Original Article

Family-Based Palliative Care Model for Advanced Cancer Patients in Community Settings in the Northeast, Thailand

Waraporn Savisit PhD[1], Pissamai Homchampa PhD[1], Teabpaluck Sirithanawutichai MD[1]

[1] Faculty of Medicine, Mahasarakham University, Maha Sarakham, Thailand

Background: Advanced cancer patients (ACPs) need complex care and appropriate support from the family to relieve suffering and stress during the life-threatening course of the disease until the end of life.

Objective: To examine the current situation of family cancer care and to develop a family-based palliative care model for ACPs in community settings in the Northeast, Thailand.

Materials and Methods: The present study was a participatory action research study comprised four phases, situation analysis, model development and planning, model implementation and assessment, and follow-up assessment and model remodification. The participants included 12 dyads of ACPs-family caregivers (FCGs), 44 community network committee members (CNCs), comprising 28 community network volunteers-CNVs such as local leaders, teachers, Buddhist monks, nurses, and village health volunteers (VHVs), 11 health personnel, and five other local leaders. Data collection used interview schedules, in-depth-interview guide, focus group discussion guidelines, and observation checklists. Data analyses used descriptive and analytical statistics for quantitative data, and content analysis for qualitative data.

Results: The results showed that the participatory model developed was called "the integrated family-based palliative care for ACPs in community or IFPC-ACPC model". It was composed of 1) the CNCs for ACPs and families, 2) the roles of the CNC in providing social support to the ACPs and families, 3) the palliative care guidelines for ACPS, FCGs, and CNCs, 4) the three-workshop training on palliative care for ACPs, FCGs, and CNCs, and 5) the home visits and the home environmental modification. This eight-week model was applied to all patient-caregiver dyads after the CNCs agreed upon its potential for implementation at a high level. The satisfaction of the FCGs and CNCs changed, and the ACPs' symptoms were significantly changed at the end of the implementation at post-test and follow-up. The clinical outcomes revealed that the ACPs had PPS duration of 70 to 90 reflected by multidimensional adverse symptoms of the ACPs. The ESAS were improved significantly at post-test and follow-up ($p<0.05$). The ACPs' knowledge, perceptions, palliative care behavior, and social support were improved significantly at post-test and at follow-up ($p<0.05$). The received symptom management from his/her FCGs were also at a higher level.

Conclusion: The developed IFPC-ACPC model can be implemented in semi-urban communities in the Northeast, Thailand with adjustments based on local problems and needs. However, outcome evaluation for the model effectiveness in the long term needs further study.

Keywords: Advanced cancer patient; Family-based care; Integrated palliative care model; Family caregiver; Community network

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The incidence of cancer is on the rise, and it is one of the leading causes of death throughout the world. There were approximately 19.3 million new cancer-affected people and 9.9 million deaths worldwide, increased from 14.1 million and 8.2 million deaths in 2012[(1,2)]. Of these, cancer of the breast, lung, colorectum, prostate, stomach, liver, and cervix uteri were highly reported. In Thailand, a recent report on cancer in 2020 revealed that 426,000 were affected and 124,866 died. There were 190,636 new cancer affected people in 2020, which was an increase from 122,757 of the newly reported cases in 2010[(3,4)]. Cancer of the liver, lung, breast, colorectum, cervix uteri, and prostate were recently reported as high in Thailand. Advanced cancer patients (ACPs) stage III and IV need complex care and support over the time of the progressive impairment of the disease. Family caregivers (FCGs) are the primary providers of assistance to the ACPs from diagnosis through the end of life. A shift of the health care system in Thailand from hospital to home settings, particularly for chronically ill patients in long term care and

Correspondence to:

Savisit W.

Faculty of Medicine, Mahasarakham University, Maha Sarakham 44000, Thailand.

Phone: +66-80-4049285, **Fax**: +66-43-722991

Email: fruk2546@hotmail.com

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palliative care, has made family-based care an active form of healthcare delivery for ACPs(5).

The World Health Organization (WHO) definitions palliative care improves the quality of life (QOL) of patients and their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social, or spiritual. The QOL of caregivers improves as well(2).

Current palliative care model, there are four main core, 1) principles, patient, and family-centered care, 2) holistic care such as physical, mental, social, and spiritual, care to facilitate patient autonomy, access to information, and choice(6,7), legal care, and comfort care to keep ACPs the longest with FCGs(3,8), 3) collaborative and coordinated care with multidisciplinary teams professionals and network partners, and 4) continuity care, while the patient is being treated at the hospital, at home, and after death(9).

In the North-East region, palliative care focuses on receiving patients referred to the home care by central hospitals. General hospital near home or cancer center are used to receive palliative treatment at home, but some patients who live in the community do not receive treatment in hospital, resulting in no access to the services, and no symptomatic management when symptoms are abnormal(10). Caring is not a holistically comprehensive care, especially in the spiritual dimension. Spiritual preparation for terminally ill patients faced with perceptions of disease progression, hopes, fears, and impending loss is important. Palliative care model will help ACPs and FCGs search for the meaning of life, hope, encouragement, and forgiveness. Religion is based on a patient's beliefs and hopes(11). A gap exists in the support system, equipment, and tools for patient care at home. There is no referral management system linking the core database in the patient care coordination network between the multidisciplinary team in the hospital and the community. Clearly, a gap exists between integration teams and social networks to care for patients together. The community has become less involved. There is a lack of knowledge and skills of the health care team in holistic patient care, in particular in the spiritual dimension. Caregivers experience stress, discouragement, and distress(12).

