

Experiences of People with Advanced Cancer in Home-Based Palliative Care

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Abstract: People with advanced cancer who are receiving palliative care at home has increased dramatically in Thailand. The aims of this study were to explore the experiences of people with advanced cancer in home-based palliative care and to study and inform caregiving for them. A qualitative approach was employed using a phenomenological investigation of people with advanced cancer with data gathered from 2011 to 2012. There were seven participants engaged through multiple in-depth interviews. In addition, their family caregivers, and five public health nurses provided perspectives on caregiving through focus group discussions. Three main themes emerged: 1). 'State of being', experience facing the end of life. 2). 'Quality of life', experience of life satisfaction and satisfaction with care; and 3) 'Compassionate care in the Buddhist view', a holistic approach through caregiver assistance, resources and supplies. Palliative care experiences served to enhance the quality of life for people with advanced cancer through a culturally-appropriate, holistic approach of family and nursing care.

This study shows how persons with cancer and their relatives faced end of life crises while fighting to maintain peace and dignity. Sufferers' life experiences and how caregivers helped people with advanced cancer deal with their cancer, suffering, and enabled them to have a better quality of life.

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Introduction

Global trends have created a better understanding of useful concepts for comprehensive practice patterns, both direct and indirect, with positive and appropriate responses to the needs and problems of people with advanced cancer (PAC) in maintaining optimal health and quality of life (QOL). However, PAC and their families can manage chronic care through the stages

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of the cancer pathway to a good ending, death with dignity. Early discharge from hospital necessitates setting up and implementing a continuing care plan in the home, in order to reduce what otherwise would balloon national health care debt.^{1,2} Current hospital policies aim to reduce hospital stays. In Thailand, public health service policy has established and extended this national strategy to practice through home care for chronic illness, often ending with dying at home.³

Severe illnesses, like cancer, require ongoing, comprehensive palliative care during a person's last stages of life. Patients often prefer to be at home during these times but the required active and holistic care is rarely available, causing family caregivers (FC) to bear the burden of care. Recently, new home palliative care strategies for pain relief, symptom control, and spiritual healing have been developed.⁴ Palliative care for PAC aims to reduce institutional burdens and increase the possibility of dying at home instead of in a hospital or health care institutions.⁵ However, translating knowledge into policy and practice can be limited due to lack of planning, human resource preparedness and effective utilization.

Home-based care necessitates essential continuing care from hospital to home and this requires a natural extension of the roles and function of public health and community nurses. The Bangkok Metropolitan Administration Health Department has provided home care delivery for all kinds of illnesses for Thai patients at home since 1974,⁶ including taking care of patients with cancer.

Cancer was the third leading cause of death in Thailand in 2014.⁷ The Health Information Unit, Bureau of Health Policy and Strategy⁴, reported that one of the major challenges facing the health service system is cancer. The National Cancer Institute report of 2014 stated that the number of patients with cancer was 2,955 per 100,000 population² and more than one fifth of people with cancer live in Metropolitan Bangkok.⁷

Moreover, in the case of advanced cancer, Walshe and Luker⁸ indicated that PAC have a wide range of problems and needs; resulting in anxiety and uncertain conditions not only in daily activities, but also from a complexity of signs and symptoms which impedes responding with effective psychological and spiritual care. Structural support is needed for effectively coping with fear and reducing the fear of suffering. There are few comprehensive studies of dying patients in home-based care in Thailand,⁹ especially regarding psychosocial and spiritual healing. Yet, home-based care must provide continual care with reference to patients' needs.¹⁰ Although a few international studies on palliative care at home from foreign countries have revealed special needs of patients and relatives, nurses need a deep understanding of the cultural context in their own country for meeting home care needs.

In Thai culture, people want to die at home, in a familiar environment and surrounded by family and friends. Older people may be reluctant to live at home during the last stage of life due to fear and uncertainty.¹¹ PAC are dependent on others to meet common living conditions and require care by their family/relatives and/or a visiting nurse. Home-based palliative care leads to the extension of the roles and function of Public Health Nurses (PHN) to be responsible for informing palliative care by FC.¹² However, most PHN are not well prepared to provide chronic care to clients at home. There is very scant knowledge and training regarding palliative home-based care in Thailand.

