Caring for Terminally Ill Persons with Cancer: Experiences of Thai Buddhist Family Caregivers

Wipa Wiseso, Warunee Fongkaew, Nitaya Pinyokham, Jude Spiers*

Abstract: Previous studies about family caregivers of terminally ill persons with cancer in Thailand focused on primary caregivers individually. In order to promote family well-being, it is essential to explore how individuals' construct the perspective of the family as a unit in caregiving. This study aimed to gain an understanding of the experiences of family members in caring for terminally ill persons with cancer in the Thai cultural context. The design was a qualitative focused ethnography. Purposive sampling was used to recruit 30 individuals from 13 families. Data were generated through participant observation and in-depth interviews and were analyzed using thematic analysis.

Participants discussed how family values and shared expectations were reflected in their caregiving practices as a family. Experiences of Thai families in caring were reflected in two major themes: 1) *promoting comfort and preparing for a peaceful death* by respecting the patient's wishes, valuing patients as dearly loved, understanding death is a natural law in life, performing religious activities to compensate bad karma, and arranging a calm environment, and 2) *mutually managing care* by providing care wholeheartedly, reprioritizing life plans, sharing responsibilities for caring, and managing family finances. These findings provide essential information to understand how individual family members work as a unit in caregiving practices. Understanding the experiences of family members in caring for terminally ill persons with cancer can contribute to the further development of health care services for promoting family well-being.

Pacific Rim Int J Nurs Res 2017; 21(4) 317-330

Keywords: Caregiving, Focused Ethnography, Terminally Ill Persons with Cancer, Thai Family

Introduction

Family caregivers have major responsibilities in caring for terminally ill persons with cancer.[1, 2] They are involved not only during the diagnostic and treatment phases of care, but also across the care trajectory until the patient's death.[1] When a family member is confronted with a terminal illness, their imminent death is a critical point, and the homeostasis of the family system is affected.[3] Previous studies

Correspondence to:* Wipa Wiseso, *RN, PhD (Candidate), Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, Chiang Mai, 50200 and Assistant Professor Faculty of Nursing, Burapha University Chonburi, 20131Thailand.* ***E-mail:*** *wi_wiseso@hotmail.co.th*
Warunee Fongkaew, *RN, PhD, Professor, Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, 50200 Thailand.* ***E-mail:*** *warunee.fo@gmail.com*
Nitaya Pinyokham, *RN, PhD, Assistant Professor, Faculty of Nursing, Chiang Mai University, 110 Intawaroros Road, Muang District, 50200 Thailand.* ***E-mail:*** *npinyo13@gmail.com*
Jude Spiers, *RN, PhD, Associate Professor, Faculty of Nursing, University of Alberta, 11405-87 Avenue, Edmonton, Alberta, T6G 1C9 Canada.* ***E-mail:*** *jude.spiers@ualberta.ca*

indicate that cancer-related end of life caregiving has both positive and negative significant impact on family caregivers' well-being in physical, psychological, social, occupational, financial, and spiritual realms.[4, 5, 6, 7] The negative impact includes sleep disturbance and deterioration of the caregivers' health; grief and loss, caregiving burden, and caregiver depression as well as social burden.[2, 4, 5, 6] Family caregivers face difficulties managing regular employment, difficulties in managing economic status, and loss of motivation and purpose of living.[8, 9, 10, 11] The looming loss of a family member is a tremendous challenge; the family must try to find a new equilibrium during the illness to maintain both individual and family health.[3] The positive aspects on the other hand, include having shown love and responsibility as well as a feeling of reward and a sense of accomplishment.[5] These impacts are found in studies of family caregivers in Western and other cultures and are based on investigating individual primary family caregiver experiences.[12]

However, families in different cultures also have differing interpretations of meaning and experience in caring for terminally ill persons.[13, 14, 15] In Thailand, strong intergenerational relationships based on cultural values and norms around interdependence, respect and reciprocity mean that when someone in family has an illness, other members from different generations will support the sick family member.[3] Cultural values such filial piety are an important part of many Asian cultures including Thai culture.[16] Filial responsibility, a strong cultural norm, may be beneficial for caregiver self-rated health and well-being.[17] Additionally, Buddhism, the major religion in Thailand, influences values and practices that Buddhist family members tend to work together in providing care to support achievement of a peaceful death.[18] As a result, cultural values and religion can be expected to affect the Thai family function as well as traditional family practices for persons with terminal illness.

In order to understand the experience for the whole family, an individual caregiver's points of view cannot fully represent the experiences of the family as a unit. Conversely, an individual member cannot be understood outside of the parts of the family.[3] Therefore, how these parts relate, communicate, and act are important to the overall understanding of the family as a whole within the context of Thai culture.

Study aim

The purpose of this study was to explore the experiences of family caregivers and their perceptions of how Buddhist Thai families function in caring for terminally ill persons with cancer.