A systematic review study revealed that the FCGs for cancer patients in Thailand had limited knowledge of palliative care. Nearly half of them already had health problems prior to the caregiving and over one-third developed such problems afterward. Some of them manifested with moderate to high stress and their applied coping mechanisms included seeking social support, problem-solving, confronting, emotional strategies, and positive reappraisal. The FCGs' burdens from caregiving involved a wide range of aspects, including physical such as fatigue, emotional and psychological such as stress from highly perceived family hardness and depressive patients, and social such as having to deal with the patients' behavior and emotions aspects. However, the same study also indicated that the FCGs were able to provide suitable care towards spiritual needs to the ACPs(12). In addition, the FCGs in one study under the same systematic review study indicated that the caregivers received support mostly from family, friends, and health care professionals and their QOL was at a moderate to a fairly good level(12,13). The ACPs and the FCGs should be informed and understand the palliative care model, so they and their families can make informed decisions about seeking palliative care at home in the early stages of the patient's returning home. ACPs will exhibit symptoms changed and the severity of the illness will increase over this period. The ACPs and the FCAs must have the knowledge of the disease, understanding of the illness and the progression of the patient's disease. A person is needed for help in case of an emergency, to solve urgent problems and help in their knowledge and skills to manage the patient. Symptoms include providing necessary and symptomatic medications(14) and supportive FCGs line contact to get help when needed, including liaising with various services(15). Develop the patient's capacity for self-care and participation in FCGs. Planning care until the end of life and living peacefully should be integrated. The use of alternative medicine care using music therapy and massage therapy, are considered the basic therapy of non-drug therapy(16). Music therapy was found to reduce stress and anxiety by listening to sounds of nature, including running water, rain, and seawater. The listening device can be listened to an audio player or listen through headphones by having the patient listen continuously for 20 minutes at a time for three consecutive days(17). Music therapy is used in combination with morphine or other pain relievers to help reduce pain in patients. It was found that the pain relief effect was better than talking to counselor alone(18). FCGs with ACPs suffer from the negative consequences of the presence and severity of the symptoms of these patients. Therefore, optimizing symptom control would benefit not just patients, but their caregivers as well. Thus, interventions should be designed to improve the outcomes of the patient, and caregiver dyads in such cases(19,20).

Non-communicable diseases including cancer have been the top leading causes of death in the Thai population for a decade, and only slightly more than half of such deaths occurred in hospitals. The quality of death and dying (QOD) index comprised of the following criteria, palliative and healthcare environment (20%), human resources (20%), affordability of care (20% weighting), quality of care (30% weighting), and community engagement (10%). Thailand was positioned forty-fourth in the QOD index ranking(21). Given a shift of health care system in Thailand from hospital to home settings has been widely evidenced, particularly for chronically ill patients in long term care, and an increasingly aging population in the recent years and the future, an effective form of palliative care provision is needed. Palliative care in Thailand has been developing since 1997 and gained wide acceptance in the recent decade. Palliative care in Thailand is accessible. The study on the palliative care model in the four regions of Thailand indicated several forms of the available palliative care deliveries based on social contexts. Health problems of ACPs receiving palliative care while being admitted to the hospital found that most ACPs lack of balance of water and mineral substances in the body, infection, discomfort, including pain, loss of appetite, nausea, vomiting, and constipation as well as having concerns about discomfort. These lead to frequent visits to the emergency room, especially for pain. These issues can be solved by telephone consultation and effective follow-up visits by a team of physicians, nurses, family physicians, and volunteers. It will allow ACPs and FCGs who lack of knowledge to adapt to pain medicines. The patients can take medicine and manage the discomfort by themselves. Usually, patients do not need to seek emergency pain treatment. Organizing a holistic nursing system through participation of patients, families, and communities, the continuation of care from hospital to homes and communities is important as it can improve the QOL of ACPs and FCGs(22).