Public health care system policies in Thailand need to embrace home-based care, especially regarding the home health care concept. PHN have the opportunity to provide benefits in terms of both psychological and palliative care⁵ through support of FC by providing information and building relationships. PAC would then have more options to live the rest of their lives at home surrounded by family.

This study provided insights into home-based care for PAC; home-based care affects families and relatives' emotional, social, physical, and spiritual well-being more than in any other setting.⁶

Review of Literature

Palliative care is based on pain relief, addressing symptoms and providing emotional and spiritual support for the patient and their family members.⁶ Palliative care is multi-level care and with various methods of care provided by PHN and formal and informal caregivers. Palliative care addresses the relief of suffering and healing help directed at improved QOL and a good death. A good death in cancer care is composed of physical and psychological comfort, dying in a favorite place, a good relationship with medical staff, maintaining hope and pleasure, and dignity in terms of not being a burden to others. Santina and Bernstein¹³ stated that a good death is one:

That is free from avoidable distress and suffering for people, families and caregivers; in general, according with patients' and families' wishes for peace and dignity; a good death has been described as one that is pain free, where dying is acknowledged and preferably occurs at home in the presence of family and friends, with the patient aware and alert so the unresolved business of life can be accomplished.

Human experiences are reflected as phenomena, as lived realities. Based on the purpose of this study, the researcher applied the phenomenological approach outlined by Martin Heidegger. Phenomenology can be understood as a process of discovering the objects of attention in one's 'life-world', revealing oneself as 'those to whom things appear'. So it is potentially a rich source of experience, revealing subjective meanings.^{14,15} Heidegger argues that his phenomenology is based on the concept of "dasein", in German, meaning "there being", an expression of being in the world; this is a specific understanding in which lived expression always

comes to be understood as something performing an important function, as performing a type or state of being, and is found in the human experience by analyzing relationships and lived experiences.¹⁶

According to previous studies, there are many accounts about people with cancer who have had both positive experiences, appreciating their families, and negative experiences,¹⁷ extreme feelings of suffering and uncertainty.^{18,19} PAC frequently have existential experiences about the severity of physical disease and spiritual distress.²⁰ The best way to understand them is to examine their experiences and relationships in order to deal with advanced cancer and life-threatening diseases, through translating this experience to serve nursing care practice.^{21,22}

Study Aims

1. To explore lived experiences of PAC in home-based palliative care.
2. To study and inform caring for PAC in the home.

Method

This study utilized a qualitative approach to explore the experiences of PAC. Using purposive selection, researchers selected individuals for study participation based on their experiences of the phenomenon for the purpose of sharing that experience.²³ Experiences were shared through in-depth interviews from PAC, cared for at a pain control clinic, home care clinic of the National Cancer Institute, or those staying in their homes in Metropolitan Bangkok. Select FC and PHNs provided context and insight to PAC experiences through focus group discussions.

The inclusion criteria for the participants were people diagnosed with advanced cancer, located in Metropolitan Bangkok and surrounding vicinities who could communicate effectively with the researcher, and consented to participate in the study.

Data collection: In-depth interviews using open-ended dialogue were used for in-depth interviews with PAC which were tape recorded, reviewed and confirmed in follow-up interviewing. Interviews were carried out in participants' homes. During 2011 and 2012, two or three interviews were conducted per study participant. The 18 in-depth interviews each averaging 40 minutes were conducted over six months (see table 1). Field notes were recorded immediately after each interview.

Guidelines for questions in each interview were designed to elicit information about lived experiences such as; "Could you please describe your experience living with your disease? "What is your life like?" and "Please tell me about your care and how you feel about it?" Sub-questions or probing questions were sometimes used to elicit feelings about needs: "What needs/cares are most important to you?"

Focus group discussions: Focus group discussions were held at health centers with PHN who cared for PAC, had focus groups averaging one hour at mini-health centers at their convenience. A total of two focus groups were held with each FC group; the first with FC1-4, the second with FC 5-7, and there was one focus group discussion with PHN. The focus group settings were prepared in advance by the researcher for privacy and to ensure useful interviews.