Theoretical framework

In this study, family caregivers were viewed in the context of the family as a unit. Family System Theory[3] offers a way to understand experiences of family in providing care for terminally ill persons with cancer in component of holism and homeostasis. Family is seen as an interactive unit, for no individual member exists in isolation from another. Describing a family using its key subsystems can provide an insight into family members' interaction patterns and reactions to certain events.[3] Any significant change or event in one family member affects all the family members. Hence, when a family member is diagnosed with a terminal illness, the family has to reorganize itself. The individual members and the unit as a whole may not function as they previously had. Therefore, we used concepts of holistic system and family homeostasis from Family System Theory as sensitizing concepts to inform the research questions and find direction for collecting and interpreting the data. As the study progressed, we carefully examined how this framework was useful in initiating interpretation and the points at which the uniqueness of the Thai cultural context meant the concepts were no longer appropriate.

Methods

Study design

A focused ethnographic approach was the methodology employed in this study. This is an adaptation of classic ethnography commonly employed in nursing and health care research.[19] Our assumption was that by virtue of Thai culture and dominant religion as well as commonalities within the subculture of cancer and palliative treatment and care, we would find similarities in perspectives, expectations, and practices amongst the group of family caregivers. This method is characterized by a predefined problem (family caregiving, a clinical issue identified as needing Thai-specific investigation to inform clinical interventions), a researcher with insider or background knowledge of the cultural group (the Principal Investigator (PI) is an oncology nurse), short-term field work with intensive data collection and privileging of specific forms of data (in this study, interviews).[19, 20] In this article, we report primarily the findings from the interview data.

Study setting

The setting for this study was a major regional cancer hospital in Eastern province of Thailand and the patients' homes.

Participants

Purposive sampling was guided by inclusion criteria consisting of family caregivers who cared for family member with terminal cancer for at least one month, >18 years, able to communicate in Thai, and self-identified as Buddhist. Family members had to live in the same household. Inclusion criteria for patients were people diagnosed with any kind of terminal cancer, of any age, and who had family members as caregivers. Recruitment was facilitated by palliative care nurses introducing the PI to the patients and families.

Data Collection Procedures

Observational and semi-structured interview data provided a view of the family caregiving experiences through more than one vantage point[21] to illuminate how the family's norms, expectations, values and behaviors around caregiving were constructed and perceived by the individual family members. The PI shadowed palliative care nurses to get to know potential participant families. Once rapport and trust were established, the PI reviewed the research procedure and obtained informed consent of individual family members. In the process of informed consent of family members, the PI asked the first family member who was interviewed to speak to the other family members who met the inclusion criteria and to ask if they wanted to participate in the study.

To complement the interview data, the PI asked for permission to observe family caregiving activities at the hospital and at home approximately two to four times, either at home or in hospital. This was to familiarize the PI with the types and range of caregiving activities, and to inform the interviews that explored participants' values and practices. Observations focused on family activities and interactions between the family members who participated in caring. Each observational period was approximately two hours and was recorded with written descriptive field notes.

Individual in-depth semi-structured interviews in Thai language with family caregivers were conducted with at least two to three family members in each family. The interviews were semi-structured in that they consisted of a range of flexibly employed broad open-ended questions and probes about the participants' perceptions, family caregiving activities, and participation of family members in providing care. For example 'Within your family, can you tell me who participated in caring for your loved one?' 'How was caregiving organized?' 'How has your family adjusted to these caregiving needs and activities?' 'How do you, and your family feel about participating in caring?' 'How have you all as individuals come to consensus about what needs to be done and what your loved one, and the family wants?' The interview protocol evolved throughout the study as data analysis informed future areas of interest. Follow up interviews were requested when there was need for extra exploration into specific areas following data analysis. Individual interviews permitted exploration of sensitive topics by promoting the confidential disclosure of individual narratives without the immediate influence from other family members. All interviews lasted for approximately 90 minutes and were digitally recorded. Data collection continued until analytic redundancy occurred [20] and no new information contributing to theoretical categories was forthcoming.

Data Analysis

Recorded interviews were transcribed verbatim in Thai and then analyzed by family group using thematic analysis procedures described by Braun and Clarke.[22] The PI was the primary analyst. Each line of each transcript was reviewed for meaningful and significant statements. Codes relevant to each family were developed and constantly compared and contrasted within and across families. Following this initial analysis, we re-focused the analysis at the broader level of categories and themes. Mind-maps were used to explore relationships between categories and themes within and across families. This produced a collection of candidate themes that were then analyzed to clarify meaningful coherence to distinguish relationships and distinctions among the themes. Reviewing and refining categories and themes continued until the thematic map was complete and the final themes and categories were clearly described.