The present study was built on the palliative care approach based on the WHO's definition. Consequently, palliative care is viewed as a holistic approach that improves the QOL as well as prevents and relieves the suffering of the ACPs and their families facing the life-threatening health problem. Palliative care focuses on the provision of comfort and compassionate care for each unique ACP, whose health might not be responding well to remedies, to satisfy the patient's physical, psychological, social, cultural, and spiritual needs, with the QOL and death with dignity, and to support the FCGs and families with manageable bereavement and appropriate coping strategies(23). Palliative care used the palliative performance scale (PPS). This is a validated and reliable tool to assess the patient's functional performance and to determine progression toward the end of life. Palliative care is divided into three stages, stable stage with PPS 70 to 100, transitional stage with PPS 40 to 60, and end of life with PPS 0 to 30. The present study also incorporated the Watson's Theory of Human Caring and social support theory (SST) to examine the current situation of family cancer care. The Watson's Theory of Human Caring is one of the nursing theories view an ACP and his/her family as unique entities with intrinsic attributes that promptly respond to confronting circumstances through the use of self-reflection and past accumulative experiences and spirituality for better understanding of one-self and surrounding situation, particularly at the time of life-threatening situation. This theory allows researchers to focus on holistic caring of the ACP and his/her family based on sociocultural and environmental context in which they live while keeping the transpersonal relationships and respecting patient's independence, and the ability to make decisions, which, in turn, provides opportunities to the patient and family to learn and grow in a new direction(24). The SST recognizes positive impacts of meaningful assistance people provide to support and enhance other individuals to be able to cope with stressful life events. There are initially four types of support, namely emotional such as giving empathy, love, and caring, instrumental such as giving assistance, monetary, facilities, services by significant others, including FCGs and CNCs, informational such as giving advice, suggestion, and training, and appraisal such as giving feedback to assist self-evaluation(25). The SST assists researchers to tighten relationships among people through social networking, which allows the community to not only provide social support but also empower an individual family to have increased control over factors that might affect the ACP's health and living conditions. The integration program performs palliative care for patients receiving care at home. This program can reduce the incidence of emergencies in cancer patients more than those cared in end-of-life care units(26). ACPs access to the service system to receive holistic care from a community-based patient care model developed using a community participation process is important. Developing the capacity of caregivers, getting a follow-up visit by a multidisciplinary team from the hospital communication channel, continuous follow-up assessment helps patients to have a satisfactory and good QOL(5,12,27). Therefore, the present research aimed to develop a family-based palliative care model for ACPs in community settings in the Northeast, Thailand. The present study was done out in seven semi-urban communities in one out of 20 provinces in the Northeast, Thailand, between January 2020 and March 2021. The Northeast is one of the four main regions of Thailand, with a current total population of approximately 22 million, constituting one-third of the country's total population(28). Recent studies explored the palliative care situation in the Northeast in 2017 and indicated that 43.0% of older patients receiving palliative care within the region suffered from cancer and 56.0% of the present study group were discharged to home(29). The results from a mixed-method study exploring the needs of the advanced-stage cancer patients in one of the provinces in the Northeast in 2018 revealed that the majority of the patients studied (77.5%) had a strong will to receive care at their home. Their four most needed matters in palliative care included more information about the disease and medical treatment (98.2%), more treatment for pain (97.3%), health education for family caregivers (95.5%), and having health volunteers visit to home (95.5%). The qualitative research results showed that the participants needed health care providers to deliver open communication. They also had high need for pain management and psychosocial supports(30).

Materials and Methods

The present study was a participatory action research that used the participation process of Kemmis and McTaggart(31), which comprised four phases, namely situation analysis, model development and planning, model implementation and assessment, and follow-up assessment and model remodification. The participants included 12 dyads of ACP-FCG, 44 community networking committee members (CNCs), comprising 29 community network volunteers (CNVs) such as local leaders, nurses, and village health volunteers (VHVs), four local health personnel from the health promotion hospital (HPH) such as two nurses, a Thai traditional medical doctor, and a public health personnel, a team of four palliative care specialized personnel from the provincial hospital such as a palliative care specialized nurse, a Thai traditional medical doctor, a nutritionist, a family physician, five Buddhist monk, and three teachers.

Data collection used interview schedules for ACPs, FCGs, and for CNVs, an in-depth-interview guide for the ACP family, focus group discussion guidelines for the CNCs clinical outcome assessment tools, and observation checklists.

The Tool 1 comprised five parts, personal and family background with 13 questions, health information with eight questions, cancer and palliative care knowledge with 15 questions and illness perception with 15 questions, palliative care behaviors with 14 questions, and perceived social support with 12 questions. The tool 2 comprised two parts, the health condition with seven questions and PPS with eleven questions for the first part, and the Edmonton Symptom Assessment System (ESAS) Thai with ten questions and the QOL BREEF with 26 questions for the second part. The interview schedule for FCGs comprised four parts, the personal background with eight questions, the cancer and palliative care knowledge with 15 questions and perception of the ACPs illness also with 15 questions, the palliative care behaviors with 18 questions, and the satisfaction on palliative care provision with seven questions. The interview schedule for CNVs comprised four parts, the personal background with eight questions, the cancer and palliative care knowledge with 15 questions and perception, attitude, and belief related to palliative care with 34 questions, the participation in the provision of care to the patients with ten questions, and the satisfaction on palliative care provision with 12 questions. The ACPs family in-depth interview guideline comprised questions related to illness perception and meaning, perceived social support, participation in the provision of palliative care to the ACPs, and satisfaction with palliative care. All interviews were conducted at the patient's home. Individual oral interviews were conducted in the Isan dialect.