A standard questionnaire was used in the focus group discussions with the seven FC and five PHN about the care for PAC. Focus group questions included such questions as, "What kind of care did you provide?" "How has this impacted your life?" Follow-up questions included, "Please tell me how you felt when you discovered that" and "So what happened next?"

Credibility and Trustworthiness: The researcher was familiar with home health care concepts and the care of those with chronic illness in families of the Thai culture. The researcher had an understanding of participants' culture, dialects and their social values as well as general home care practice, all useful throughout the interview process. Research analysis relied on narrative data and personal accounts of human experiences.²⁰ A variety of alternatives have

been suggested to evaluate analytical research.²¹ In this study, reliability checks were undertaken regarding the themes derived within completed interviews and related themes by two members of the research team. High levels of agreement were expected while any minor differences were resolved by consensus. The validity of information was verified and clarified with each participant over the course of their interviews.

Data analysis: The phenomenological approach of Martin Heidegger was used to study aspects of experience of the participants.^{14,15} Field notes and researcher observations were recorded and transcribed for content analysis. Kvale²⁰ explained this method as follows: "the researcher begins the process after the first interview by listening to the audiotapes, performing verbatim transcription, and reading the extracted transcripts to understand the hidden meanings in the text. The researcher re-examines the text with a back and forth movement of both the whole text and parts of the text to gain deeper comprehension of the emerging themes." The thoughts, daily life activities and actions of the participants related to palliative care were presented through their life story, social values, feelings and emotions, and language based on Thai custom in their home and community. Through this process, insights were gained about the beliefs, practices, and lived experiences of PAC. FC and nurse practices and roles were among the topics discussed. The optimum content from interviews was achieved when data analysis reached a point of saturation of themes from PAC's experience.

Ethical approval was provided by the Institutional Review Board of Mahidol University (Coding; MUPH 2011-075), and the Ethics Committee of the National Cancer Institute of Thailand (Coding; EC 251/2011). All participants gave their consent and were informed that they could withdraw from the project at anytime they wanted without any consequences. PAC interviews were suspended and rescheduled if the participants became sick or upset in relating their personal experience. Confidentiality of all data was explained to participants and all tape recordings of interviews and focus groups were destroyed once the project was finished.

Results

The participants with advanced cancer had a mean age of 59 with a range of 37–84 years. Five of seven had received home-based care from both PHN and FC, and two only from FC. Three participants were male and four were female. Four of seven

participants were married and their spouses were their caregivers. Two participants had brain cancer, two had stomach cancer and the others had colorectal, lung and cervical cancer. Five of them had access to universal health coverage insurance and the other two had government welfare or social security. The characteristics of the PAC are given in Table 1:

Table 1 The demographic Characteristics of the PAC.

No/ code	Age Gender	Marital status	Prior occupation	Level of education	Site of cancer	No of In-depth interview	FC	PHN*** caring
M1	68 M*	married	small trade	Elementary	stomach	3 times	wife FC1	PHN1
M2	58 M	married	wage workers	Elementary	Lung	2 times	wife FC2	PHN2
W3	58 W*	married	housewife	Elementary	stomach	3 times	husband FC3	PHN3
W4	53 W	widow	housewife	Elementary	brain	2 times	daughter FC4	PHN4
W5	84 W	widow	none	Literacy	brain	3 times	daughter in- law FC5	PHN5
W6	55 W	widow	housewife	Elementary	Cervical	2 times	Sister in-law FC6	No one
M7	37 M	married	employee	Bachelor	Colorectal	3 times	wife FC7	No one

Note; M= Male; W= Female;

The FC participants had a mean age of 42 with a range of 26–58 years. Six of seven FC were female. Four of seven were spouses, two were siblings, and another sister in-law. Most of them had an elementary education. The five female PHN participants had a mean age of 35 with a range of 32–56 years. All of them had a bachelor degree in nursing science.

Three themes emerged from PAC interviews and caregiver focus groups: State of being, Compassionate care in the Buddhist view, and QOL. Two themes emerged from PAC through in-depth interviews: State of being and QOL. The other theme emerged from PHN and FC in the focus groups: Compassionate care in the Buddhist view. In the text, participant quotes are used to illustrate the results presented in Table 2.

