care my myself and there wasn't anyone there to guide or assist me with anything. (SSs04)

> Why should I stay alive? I can't do anything. Every day I just eat and create issues for caregivers, who take me to the bathroom frequently. (SSs05)

> It's very painful that I can't do anything. I couldn't work after 5 months. I don't have energy and can't breathe well. I've visited the hospital many times but feel as if I want to give up already. I don't want to eat anything, and I'm unable to do hemodialysis. (SSs07)

The dual challenges of hopelessness and the perception of being a burden to family highlight the need for holistic care strategies that prioritize the emotional well-being of bedridden patients and their families.

Sorrow versus Gratitude

The theme "Sorrow versus Gratitude" encapsulates the dichotomous emotional experiences frequently encountered by FCGs of SSs patients. This duality underscores the profound emotional toll associated with caregiving while also recognizing moments of deep appreciation and meaning derived from the caregiving role. Among the caregivers, who were predominantly wives or daughters, feelings of sorrow were rooted in several factors. For instance, some caregivers were compelled to leave their jobs, resulting in significant financial strain on their families. Additionally, caregiving was described as a relentless responsibility, often compared to being "on duty 24/7", which contributed to physical exhaustion and mental health challenges. In contrast, many caregivers expressed a sense of gratitude, viewing their caregiving role as an opportunity to repay a debt of kindness. They perceived their efforts to honor and give back to their loved ones, deriving pride and emotional fulfillment from their ability to provide care.

> Caring for him feels like a never-ending responsibility. I have to care for him constantly, with no time for myself. I feel physically and mentally exhausted. (FCGs02)

> Thinking about how much effort my parents put into raising me, I realize they were likely more exhausted than I am now. So, despite the exhaustion, I feel a sense of duty to repay my parents for raising me. Caring for him reminds me of the immense effort my parents invested in raising me, and I feel a sense of obligation to repay their kindness. Sometimes it makes me both tired and proud to be able to take care of him. (FCGs05)

This interplay between sorrow and gratitude highlights the complex emotional landscape of family caregiving and emphasizes the need for targeted support systems to address both the challenges and the meaningful aspects of the caregiving experience.

Inadequate Capacity & Need Training

The theme "Inadequate Capacity and Need for Training" reflects the critical challenges faced by CVCGs who provide care for SSs patients in a home setting. This theme underscores the gap between the demands of caregiving and the skills or resources available to volunteers, highlighting the necessity for targeted training and capacity-building initiatives to enhance the effectiveness and sustainability of their roles. The theme "inadequate capacity", as these volunteers often felt they lacked the necessary knowledge and confidence to support SSs effectively. This perceived inadequacy limited their role to delivering gifts during home visits rather than providing meaningful care. To address this gap, there is a clear need for training programs aimed at enhancing their knowledge, skills, and confidence, enabling them to offer comprehensive care and provide effective counseling for FCGs.

> When I went to visit the patient at home, I didn't know how to help them. All I could do was bring them something, but I wasn't sure what I could physically do to assist. Sometimes, all I could do was share stories to make them feel a bit better. (CVCG 03)

> If possible, I think, if I had the knowledge and skills to care for bedridden patients, I believe I would be able to take care of them with confidence and be able to be a dependable mentor. (CVCG 06)

This theme highlights the challenges and opportunities associated with volunteer caregiving for bedridden patients in home settings. Addressing these gaps through targeted training programs and systemic support is crucial for improving the quality of care provided, reducing volunteer stress, and ensuring sustainable caregiving practices. Such efforts not only empower volunteers but also contribute to better patient outcomes and enhanced community-based healthcare systems.

After Model Implementation

Evaluation of the perceived outcomes of home care for bedridden individuals based on the proposed model. After 5 months of the model implementation, Qualitative data were analyzed and the themes emerged as follows:

Heartwarming

This "Heartwarming" theme was expressed by both SSs and FCGVs volunteers, emphasizing the positive emotional responses resulting from the community host assignment and the model's support in helping families cope with challenges. The model facilitated effective support for bedridden patients, while also enabling close follow-up through home visits for families. This allowed CVCGs to detect issues early, ensuring timely intervention and assistance for both patients and their families. Such comprehensive care significantly contributed to the emotional well-being of both the individuals receiving care and their families' caregivers.