The clinical outcome assessment vital sign of ACPs(32) by tools used included a thermometer for body temperature measurement in degree Celsius (°C) with the cut-off point of 37.3°C being in a normal temperature, a standardized weighing machine and a stadiometer for body weight and height and body mass index or BMI assess for nutrition of ACPs, BMI normal of 18.5 to 22.9 kg/m² being in a normal range, a digital sphygmomanometer for blood pressure or BP measurement in millimeter mercury (mmHg) with the range of 120/80 mmHg being considered a normal, a capillary blood glucose meter and testing strips for capillary blood glucose or CBG in milligram percent (mg%) with the cut-off point of more than 200 mg/dL were used to diagnose diabetes mellitus, if serum sample were taken after consuming food for at least two hours, and a pulse oximeter for oxygen saturation in percent (%) with the cut-off point of more than 90% being in a normal point. In addition, the PPS and ESAS-Thai were used. The PPS was used to assess performance of body(33,34), which is the ACP's five abilities, including mobility, daily activities and the severity of illness, self-care behaviors, eating, and consciousness. With the total score of 100 points, the PPS was divided into three categories with 0 to 30 points being totally dependent or in a late-stage, 40 to 60 points being partially independent or in a transitory phase, and 70 to 100 points being independent or in a stable phase. PPS score is for nursing care plan. The ESAS-Thai evaluated the ACP's nine perceived symptoms, namely, pain, tiredness/fatigue, nausea, depression, anxiety, drowsiness, anorexia, wheezing, and other symptoms that the patients described by answering open-ended questions. The measurement of each symptom was divided into 0 to 10 points as visual analog scales (VAS), where "0" means no symptoms and "10" means the most severe symptoms. The ESAS symptom scores were categorized by severity level with none as 0, mild as 1 to 3, moderate as 4 to 6, and severe as 7 to 10. ESAS accessed the plan symptoms management in ACPs(35,36).

An observation checklist was used in participant observation such as verbal, characteristic, facial expression, environment, and behavior expression, comprising observation on the participation of the ACPs, FCGs, and for CNVs in each step of the research.

Tool quality inspection met that the researcher has developed a research tool and checked the content. By inspection method index of concordance between questions and objectives as index of item objective congruence or IOC by five experts, and the reliability of the instrument used in the study were determined with ACPs from patients with metastatic cancer, with the characteristics. Thirty people close to the sample group were used to test the data to determine the quality of the tools with a confidence determination formula type alpha coefficient of Cronbach of the questionnaire on the opinions of the stakeholders regarding the suitability and the feasibility of utilizing all confidence values from 0.60 or above all criteria(37). Data analyses used descriptive and analytical statistics for quantitative data and content analysis for qualitative data. Compared mean ranking was used to assess symptoms and QOL in patients before the experiment, after the experiment, and follow-up experiment by Friedman analysis. The presented research was approved by the Ethics Committee of Mahasarakham University (Ref. No. 0109/2018; 2018 Oct 26, Ref. No. 037/2020; 2020 Feb 19).

Table 1. Personal and health information of the ACPs, FCGs, and CNVs

Personal and health information	n (%)
ACPs (n=12)	
Sex: female	7 (58.3)
Age in years; mean [SD]	64.58 (10.9)
Marital status: married	8 (66.7)
Education: primary or lower	10 (83.3)
Occupation: agriculture	11 (91.7)
Income (THB/month); mean [SD]	1,233.33 [1,512.5]
Family income (THB/month); mean [SD]	5,916.66 [3,260.1]
Family characteristic: extended	6 (50.0)
Buddhism	12 (100)
FCGs (n=12)	
Sex: female	8 (66.7)
Age (years); mean [SD]	55.75 (14.2)
Marital status, Married	7 (58.3)
Education, Primary	7 (58.3)
Occupation, Agriculture	10 (83.3)
Income (THB/m); mean [SD]	3,083.33 [3,564.1]
CNVs (n=12)	
Gender, Women	9 (75.0)
Age in years; mean [SD]	55.75 (14.2)
Marital status, Married	8 (66.7)
Education, Primary	9 (75.0)
Occupation, Agriculture	8 (66.7)
Income (THB/m); mean [SD]	8,750.00 [10,199.1]
Cancer diagnosis	
Gastrointestinal (colon 1, liver 3)	4 (33.3)
Lymphoma	3 (25.0)
Cervix cancer	2 (16.7)
Breast cancer	2 (16.7)
Laryngeal cancer	1 (8.3)
Relation with ACPs: son/daughter	5 (41.7)
Position in the community public health volunteer	7 (58.3)

ACP=advanced-stage cancer patient; FCG=family caregiver; CNV=community network volunteer; SD=standard deviation

Results

The results of the participatory action research consisted of four phases, namely, situation analysis, model development, and planning, model implementation, and assessment, and follow-up assessment and model remodification (Table 1).

Phase 1 dealt with namely situation analysis. The situation of palliative care in ACPs comprised cancer and palliative care knowledge, illness perception, palliative care behaviors, and perceived social support, all of which were evaluated as being lower than the accepted level. The situation of palliative care in FCGs comprised cancer and palliative care knowledge, perception of the ACPs illness, palliative care behaviors, and satisfaction with palliative care provision, all of which were evaluated as being lower than the accepted level. The situation of palliative care in CNVs comprised cancer and palliative care knowledge, perception, attitude, and belief related to palliative care, participation in the provision of care to the patients, all of which were evaluated as being higher than the accepted level. However, satisfaction on palliative care provision was evaluated as being lower than the accepted level.