Table 2: The Experiences of PAC

Main Theme 1: State of being			
Theme	Suffering in dying process	End of life	
Subtheme	Physical, emotional and mental, Psychosocial and Spirituality function	Deterioration of Physical cognitive, Psychosocial, and Spirituality changed	
Main Theme 2: Compassionate care in the Buddhist view			
Theme	Holistic approach	Caregiver care	Resources and materials
Subtheme	Goal and vision sharing, Clients' problem- orientated decision making, decision making, Relationship, Communication, and trust	bereavement care and respite care	Information and equipment, materials for home health care
Main Theme 3: Quality of life			
Theme	Satisfaction in caring	Life-Satisfaction	
Subtheme	Caring meet the need, Competences, Continuity of health care providers, adjustment	Alleviated pain, surrounding their loved ones, dignity/not restrained, Religious practice, and touch in calm and peaceful (<i>decent leave all behind</i>)	

State of being

PAC experiencing suffering in dying process when approaching the end of life and often expressed their suffering in four dimensions: in physical, emotional/mental, psychosocial, and spiritual dimensions as revealed through the process of their decline. The end of life themes was crucial to the predicaments of change and decline in physical health, and psychosocial and spiritual circumstances of the PAC.

Suffering in dying process:

“I have been suffering from the side effects of treatment, I still have diarrhea and nausea, so I have increased weakness and am disheartened, but I still have relief from tension due to my daughter staying with me all the time, and also the presence of my niece. I feel happy whenever my children are around.” (W5)

W5 spoke in a whisper with a weak voice, saying it was important to maintain normal activities and be engaged even when dependent on others. The physical and emotional distress of people dying from cancer and its treatment has a significant impact on peoples' lives which can lead to difficulties in doing daily activities until the end of one's life. Severe illness affects the life of people as participants explained their physical circumstances and how these handicaps resulted in pessimistic perceptions developing. Due to family inter-relationship, one PAC expressed the wish to see her niece grow up to adulthood, so she hoped to live although she knew she could die at any time.

Likewise, negative points of view when coping with cancer progression can lead to psychosocial conditions which made two PAC feel angry like they were being punished and wished to die as expressed below:

“I feel anxious as if it (the drug) is a poison running into my body via the infusion of a venous solution” (W3)

End of life: People with advanced cancer often encounter physical, psychosocial and spiritual decline. “When your days depend greatly on others, you are valueless” said one interviewee, M7, who is the head of his family. His wife (FC7) who provided constant care for him, confirmed he wishes to regain his independence and life. On the other hand W6, who has faced declines from physical and psychosocial changes, wished to die as soon as possible as he explained:

“What should I do? You know what; I would love to die to get away from this suffering?”

When the severity of the illness increased and moved one closer to the end of life, the PAC had deteriorating physical conditions. Among those who considered they had received decent care and clear communication from caregivers, there was a spiritual change in their acceptance in leaving all behind, calmly countering fear and accepting the end of life. This means that they wish to die naturally. The two participants explained:

“I need my wife (FC1) to help me to explain to the doctor that I don't want the operation (tracheotomy). I don't want anything else. It is all the best for me” (M1)

In a positive view, he expressed that:

“I've always decided the true situation for deciding the best direction on matters relating to my life, but treatment has changed that, and it is only my luck that I have a caring spouse who can now meet my needs.” (M7)

Quality of life

QOL is perceived differently for everyone. The main thing is the ability to enjoy what one has in life. QOL for PAC derived from good care provided to them. This was revealed through two themes: Satisfaction in caring and Life satisfaction. The Satisfaction in caring theme consists of knowing that PAC needs for health care are being met through

continuity of care and provision of competent care. The Life satisfaction theme consists of PAC having their pain alleviated, being surrounded by loved ones, having one's human dignity maintained without restraint, having freedom of religious practice, and touch that calms and brings peace.