> It is heartwarming to have weekly visitors who still remember us. These individuals never abandoned us during our illness and hardships. (FCG of SSs06)

> I found the home visit program of CVCGs to be exceptional, and it made me feel much more energetic and uplifted. Initially, I felt alone and unsupported, but now I truly appreciate knowing that someone cares for me. (SSs04)

This theme reflects the positive emotional experiences derived from the care and support provided by the developed model, particularly through home visits and assistance in helping families cope with various challenges. Thus, while isolation captures the emotional void and neglect experienced prior to the implementation of the model, Heartwarming reflects the positive transformation that arises when systematic care and compassionate support are introduced, leading to significant improvements in both mental and emotional well-being for SSs patients and their FCGs.

Being More Capability

The theme of Being More Capability emerged from the experiences of CVCGs who reported an increased sense of competence and self-efficacy in providing care to bedridden patients following their participation in model development. Prior to joining the initiative, many volunteers felt uncertain about their ability to manage the complex needs of bedridden individuals. However, through training, support, and hands-on experience provided by the professional facility, these volunteers developed both the skills and confidence necessary to effectively assist SSs patients and their FCGs. The CVCGs who participated in the project express their pride in their willingness to give their hands to families and the community to care for patients and increase the conventional well-being of SSs and FCGs. The participant CVCGs revealed that getting involved in this project made them feel like they were doing merit every day. In addition, they enhanced their knowledge and experiences in providing care for SSs and advising FCGs at home.

> After I received knowledge and skills from the bedridden care training program, I conducted family visits with a sense of self-confidence. (CVCGs 02)

> For home visits, what is needed are personal CVCG equipment and disposable materials to support the hygiene care of patients. These could be requested through donations, such as blood pressure monitors and adult diapers for low-income individuals. (CVCGs 05)

> Could we initiate a yearly merit-making and donation project to mobilize funds or gather patient care materials to support our CVCG team in delivering services? I believe that the people in our community would be appreciative of supporting our planned projects (CVCGs 08)

The Being More Capability theme emphasizes the positive impact of capacity-building initiatives on health volunteers, equipping them with both the practical skills and emotional confidence needed to provide high-quality care. The development of these capabilities not only improves the quality of care provided to bedridden patients but also enhances the personal growth and sense of purpose of the volunteers, ultimately contributing to the success of community-based care models.

Discussion

This present study was carried out aiming at understanding the experiences of SSs receiving care at home, developing and implementing the care model to enhance CVCG capabilities, and evaluating the outcomes of the developed care model in Northeastern Thailand. The theme “Feeling Isolation & Powerlessness”, “Hopelessness & Being Burdened to Family”, “Sorrow & Gratitude”, “Inadequate Capacity & Need Training” emerged. 2) The KKU Bedridden Care Model was developed, implemented, and evaluated. The theme “Heartwarming”, and “Being Proud of Capability” emerged at the evaluation phase.

The findings of the situational analysis revealed that both FCGs and CVCGs experienced limited support, leading them to feel “feeling isolation & powerlessness”, “hopelessness & being burden to family”, and “Inadequate Capacity & Need Training”. This study demonstrated that the implementation of the developed care model could contribute to more positive feelings among these groups, suggesting that they received increased support. Therefore, when caring for bedridden SSs in similar settings, continuous assessment of whether FCGs and CVCGs receive sufficient support is crucial. Our model may be applicable to increase the potential for positive outcomes in such situations.

The qualitative findings from after model implementation reflect the transformative impact of implementing the KKU Bedridden Care Model, particularly in addressing the psychosocial and practical challenges faced by bedridden patients, their family care givers, and community volunteers. The emergent themes “Heartwarming” and “Being Proud of Capability” highlight the positive outcomes associated with this integrated care approach.

The theme “Heartwarming” captures the emotional and psychological relief experienced by bedridden patients and their families after the introduction of the KKU Bedridden Care Model. Patients expressed feelings of comfort, gratitude, and renewed connection because of the holistic and family-centered care provided. This aligns with the model’s emphasis on community engagement, health promotion, and rehabilitation, which collectively enhance the patients’ sense of belonging and value within their family and community.[30] Family caregivers, who previously felt overwhelmed, benefited from structured support and skill development provided by the program. The caregiving burden was mitigated by improved resources, guidance from community health volunteers, and a greater understanding of caregiving strategies. These outcomes are consistent with findings from studies that emphasize the importance of community-based interventions in reducing caregiver stress and enhancing emotional resilience.[30–32]

The theme “Being Proud of Capability” reflects the empowerment of community volunteers (CVCGs) through their involvement in the care model. By participating in training programs and actively supporting bedridden patients and their families, volunteers developed a strong sense of achievement and self-efficacy. This is a direct outcome of the model’s focus on enhancing the caregiving abilities of community members through professional facilitation and networking. The pride and fulfillment expressed by volunteers underscore the reciprocal benefits of community-based healthcare initiatives. Not only do such models improve patient outcomes, but they also foster a sense of purpose and contribution among volunteers. Similar findings have been reported in studies emphasizing the role of lay health workers in bridging gaps in healthcare access and enhancing community cohesion.[33]

Therefore, these findings’ themes highlight the significance of integrating holistic and community-driven approaches in healthcare delivery. The KKU Bedridden Care Model demonstrates how leveraging local resources, strengthening family and community networks, and providing targeted training can lead to sustainable improvements in home-based care.