Phase 2 dealt with model development and planning. The 44 CNCs comprised 29 CNVs and included local leaders, nurses, and VHVs, four local health personnel from the HPH as two nurses, a Thai traditional medical doctor, and public health personnel, a team of four palliative care specialized personnel from the provincial hospital as a palliative care specialized nurse, a Thai traditional medical doctor, a nutritionist, a family physician, five Buddhist monks, and three teachers. The committee was to 1) make an action plan of delivering palliative care to the target group in the community for betterment of their QOL, 2) integrate its work with the funds for vulnerable groups and mobilize resources available in the sub district from the government sector, private sector, and public sector, 3) direct, supervise, coordinate, monitor, and evaluate the operation and coordinate collaboration of concerned agencies to help them carry out their task efficiently, 4) report the achievements, problems, and obstacles of the operation to the committee with recommendations, and 5) publicize in details the palliative care delivery in the community and induce people in the target area to join the palliative care volunteer group as well as to donate money to the fund for patients. The action plan's duration was eight weeks. The activities were 1) imparting cancer and palliative care knowledge to ACPs, FCGs, and CNCs, and 2) teaching and practicing how to conduct physical assessment by using PPS, and ESAS for symptoms and symptoms management, SKT 1 to 7 therapy, skill emotion by music therapy, and pray therapy. Integrated home visits to ACPs/FCGs by CNCs and PCSTs were made to monitor the patients' eating, exercise, early sleep, and environment, and to see if there were symptoms of unwell being.

Phase 3 dealt with model implementation and assessment, considering problems that the ACPs revealed to the CNMs, and carried out appropriate improvement of the model for the ACPs. Improvement was also made on how to carry out also made the work. Training on palliative care was given to the Buddhist monk volunteers (BMVs) and the student care givers-SCGs who volunteered to look after the ACPS. There were home visits to review the knowledge of meals, exercise, resting, management of discomfort, adjustment of the environment, and giving assistance based on the problem condition of each individual patient. Integrated home visits to ACPs/FCGs by CNVs, PCSTs, BMVs, and SCGs for mental support and encouragement were done. This was the results of the development of the care system.

An ACP who had already been in the hospital listed during the treatment period knew the disease and dietary guidelines for self-care after treatment. At first, he was strict, but over time he began to reduce his strictness and ate whatever the family provided, not the food properly assigned. For example, salt was not restricted, fermented foods, pickled fish, and meat other than beef was consumed. It affects the disease as the patient has colon cancer. These foods aggravate the disease, so it is difficult to eliminate, but for patients who have received ongoing treatment, and for patients who are receiving treatment, they have knowledge and guidelines for good behavior, which strengthen their health for healing.

The FCGs understood the patient's current condition and had good morals to care for the patient without thinking of this as a burden. They tried to avoid anything that might be detrimental to the patient's health. For example, the husband still smoked but he would smoke outside the house. However, there were still side effects of third-hand smoking, so the specialized nurse advised the patient's husband to stop smoking and he was willing to do so. The nurse also gave mouthwash for giving up smoking with 0.5% sodium nitrate to the patient's husband. Thus, the family members needed to be trained to reduce the risk factors in the family where the patient cooked for herself and the family member ate the same type of food as the patient, by focusing on organic vegetables and chili paste.

The CNCs also caregivers were interested in inquiring about patients' symptoms as well as encouraged patients to practice palliative care. They used a questionnaire on various complaints and the

Table 2. Knowledge, perception, palliative care behavior, social support, ESAS, and QOL outcomes of the ACPs at pre-test, post-test, and follow-up (n=12)

Variables	Assessment phases			Friedman χ^2	p-value
	Pre-test	Post-test	Follow-up		
ACPs (n=12)					
Knowledge				14.11	<0.01*
• Median (IQR)	11.50 (6.00)[ab]	20.00 (1.00)[bc]	20.00 (0.75)[ac]		
• p-value	<0.01*	0.16	<0.01*		
Illness perception				23.53	<0.01*
• Median (IQR)	70.50 (18.75)[ab]	104.00 (12.50)[bc]	109.50 (15.00)[ac]		
• p-value	<0.01*	<0.01*	<0.01*		
PCB				20.22	<0.01*
• Median (IQR)	73.50 (31.25)[ab]	106.00 (22.00)[bc]	107.00 (23.00)[ac]		
• p-value	<0.01*	0.59	<0.01*		
Social support				21.41	<0.01*
• Median (IQR)	73.00 (16.75)[ab]	117.00 (13.75)[bc]	117.00 (13.75)[ac]		
• p-value	<0.01*	0.32	<0.01*		
ESAS					
Pain				2.40	0.30
• Median (IQR)	3.5 (6.75)[ab]	3.50 (3.50)[bc]	2.50 (1.75)[ac]		
• p-value	0.39	0.33	0.31		
Tiredness				10.64	<0.01*
• Median (IQR)	3.50 (7.00)[ab]	3.00 (4.00)[bc]	2.00 (3.00)[ac]		
• p-value	0.06	0.04*	0.02*		
Anxiety				5.00	0.08
• Median (IQR)	0.00 (2.25)[ab]	0.00 (2.75)[bc]	0.00 (1.50)[ac]		
• p-value	0.41	0.10	0.11		
Appetite				3.71	0.15
• Median (IQR)	0.00 (1.50)[ab]	0.00 (2.00)[bc]	0.00 (1.50)[ac]		
• p-value	0.65	0.10	0.18		
Wellbeing				15.20	<0.01*
• Median (IQR)	4.50 (5.25)[ab]	3.00 (1.75)[bc]	2.00 (2.00)[ac]		
• p-value	0.03*	0.01*	0.01*		
Shortness of breath				2.00	0.36
• Median (IQR)	0.00 (0.00)[ab]	0.00 (0.00)[bc]	0.00 (0.00)[ac]		
• p-value	0.32	1.00	0.32		
Constipation				3.71	0.15
• Median (IQR)	0.00 (0.00)[ab]	0.00 (0.00)[bc]	0.00 (0.00)[ac]		
• p-value	0.32	0.16	0.18		
Quality of life				18.66	<0.01*
• Median (IQR)	78.00 (16.75)[ab]	78.00 (1.75)[bc]	104.00 (0.00)[ac]		
• p-value	0.03*	<0.01*	0.01*		