Satisfaction in caring: This should be considered to be one of the most desirable outcomes of care, even as an element of one's health status (state of being). When the severity of illness brings one close to the end of life, the last stage, PAC in this study had deteriorating experiences. Two received close care from their caregivers, very supportive care, even when they had great suffering from their health conditions. Satisfaction in caring was reflected in the following experience:

“...now that it is more serious, I’m ready, knowing that it (severity of complications and health conditions) are close and coming. It will soon arise after all. It is what we as human beings have to face. I am satisfied with the dedicated care my family members have given me.” (W5)

“She (PHN) has provided proper care, particularly when my relative has emergency signs or severe pain and becomes uncertain; when I can’t make a decision by myself...I ask her even outside office hours...I feel confident in her caring for my relative.” (FC2)

Life satisfaction: This was reflected in their state of being and favorable attitudes, and expressed through alleviation of pain, being surrounding by loved ones, dignified, unrestrained care, freedom of religious practice, and gentle treatment with a calm and peaceful touch.

“I feel good to be with my close siblings”(W5)

PAC and FC described continuity of health care at home as follows:

“...I’ve been taking care of my relative and the nurse visits our house regularly,...I feel appreciated, get good advice, even outside office hours...” (FC1)

One theme emerged from the focus groups with PHN and FC:

Compassionate care in the Buddhist view:

Caring for PAC from the perspective of formal and informal caregivers had numerous meanings and some differences. The PHN and FC care for PAC, who had experiences suffering during the dying process and at the end of life, expressed compassionate care through three subthemes in focus group discussions: the Holistic approach, Caregiver care, and Resources and materials.

Holistic approach:

Total holistic care, physical, emotional, psycho-social, and spiritual, was expressed by PAC and caregivers as below:

One PAC expressed relationships at end of life as follows:

“... due to my dreadful sickness, I cannot have daily life activities by myself. I need someone to help and understand me.” (M7)

One PAC explained their dilemma in receiving care as follows:

“Because I did not eat anything for a long time, and I threw up and had diarrhea and anorexia, the result was that my bodyweight dropped by over 10 Kg. and I nearly had cachexia. I required my wife to take care of me and stay with me all the time. Unfortunately, she cannot... she is the only source of money for my family.” (M2)

The care which one FC gave to their loved one is shown as follows:

“I took care of him providing all kinds of food as he asked, cleaned his body ... as I could, because sometimes I had to work, anyway I tried to let him know that this is his destiny

or fate and we would pass this critical period with our faith in Buddhist ritual, alms, chanting and especially by releasing sin through freeing birds or fish; believing that this merit will bring balance to his spiritual life.” (FC7)

Among the PHN, three of five explained palliative care through a holistic approach as consisting of physical, psycho-social and spiritual care, assisting with functional aspects of life, and social and family care. They expressed great importance for palliative care that home-based nurses are prepared to integrate palliative care into their practice:

“Caring for people in the last stage of life is very complex. Holistic care is required at all times... to deal with physical symptoms of the disease, such as the side effects of treatment.... Therefore, I am concerned with the needs of the patients and holistic care, making me unsure I can provide the extensive care for these patients; sometime I feel unsure that I am prepared to provide end stage of life care.” (PHN4)

“We care by understanding our client’s belief and value in the doctrines of Buddhism, and faithfulness, and having rituals for care with our clients. Some of them give alms in the morning or chant praises, some have careful consideration of their breathing in and out like in meditation, some have a little Buddha image pendant or amulet laying under their pillow” (PHN 5)

“I took care of her comfort, and she didn’t need anything more. I tried to ask for my brother (her son) to be a monk one time, because my mom had a great expectation to see her son temporarily become a monk as merit, as is Buddhist tradition.” (FC4)

The trusting relationship of PAC, their family and PHN in home-based care is revealed in these PAC experiences:

“She (FC4) came to my room and looked at me for a long time, she touched me to make me calm and told me to care for myself and ... I felt serene and confident.” (W4)

Family relationships and information are the most important for those being supported in home-based palliative care by PHN as one FC explains:

“I was given useful information about my life and health from the PHN at my times of need. I felt generosity when I ask for her idea...I could contact them (the nurses) to get help from PHN at the time I needed.” (W3)

Caregiver care: Bereavement care is considered a normal response to death and loss which is a universal human experience. It was reported that this care can help with sleep and other physical symptoms and includes using prayer and meditation.