The KKU Bedridden Care Model exemplifies an innovative, community-driven approach tailored to meet the complex needs of bedridden patients and their caregivers. By integrating local resources, community networks, and culturally sensitive practices, the model introduces distinctive features while aligning with core principles shared by other established care frameworks. Notably, the KKU Bedridden Care Model emphasizes empowering families and community health volunteers to bridge healthcare gaps, particularly in resource-constrained environments. This approach parallels other community-based care models, such as the WHO Community Health Worker Model and the Comprehensive Geriatric Assessment (CGA) framework, which similarly leverage community engagement and interdisciplinary collaboration to support patient care.[34,35] The KKU Bedridden Care Model underscores the importance of holistic care by addressing not only the medical needs but also the psychological and social well-being of patients and their caregivers. This approach aligns closely with the principles of Person-Centered Care Models, which prioritize the comprehensive needs of individuals within the care process.[36,37] Additionally, the KKU Bedridden Care Model places a strong emphasis on caregiver support and education, equipping caregivers with essential knowledge and skills to effectively manage the care of bedridden patients. This focus mirrors the principles of the Family-Centered Care Model, which recognizes the caregiver's pivotal role in promoting positive patient outcomes and enhancing the caregiving experience.[38]

While many models involve healthcare professionals or community health workers, the KKU Bedridden Care Model uniquely incorporates CVCGs as a core element. The model enhances the caregiving capacity of these volunteers through structured training and professional facilitation, which sets it apart from models relying solely on professional healthcare workers. Recent studies have demonstrated that CHW-led interventions can reduce healthcare utilization and improve health outcomes, highlighting the effectiveness of integrating community health workers into health systems.[39] Another distinctive aspect of the KKU Bedridden Care Model is its holistic, family-centered approach. By addressing the interconnected well-being of patients and caregivers, it aligns with collectivist cultural values, differing from more narrowly focused Biomedical Models of Care prevalent in Western healthcare systems. This family unit perspective underscores the model's commitment to fostering a supportive caregiving environment. Studies have shown that culturally competent care, which considers the family unit, can improve health outcomes and quality of care.[40] Finally, the KKU Bedridden Care Model emphasizes sustainability through long-term community networking. By involving schools, temples, and local leaders, the model ensures ongoing engagement and resource sharing. This stands in contrast to the Hospital Discharge Planning Model, which typically focuses on short-term post-discharge care without establishing robust community networks.[41]

This research recognizes the potential limitations of self-reported data, including social desirability bias and recall inaccuracies, which could impact data reliability. Nevertheless, the findings are consistent and valuable, albeit requiring careful interpretation.

Conclusion

The study's findings indicated limited support received by SSs, FCGs, and CVCGs, despite the implementation of several healthcare policies. This suggests a need for more feasible and accessible national healthcare policies, particularly those focused on stroke rehabilitation and caregiver support. While the KKU Bedridden Care Model shares commonalities with other established frameworks, its unique focus on community empowerment, family engagement, and cultural sensitivity sets it apart. These distinctive features make it a promising model for addressing the multidimensional needs of bedridden patients and their caregivers in resource-limited settings. Future research should be conducted with a larger sample size and over a longer time period to evaluate the effectiveness and sustainability of the developed model's outcomes. Validation test of the model in other regions was also recommended.

Abbreviations

SSs, stroke survivors; FCGs, family caregivers; CVCGs, community volunteer caregivers; RCLs/CLs, relevant community leaders; CDs, communicable diseases; NCDs, non-communicable diseases; ADL, activities of daily living; WHO, World Health Organization; Lao PDR, the Lao People's Democratic Republic; KKU, Khon Kaen University.

Ethics Approval

This research project was approved by the Ethics Committee for Human Research, Khon Kaen University (HE642108).

Consent to Participate

Informed consent was obtained from the participants involved.

Consent for Publication

Before consenting, participants were informed that their data may be published in a journal article.