ACPs=advanced-stage cancer patients; ESAS=the Edmonton Symptom Assessment System; PCB=Palliative care behavior; IQR=interquartile range

[a, b, c] Analysis data Pre-test, Post-test, and Follow-up by Wilcoxon signed rank test(38), [ab] Analysis data compared duration of Pre-test and Post-test, [bc] Analysis data compared duration of Post-test and Follow-up, [ac] Analysis data compared duration of Pre-test and Follow-up

* p<0.05, statistical significance

ESAS for other people. If there were patients who had problems that needed help, they immediately rushed to help. There was continuous monitoring during the activity period (Table 2, 3).

Phase 4 dealt with follow-up assessment and model remodification.

The experimental and the clinical outcomes in the ACPs revealed differences in the patients'

Table 3. Knowledge, perception, palliative care behavior, satisfaction, attitude, belief, and participation outcomes of the FCGs, and CNVs at pre-test, post-test, and follow-up (n=12)

Variables	Assessment phases			Friedman χ^2	p-value
	Pre-test	Post-test	Follow-up		
FCGs (n=12)					
Knowledge				22.00	<0.01*
• Median (IQR)	3.50 (12.00)^{ab}	20.00 (0.00)^{bc}	20.00 (0.00)^{ac}		
• p-value	<0.01*	1.00	<0.01*		
Illness perception				22.40	<0.01*
• Median (IQR)	65.00 (15.00)^{ab}	97.00 (17.00)^{bc}	98.00 (17.00)^{ac}		
• p-value	<0.01*	0.06	<0.01*		
PCB				20.22	<0.01*
• Median (IQR)	75.50 (16.00)^{ab}	118.00 (28.75)^{bc}	120.50 (28.75)^{ac}		
• p-value	<0.01*	0.32	<0.01*		
Satisfaction				22.00	<0.01*
• Median (IQR)	19.00 (7.00)^{ab}	43.50 (7.75)^{bc}	43.50 (7.75)^{ac}		
• p-value	<0.01*	1.00	<0.01*		
CNVs (n=12)					
Knowledge				20.00	<0.01*
• Median (IQR)	17.00 (6.75)^{ab}	20.00^{bc}	20.00^{ac}		
• p-value	<0.01*	1.00	<0.01*		
Perception of palliative care				5.2	0.07
• Median (IQR)	28.00 (14.75)^{ab}	28.00 (15.50)^{bc}	39.90 (21.25)^{ac}		
• p-value	0.32	0.08	0.07		
Attitude towards palliative care				10.00	<0.01*
• Median (IQR)	45.50 (10.50)^{ab}	45.50 (10.50)^{bc}	54.50 (5.75)^{ac}		
• p-value	1.00	0.04*	0.04*		
Belief related to palliative care				5.20	0.07
• Median (IQR)	27.00 (4.50)^{ab}	27.00 (0.75)^{bc}	30.00 (9.00)^{ac}		
• p-value	0.32	0.08	0.07		
Participation in provision of care/support to the patients				7.00	0.03*
• Median (IQR)	16.00 (10.00)^{ab}	18.00 (13.00)^{bc}	27.00 (23.00)^{ac}		
• p-value	0.32	0.04*	0.04*		
Satisfaction on palliative care				23.13	<0.01*
• Median (IQR)	38.00 (3.75)^{ab}	74.00 (0.75)^{bc}	76.00 (0.00)^{ac}		
• p-value	<0.01*	0.04*	<0.01*		

FCGs=family caregivers; CNV=community network volunteer; PCB=palliative care behavior; IQR=interquartile range

$^{a, b, c}$ Analysis data Pre-test, Post-test, and Follow-up by Wilcoxon signed rank test(38), ^{ab} Analysis data compared duration of Pre-test and Post-test, ^{bc} Analysis data compared duration of Post-test and Follow-up, ^{ac} Analysis data compared duration of Pre-test and Follow-up

* p<0.05, statistical significance

health condition that included pain, tiredness, physical discomfort uneasiness, and QOL, with statistical significance at the 0.05 level; the FCGs had a difference in knowledge, perception, behavior, and satisfaction, with statistical significance. The community network partners' knowledge, attitude, social support, and satisfactions were also different, with statistical significance at the 0.05 level. The results of the individual in-depth interviews assessment were kept confidential with assigned codes, and the participation in the present study of all participants was voluntary.

The changes in the ACPs, FCGs, and CNVs after the experiment can be seen from their expression of feelings below:

Patient Mr. A: "My life has certainly been worthwhile, Doctor, because I have survived until now. Many other patients who fell ill at the same time have all gone. I really think I have made my own life worthwhile". "Since the day you first came, I have followed your instruction and have observed myself. I think I have been good alright, but sometimes I violated your instruction a little bit because I couldn’t resist my friends”.

Patient Mr. B: “I intend to follow all of your instructions. I avoid food taboos, strictly, and now I think I have been much better. People in the village had said I would not live long, but when they saw me walking in the flea market, they said I looked a lot better; I was glad”.