“The FC do need bereavement care from my experience; some have high sorrow and are extremely upset.” (PHN5)

Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. The respite care subtheme emerged from PHN’s views as below:

“I suggested the main caregiver to leave for her own enjoyment to be replaced by friends/neighbors/relatives/health volunteers.” (PHN4)

Resources and materials: In PAC, resources are essential elements for support through palliative home-based care. Resources and materials include experiences with three subthemes: information, equipment, and meeting demands on time and at the right place. One caregiver explained:

“Some health materials and instruments are very expensive. We cannot afford tubes and disposable pampers which are not covered...I always receive useful information from the PHN about these needed items.” (FC1)

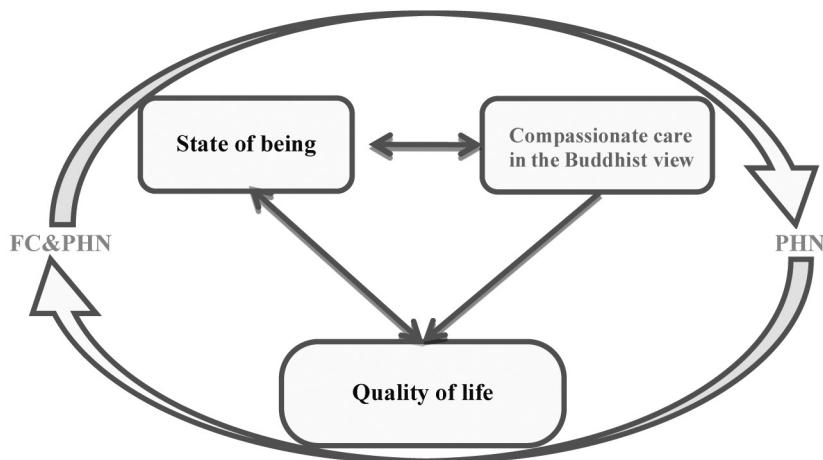


Figure 1. The major themes of experiences of PAC and caregivers are state of being, compassionate care in the Buddhist view, and quality of life.

In order to present the data more clearly for readers above, the researcher first presented only the data in each theme and subtheme that came from PAC life experience, and then from information of caregivers and the researcher's observations. This draws on the three themes: state of being, compassionate care in the Buddhist view and QOL. The state of being directly interacts with compassionate care in the Buddhist view and QOL, while compassionate care in the Buddhist view directly affects one's QOL. In the same way, the effect of caring and support from PHN and FC increases QOL. Finally, caring and its consequences for PAC were summarized and the constitutive patterns of the three main themes emerge as state of being, compassionate care, and QOL.

Discussion

The results from considering the experiences of PAC and caregivers views brought forward three themes. State of being and QOL were revealed by PAC. Compassionate care in the Buddhist view grew more out of caregiver discussions in the focus groups. In this study, PAC, FC and PHN had two to three sessions (in-depth or focus group), which provided

enough time for the researcher to consider the themes emerging from these encounters, and to confirm them in subsequent sessions. This resulted in prolonged engagement and the establishment of trust.^{21,22} During the data collection processes the researcher observed the participant's behaviours, expressions and the surrounding environment. These observations were recorded in field notes at the end of each session. This technique achieved credible, persistent observation.¹⁹ The twice conducted in-depth interviews and focus sessions provided an opportunity for the researcher to clarify important points from the previous sessions that may have been unclear. Multiple interviews of PAC served as a way to achieve trustworthiness in providing shared experiences. State of being and QOL revealed by PAC are discussed below:

For the participants in this study suffering in the dying process was evident in the sub-themes of physical and cognitive, psychosocial, and spiritual function. Most PAC talked of the dying process consisting of two areas: deteriorated physical and cognitive function, and psychosocial and spiritual changes.

The functions in state of being in the results are consistent with the comprehensive assessment of the end of life, which Emanuel²⁴ stated in four dimensions. Although the content of results look like the comprehensive assessment that Emanuel stated, in some ways they are not the same.

Suffering in dying process as to physical and cognitive function of PAC changed overtime due to the severity of cancer progression and the effect of treatment. PAC were alert to and awakened to declines, perceived in suffering from changes in level of consciousness. In home-based care, PAC usually chose alternative or comprehensive forms of healing¹¹ such as acupuncture or herbs. However, PAC did not choose to eat “Kong-slang” (meaning injurious food) such as pickled fish that they felt compromised their physical condition, in order to maintain a better QOL.¹¹ The optimum challenge for PAC, FC, and PHN was to share their experiences, needs, and values with each other.