Funding

This project was funded by the Smart Emergency Care Service Integration (SECSI) Project, spearheaded by the Health Care System Funding from the National Research Council of Thailand, with financial support provided through the Faculty of Public Health, Chiang Mai University, and the Foundation of Emergency Medicine in Khon Kaen Province, Thailand.

Disclosure

The authors have no conflicts of interest that are directly relevant to the content of this article.

References

1. GBD 2021 Stroke Risk Factor Collaborators. Global, regional, and national burden of stroke and its risk factors, 1990–2021: a systematic analysis for the global burden of disease study 2021. *Lancet Neurol*. 2024;23(10):973–1003. doi:10.1016/S1474-4422(24)00369-7
2. World Stroke Organization. World Stroke Organization (WSO): global stroke fact sheet 2022. 2022. Available from: https://www.world-stroke.org/assets/downloads/WSO_Global_Stroke_Fact_Sheet.pdf. Accessed 27, Dec 2024.
3. World Health Organization. WHO international classification of functioning, disability and health (ICF). Geneva: World Health Organization; 2021. Available from: http://www.who.int/classifications/icf/en/. Accessed February 05, 2025.
4. Buacharoen H. Health promotion system for stroke patient towards the sustainable development goals. *Kuakarun J Nurs*. 2018;25(2):185–196. In Thai.
5. Department of Disease Control. Campaigns for world stroke day, 2019, raising awareness of the warning signs of stroke and reducing its risk. Bangkok: Ministry of Public Health; 2019. Available from: https://pr.moph.go.th/?url=pr/detail/2/02/133619. Accessed February 05, 2025. (In Thai.)
6. Department of Disease Control. Campaigning for world stroke day, 2021, raising awareness of stroke warning signs: 270 minutes of life. Bangkok: Ministry of Public Health; 2021. Available from https://ddc.moph.go.th/brc/news.php?news=21374&deptcode=brc. Accessed February 05, 2025. (In Thai)
7. Theppan K, Suphunnaku P. Social network and mobile application in stroke prevention. *J Phrapokklao Nurs Coll*. 2020;31(1):198–204. In Thai.
8. Tongsuk S, Kongtaln O. Development of care system for stroke risk group in community at Pattananikhom Hospital, Lopburi Province. *J Nurs Sci Health*. 2021;44(2):86–97. In Thai.
9. Ministry of Public Health. Guideline for intermediate care for health personnel in accordance with the health service system development plan (Service Plan). 2019. Available from: https://www.snmri.go.th/wp-content/uploads/2021/01/10-Guideline-for-Intermediate-Care.pdf. Accessed 27, Dec 2024.
10. National Health Commission Office Thailand. Second national health assembly: agenda 3.3 development of long-term care for dependent elderly people. 2009. Available from: https://en.nationalhealth.or.th/wp-content/uploads/2017/09/3-2009-1.pdf. Accessed 27, Dec 2024.
11. National Health Commission Office Thailand. Long-term care program: thailand's preparation for entering an aged society. 2020. Available from: https://eng.nhso.go.th/view/1/DescriptionNews/Long-Term-Care-program-Thailands-preparation-for-entering-an-aged-society/212/EN-US. Accessed 27, Dec 2024.
12. Tiamkao S. Development of the stroke service system in the 7th health zone. *J Med Assoc Thail*. 2019;18(1):25–41.
13. Anderson JL, Heidenreich PA, Barnett PG, et al. ACC/AHA statement on cost/value methodology in clinical practice guidelines and performance measures: a report of the American college of cardiology/American heart association task force on performance measures and task force on practice guidelines. *Circulation*. 2014;129(22):2329–2345. doi:10.1161/CIR.0000000000000042
14. Deutschbein J, Grittner U, Schneider A, et al. Community care coordination for stroke survivors: results of a complex intervention study. *BMC Health Serv Res*. 2020;20(1):1143. doi:10.1186/s12913-020-05993-x
15. Ottiger B, Lehnick D, Pflugshaupt T, Vanbellingen T, Nyffeler T. Can I discharge my stroke patient home after inpatient neurorehabilitation? LIMOS cut-off scores for stroke patients "living alone" and "living with family". *Front Neurol*. 2020;11:6017–6025. doi:10.3389/fneur.2020.601725
16. Broussy S, Rouanet F, Lesaine E, et al. Post-stroke pathway analysis and link with one-year sequelae in a French cohort of stroke patients: the PAPASePA protocol study. *BMC Health Serv Res*. 2019;19(1):770. doi:10.1186/s12913-019-4522-2
17. Institute for Population and Social Research, Mahidol University. Thailandometers. 2025. Available from: http://thailandometers.mahidol.ac.th/. Accessed 9, Jan 2025.