Patient Mrs. C: “I suffered so much earlier, but since the time you came, Doctor, I have followed your instruction. Now I feel relieved. I feel more agile to walk anywhere. Every time I meditate, I think of your face first. I must thank you a great deal to make me a lot better.”

Patient Mrs. D: “Since I joined the project, neighbors or health teams are always interested in asking for news. I feel like I’m not alone. There is a team of staff to visit the house to give advice”

Patient Mrs. E: “When I learned that I had cancer and it had advanced to the liver for the third time, I thought I would die. I felt discouraged and did not want to do anything, but when someone talked with me, I became encouraged. Now I have been on medication for the third time. Food that I used to eat such as pickled fish or salty food has been avoided. I try to eat a lot of egg white as advised by the doctor; 6 to 8 eggs a day. When I had a blood test at Srinagarind Hospital in Khon Kaen, the doctor said the result was good and I felt so good. When I was on medication in Khon Kaen, I raised my arms and meditated all the time. I did that also while lying on bed. Nobody else did it. I took long and deep breaths as told by the doctor. I think that helps. At home, I listen to the sound tape. It is my companion, calm my mind”.

Patient Mrs. F: “Sometimes I have to be alone when my children go to work. Listening to Dharma tapes can help you train your mind to not be distracted FCGs have expressed their feelings”.

Mrs. Ann: “After I joined the project, patients had better self-care behaviors. Avoiding fermented foods decreased alcohol consumption”.

Mrs. Rose: “When the patient is resting, he usually listens to music. Listening to the Dharma alone makes the patient feel calmer”

Mrs. Suay: “Patients are more careful about food intake. Do not buy herbs that are advertised on the radio to eat”.

A care giver and network member express feelings:

Mrs. A: “After participating in the project, I understood more about palliative care. Patients who need assistive devices will come to ask for advice”.

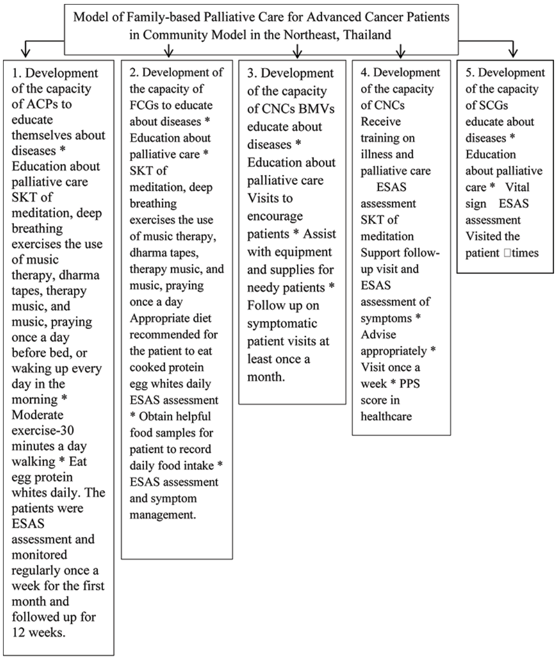

Figure 1. Result “Family-based Palliative Care for Advanced Cancer Patients in Community Model in the Northeast, Thailand”.

Mrs. B: “Villagers in the community join together to donate money, food helps patients”

Mr. C: “It’s a good project. It helps us to gain more understanding of the cancer and thus it brings about a clearer model. We are willing to cooperate; you, Doctor, just let us know.”

Mr. D: “When there is a case of illness in the village, I usually go to take a look, to encourage them and see if I can help”.

Mrs. E: “When neighbors have some things to eat, they share them with him. He has a lot of friends. He is always in a good mood. He has little amount of money because he doesn’t work, the neighbors grow vegetables, and they share them with him. Yes, it’s good. I feel that I have helped and have understood more about palliative care. I have witnessed positive changes in the patients” (Figure 1).

Discussion

Model of Family-based Palliative Care for Advanced Cancer Patients in Community takes part in the process by integrating the development of common capacity in the three areas of patients, families, careers, and network partners. This is done under the concept of palliative care that include the Watson’s Theory of Human Caring, the Pander’s

Health Promotion Theory, and the SST. It results in ACPs having a better QOL. FCGs and CNCs are more satisfied with the Model of Family-based Palliative Care for Advanced Cancer Patients in the Community. They used it in caring for the patients and discussed the situation of palliative care for ACPs.

Found in ACPs and FCGs knowledge of disease and palliative care knowledge, perception of illness, fewer self-care behaviors are in accordance with Atena et al(14). According to Fitzpatrick et al, the palliative care education among cancer patients by the care team is to reduce anxiety of the patient(15). Bridging the gap through an appropriate knowledge program plays an important role in self-care at the patient's home. ACPs received the least amount of social support in palliative care. FCGs were less satisfied with the care of patients receiving palliative care. FCGs do not know the means of communication and obtaining necessary equipment assistance. CNGs of knowledge, perceptions, attitudes, and beliefs shows less participation in palliative care, and moderately satisfied.

The process of developing the Model of Family-based Palliative Care for Advanced Cancer Patients in Community integrating ACPs, FCGs, and CNGs capacity development is done by providing knowledge of palliative care, physical, psychosocial, spiritual, cultural, and traditional care, integrated with the use of alternative medicine healing meditation(39). This includes music therapy, prayer therapy, and formulation of health behavior promotion. PPS competency assessment skills evaluated the various discomforts using the ESAS tool social support.