The meanings among PAC varied from hope in the sense of acceptance to die to a hope for death to a refusal to die based on addressing their beliefs and values in Buddhist religious doctrines.

Life satisfaction was seen when PAC had their pain alleviated through being surrounded by their loved ones. PAC, who choose not to be restrained or have an operation, sometimes seemed to retain their power and autonomy. Touch to bring calm and peace can be important in the end of life stage. The result is congruence with a good death, as stated by many educators and researchers, and as mentioned by the Institute of Medicine’s committee on the end of life care.²⁵

Some research provides different viewpoints regarding the dimensions of QOL. Wyatt & Friedman^{26,27} identified various views of QOL; most researchers generally agree that QOL is multidimensional, subjective, and related to a state of physical, psychosocial, and spiritual well-being.²⁸ However, FC sometimes expressed QOL in other ways, such as in the positive

satisfaction in meeting care needs for PAC. Furthermore, some nurse researchers use QOL together with life satisfaction, adaptation, health, and caring for PAC and their FC.²⁹

Regarding the theme compassionate care in the Buddhist view, nurses are concerned to improve FC behavior by teaching and demonstration, application, new knowledge and sharing experiences with them.³⁰ In the case of a new FC, nurses have to coach and counsel about the dying process and end of life challenges.

Nurses’ responsibilities include appropriate cultural care, support for maintaining a safe physical and psychosocial environment, and enhancing the education of FC to identify and coordinate care to protect each patient’s human rights.

FC and those with advanced cancer do need information resulting in support to face existential circumstances. FC took care of their PAC relatives mostly through providing physical and spiritual care, but also gave emotional and social support. This study was based on the research methods of Martin Heidegger.^{15,31} He investigated themes in his works focusing on man’s ability to face existential anxiety, guilt and death.

Caregiver care sub-themes included respite care with different views among nurses, caregivers and PAC. This sub-theme is clear in the actions of PHN5 who encouraged other family members, health volunteers, and neighbors to have time away from caregiving. This is particularly useful for increased FC morale and is congruent with Froggatt, and Parker³² who emphasized that caregivers need respite care, the time for themselves away from the care setting and for pleasure. They also often lack sufficient time to relax and sleep.³³ Families have to find alternative caregivers when the primary, existing caregiver is too exhausted to continue.³⁴

The experience of one who has lost a relative and has depression, propels the concept of family role after a loss. PHN must provide bereavement care to surviving family. In Thai culture and the Buddhist

religion, after the loss of a loved one, there are many complex and busy rituals; in the morning of the first seven days, family members will give alms and invite monks and priests to pray for the dead.¹¹ The forty-ninth day and the one-hundredth day, they also give alms and invite monks and priests to pray again, to heal emotional grief and sorrow from the recent experience of the end of life struggle with their relative. Thais' beliefs and rituals like mental and spiritual support from family members' gratitude help to bring PAC to peace and dignity.

In the West, respite care and bereavement care is commonly provided by nurses³², but in Thailand PAC always expect care and compassion from their relatives more than from nurses.⁶ The care for PAC can be a fragile matter due to the beliefs and faith of PAC; it cannot be viewed as a rigid construct of caring for every PAC through just one model of caring.

The relationships among the three themes are reciprocal. Starting from QOL, one might see positive or negative experience derived from compassionate care and state of being. From another direction, compassionate care interacts with state of being and has a direct effect on QOL. The goal of palliative care is a QOL for PAC and their families.^{27,34} This view is consistent with that seen in the study by Tornoe, Danbolt, Vigne, and Sorlie³⁵ who proposed that QOL is composed of well-being in physical, psychosocial, and spiritual function. The result of their study confirms previous studies and research. Suree Lemongkol³⁶ also mentions nurses' roles in palliative care with consequences for QOL. The functions of state of being in the results of this study are congruent with a comprehensive assessment at one's end of life, Emanuel's statement of the four dimensions as physical, psychological, social, and spiritual.^{11, 24, 37, 38}

Limitations of this study

The PAC in this study were compromised, dependent individuals and their experiences must be

understood with sensitivity to human rights and the culture of Thailand. Researchers doing further study in this area should consider this a challenge and opportunity. This study has provided valuable results for nursing practice in palliative care. Future studies are needed to gain a better understanding of the ways nurses can aid those with advanced cancer and their caregivers in the home care environment and to include multidisciplinary health care professionals who are involved in caring for them. For these people want to have social interaction and support from friends and familiar relatives. In the limited focus group discussions, we had a great deal of verbal and nonverbal data which was challenging to confirm and summarize and which should be investigated further. Future studies are needed to gain a better understanding of the ways nurses can aid those with advanced cancer and their caregivers in the home care environment.