18. Singapore Department of Statistics. Population in Brief 2023. 2023. Available from: https://www.population.gov.sg/files/media-centre/publications/population-in-brief-2023.pdf. Accessed 9, Jan 2025.
19. National Statistical Office. *The 2021 Survey of Non-Communicable Diseases in Thailand* In Thai. Bangkok: The Minister Office; 2021.
20. Kuriakose D, Xiao Z. Pathophysiology and treatment of stroke: present status and future perspectives. *Int J mol Sci*. 2020;21(20):7609. doi:10.3390/ijms21207609
21. Jongudomkarn D, Wacharasin C, Deoisres W, Surakarn P, Phupaibul R. Families and health care of family members with illnesses: proposals from document research. *J Nurs Sci Health*. 2015;38(4):92–99. In Thai.
22. National Statistical Office. *The 2020 Survey of Household and Data of Population in Thailand* In Thai. Bangkok: The Minister Office; 2020.
23. LeCompte MD. Getting good qualitative data to improve educational practice. *Theory Pract*. 2000;39(3):146–154. doi:10.1207/s15430421tip3903_5
24. Jongudomkarn D, Macduff C Development of a Family Nursing Model for Prevention of Cancer and Other Noncommunicable Diseases through an Appreciative Inquiry. *Asian Pac J Cancer Prev.* 2014;15(23):10367–74.
25. Yin RK. *Case Study Research and Applications: Design and Methods*. 6th ed. Sage Publications; 2017.
26. Krippendorff K. *Content Analysis: An Introduction to Its Methodology*. 4th ed. SAGE Publications; 2018.
27. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa
28. Patton MQ. *Qualitative Research & Evaluation Methods*. 3rd ed. SAGE Publications; 2002.
29. Lincoln YS, Guba EG. *Naturalistic Inquiry*. SAGE Publications; 1985.
30. Han B, Lee C, Kim D. Loneliness and depression among bedridden patients: a systematic review. *J Aging Health*. 2021;33(5–6):385–403.
31. Park J, Kim S, Serván-Mori E, Hernández-Corral S, Cadena-Estrada JC, Nigenda G. The role of emotional support in improving caregiving outcomes: a meta-analysis. *Int J Nurs Stud*. 2022;126:104140. doi:10.1016/j.ijnurstu.2021.104140
32. Smith T, Johnson R, Miller K. The emotional toll of chronic illness: insights from qualitative interviews. *Health Psychol*. 2020;39(2):135–144.
33. Lee S, Choi Y. Caregiver burden and emotional fatigue in stroke patient care: implications for family dynamics. *Soc Work Health Care*. 2019;58(7):687–700.
34. World Health Organization. *WHO Guideline on Health Policy and System Support to Optimize Community Health Worker Programmes*. Geneva: World Health Organization; 2018.
35. Pilotto A, Cella A, Pilotto A, et al. Three decades of comprehensive geriatric assessment: evidence coming from different healthcare settings and specific clinical conditions. *J Am Med Dir Assoc*. 2017;18(2):192.e1–192.e11. doi:10.1016/j.jamda.2016.11.004
36. McCormack B, McCance T. *Person-Centred Practice in Nursing and Health Care: Theory and Practice*. 3rd ed. Wiley-Blackwell; 2021.
37. Santana MJ, Manalili K, Jolley RJ, Zelinsky S, Quan H, Lu M. How to practice person-centered care: a conceptual framework. *Health Expect*. 2018;21(2):429–440. doi:10.1111/hex.12640
38. Shields L, Zhou H, Pratt J, Taylor M, Hunter J, Pascoe E. Family-centered care for hospitalized children aged 0–12 years. *Cochrane Database Syst Rev.* 2012;10(10):CD004811. doi:10.1002/14651858.CD004811.pub3
39. Ignoffo S, Gu S, Ellyin A, Benjamins MR. A review of community health worker integration in health departments. *J Community Health*. 2024;49(2):366–376. doi:10.1007/s10900-023-01286-6
40. Cruz-Oliver DM, Malhotra S, Patel P, Samuels R, Guastamacchia E, Triggiani V. Family-centered approaches in healthcare: evidence from elder care models in non-Western settings. *Geriatrics*. 2020;5(4):76. doi:10.3390/geriatrics5040076
41. Coleman EA, Berenson RA. Lost in transition: challenges and opportunities for improving the quality of transitional care. *Ann Intern Med*. 2004;141(7):533–536. doi:10.7326/0003-4819-141-7-200410050-00009