CNGs getting social support from religious organizations was in accordance with Sirisoongnern et al(8). It is said that religious organizations and nursing homes should play a part in developing a consistent palliative care system, for the local society, and culture in each context. The schools in the community also play a role, where monks, teachers, and students play a role in visiting to boost morale, together with the health team. A palliative care committee was established at the sub-district level.

Effectiveness Model of Family-based Palliative Care for Advanced Cancer Patients in Community are integrated in the present research.

It can be seen that there is continuous care for terminally ill patients from the hospital to the home. It improves the QOL of the patients and their families who are satisfied with their caregivers in accordance with the studies of Tasprasit et al(5). The palliative care system has evolved from a multidisciplinary team, giving patients more holistic care and more family satisfaction.

Hospital care system to the community in the network to care for patients reduce the number of admissions of the patients and reduce the financial burden of the families to travel to take care of the patients at the hospital. Establishing an efficient patient care system mechanism of the family doctor team network partners provide close supervision until the last moment with medications and home oxygenation equipment in accordance with Sailungka et al(22). Integrated Development of a Model of Family-based Palliative Care for Advanced Cancer Patients in Community should develop the capacity of FCGs to have knowledge of palliative care. This should be combined with alternative medicine in accordance with Puripun et al(39). The meditation therapy SKT(9) is a meditation practice, combining electrical waves between the healer and the patient. These can relieve pain and make the patient feel more comfortable. Help patients educate themselves about problem assessment and how to manage their discomfort. This is to build trust in family care together with social support from network partners by using community participation from all sectors. The network members were satisfied with the palliative care in accordance with Zendehtalab et al(40). The creation of an active partnership between the health center, elderly participants, and their families, results in the improvement of care quality and satisfaction of stakeholders.

When patients were trained in health assessment, vital signs, O_2 blood sugar, PPS score, and ESAS, they understood that the symptom, pain, and suffering management changed in disease progression, in accordance with Inpuan(41). Health awareness program helps end-stage cancer patients increase their self-efficacy. This leads to health behavior modifications, making the patients able to take better care of themselves. A manual for pain assessment and discomfort, in line with those developed jointly between the multidisciplinary team Guidelines for dispensing drugs in accordance with Tasprasit et al(5), would help relieve pain in terminally ill patients.

Conclusion

FCGs in current social conditions have to work outside the home, leaving the ACPs unattended. Thus, the ACPs is left alone and have to take care of themselves, even when the patient has severe symptoms. Therefore, the family may be unable to manage the needs of the patients. This is when the social support from network partners and communities plays an important role in maintaining care for ACPs.

Health teams and CNGs should continue to follow up on patient visits based on their PPS score. There should be meetings to exchange information. Plan for monthly care guidelines should be done to identify problems and needs, and seek assistance for patients in the community, so that the ACPs have a good QOL and continuity of the project implementation.

Encourage and support the establishment of a format or project to develop knowledge skills. Learning of the skills required by FCGs and CNGs in continuous palliative care should be taught to increase the potential for effective care of patients receiving palliative care at each level of physical ability.

Promoting and supporting FCGs and CNGs to participate in palliative care at each level of physical ability to provide continuous social support is important. It is a good encouragement and promotes the QOL of patients in the community.

Promoting and supporting communication channels resources for emergency counseling to provide ACPs and FCGs with access to counseling and resolve problems urgently is required.

There should be support for the preparation of patient manuals to enable FCGs to review their self-care knowledge from the manual, making it possible to assess symptoms when the abnormal level of severity developed and knowledge of self-care practices.

ACPs and FCGs should be given the freedom to adjust the care methods that are suitable for their living conditions, lifestyles, beliefs, cultures, and traditions that differ from professional science.

States should have a policy in patient care by providing essential and scarce equipment for community care such as oxygen concentrators, beds, and fingertip oximeters, to the sub-district health-promoting hospitals in the area in sufficient quantity for the number of patients in the community.

Promoting and supporting the continuous linkage of health information from hospitals to homes and clearly define the role of communities in participating in care is required. It is important to prepare the ACPs before going home, having clear, comprehensive information, including a clear treatment plan from the treating physician, so that ACPs FCGs have the knowledge, understanding, preparation for palliative care and how to help them.

Sub-district administrative organizations should have plans/projects to support the program. Developing a long-term palliative care program in the community includes the provision of storage facilities to prevent equipment shortages in an effort to alleviate patients suffering. Furthermore, it includes improving the home environment to be suitable for care and to prepare solution to fix problems in a timely manner.

Suggestions for doing the next research

Palliative care skills should be developed by means of pre-and post-test practice to be able to assess ACPs and find how accurate are FCGs palliative care skills.

What is already known on this topic?

Universal aspects include collaboration between family members and health care providers to define care plans that take into consideration the family contexts. It also includes the needs for flexible policies and procedures and the need for patient, family, and health care professional education. Non-universal aspects include illness-specific patient and family education. Future research should evaluate the ability of FCGs to improve important patient, family, caregiver, and health system outcomes, health care policies, and procedures.

What this study adds?

This current study aimed to develop a family-based palliative care model for ACPs in community settings in the Northeast, Thailand.

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Conflicts of interest

The authors declare no conflicts of interest.

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