Conclusions and Implications for Nursing Practice

The PAC who stays at home usually receives some on-going domestic health care services provided by PHN of local health centers and/or ambulatory services. However, not all PAC have access to such care. Some may only receive care from FC. PAC and their FC need more health care services such as palliative care. So the improvement of community and home-based programs to include palliative care services is needed. Insights from people's experiences with palliative care at home inform nursing practice.³³ Experiences of PAC in this study support palliative care services since PHN can better understand the dynamic nature of providing effective palliative care to individuals and families in their communities. It is important to understand the complexity of distress facing people at the end of life to inform an appreciation for every life. Compassionate care is a fragile balance between acknowledging the beliefs and faith of people confronting multiple human needs. It is difficult to assess and takes an ongoing and critical investigation for improvement.

Conflict of Interests

The authors declare no conflicts of interest in this research.

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ประสบการณ์ของผู้เป็นมะเร็งระยะลุกเล็กที่ได้รับการดูแลแบบประคับประคองที่บ้าน

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บทคัดย่อ: ผู้เป็นมะเร็งระยะลุกเล็กที่ได้รับการดูแลแบบประคับประคองที่บ้านมีจำนวนเพิ่มขึ้นอย่างมาก ในประเทศไทย การศึกษานี้มีวัตถุประสงค์ เพื่อศึกษาประสบการณ์ของผู้เป็นมะเร็งระยะลุกเล็กที่ได้รับการดูแลแบบประคับประคองที่บ้าน และการดูแลสำหรับผู้เป็นมะเร็งระยะลุกเล็ก การวิจัยนี้เป็นการศึกษาเชิงประยุกต์การณ์วิทยาที่บรรยายรวมข้อมูลในปี พ.ศ. 2554-2555 ผู้ให้ข้อมูลคือผู้เป็นมะเร็งระยะลุกเล็กจำนวน 7 ราย โดยการสัมภาษณ์แบบเจาะลึก สำหรับผู้ดูแลในครอบครัว จำนวน 7 ราย และพยาบาลสาธารณสุข จำนวน 5 ราย โดยการอภิปรายกลุ่มย่อย การศึกษาพบว่าผู้เป็นมะเร็งระยะลุกเล็กให้ความหมายชุดรูปแบบ 3 ชุด คือ 1) สภาพความเป็นอยู่ประจำตัว กระบวนการใกล้ตัวและระยะห่างของชีวิต 2) คุณภาพชีวิต เป็นความพึงพอใจในชีวิต และความพึงพอใจในการดูแลที่ได้รับ และ 3) การดูแลด้วยความเมตตากรุณาในมุมมองพุทธศาสนา เป็นการดูแลเบื้องต้นรวมการดูแลช่วยเหลือผู้ดูแล การสนับสนุนทรัพยากรด้านวัสดุอุปกรณ์ การดูแลแบบประคับประคองสามารถถอดส่วนร่วมคุณภาพชีวิตของผู้ที่เป็นมะเร็งระยะลุกเล็กด้วยการดูแลแบบองค์รวม ท่ามกลางวัฒนธรรมที่เน้นความสุขจากการดูแลและพยาบาล

ผลการวิจัยครั้งนี้พบว่าผู้เป็นมะเร็งและญาติสามารถเผชิญกับภาวะวิกฤตอย่างสงบและมีคัดค้าน ประสบการณ์ของผู้เป็นมะเร็งระยะลุกเล็ก การดูแลจากพยาบาลและผู้ดูแลช่วยให้ผู้เป็นมะเร็งระยะลุกเล็กบรรเทาอาการทุกข์ทรมานและมีคุณภาพชีวิต

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