Themes reflected the participants' interpretations of the meanings of the family experience of caregiving. We looked for the ways individuals spoke about "we" as the family and how data from individuals were similar within the family. Similar ideas (for example, a wife and the mother of a man in one family both talked about how they individually discussed approaching death and ways they supported him in thinking about dying) were interpreted as reflecting the family's values and practices. Attention was paid to when data seemed to reflect the individual and not the family.

All participant quotes included in final reports were translated into English and back-translated for accuracy. The analysis process was regularly discussed by the supervisory committee and a group of experts and any disagreements in interpretation were resolved through consensus.

Trustworthiness

Criteria of credibility, transferability, dependability, and confirmability which accumulatively contribute to trustworthiness[23] were employed to ensure the rigor of the study. Engagement in establishing rapport and spending time immersed in family activities was key to establishing credibility. Iterative verification of emerging themes throughout data collection ensured interpretations were accurate and when there might need to be further investigation of new dimensions or themes.[24] The PI conducted member checking by sharing and discussing the interpretation reports with three families. Confirmability was enhanced through debriefing data collection and analysis with advisory committee and sharing emerging ideas, codes, and interpretations. This helped ensure quality decision-making processes and to check the consistency of inferences and the development of codes/categories and themes during the analysis process. To ensure dependability, the analysis process was regularly reviewed by the advisory committee and a group of experts.

Reflexivity via team discussions and researcher diaries supported understanding of how the researcher as research instrument influenced all aspects of the research process. In particular, as the PI was an oncology nurse, exploring how data reflected or contradicted her own experiential knowledge was important to ensure all possible meanings in the data were considered. Dense descriptions of themes and use of quotes allows readers to determine transferability.

Ethical Considerations

This study was approved by the Faculty of Nursing, Chiang Mai University Ethics Review Board (Approval number 106-2014) and the clinical agency. All participants completed written consent procedures. Data collection, management and analysis processes met ethical standards of confidentiality and security.

Findings

Thirteen families, giving a total of 30 individual family caregivers, participated in the study. There was a range of two to four participants for each family. Seven patients of the 13 families were discharged from hospital to their homes in the study timeline. Most families were nuclear families (n=8). Characteristic of family caregivers was divided into 4 sub-groups: 1) Son/daughter providing care for a parent (n=13); 2) Parents providing care for a son/daughter (n=5); 3) Spouse providing care for a partner (n=8); and 4) Siblings providing care for a sister/brother (n=4). Most families had a fair economic status in that incomes ranged from 10,000-20,000 baht per month (US $290 - $580 per month) (n=7) and incurred monthly caregiving costs of 5,000-10,000 baht per month (US $145 - $290 per month). Most participants were female, married, and between 31 – 60 years of age.

The findings of this study are presented in two major themes: 1) promoting comfort and preparing for a peaceful death, and 2) mutually managing care. Each of these themes are discussed below:

Promoting Comfort and Preparing for a Peaceful Death

The ways in which family caregivers promoted comfort and prepared for a peaceful death for someone with terminal cancer were respecting patient's wishes, valuing patients as dearly loved, understanding death is a natural law in life, performing religious activities to compensate bad karma, and arranging calm environment.

Respecting patient's wishes

Family members collectively and mutually oriented to decisions that promoted a peaceful death by agreeing not to prolong life-sustaining treatments and transferring their loved one to provide care at home so they could die peacefully. Families often decided not to choose resuscitation efforts because they did not want to prolong suffering. They wanted their loved one to die in a peaceful state, without any suffering, as a daughter caregiver and husband of one family both said:

> *... She will only suffer if we try to sustain her life. We don't want her to suffer... I agree with that. Giving her resuscitation will only bruise her chest ... it's better to let her go in peace. So, our family has decided not to resuscitate her.* (Family 13: 19-year-old daughter)

> *...My children and I insist on not giving her any resuscitation or any puncture. We want her to go in peace, without any suffering.* (Family 13: 54-year-old husband)

Families agreed to transfer their loved one to provide care at home for a peaceful death. Families decided to honor the wishes of their loved one to be at home with the family. They would offer the best care possible until the end, to allow their loved one to be happy in his/her last moments of life and die peacefully. The following quote illuminates how the older sisters who cared for their brother of one family came to this decision:

> *We talk together; our brother [ill person] wants to go back home to stay with family. Our family had agreed, so we have to look after his symptomatically at home.* (Family 9: 59-year-old older sister)

> *...He tells us not to take him anywhere. He doesn't want to leave home. It feels good to do as he asked us to -- bringing him home into the arms of family. We do as he asks us to do, to make him happy at home in his last moments to go in peace.* (Family 9: 56-year-old older sister)

Valuing patients as dearly loved

Observational and interview data corroborated how family members endeavored to stay close to the ill person's side. Families believed that being with patients their presence and company would reduce their loved one's stress. This caring contributed to family bonding which in turn allowed the ill person to feel loved. A wife and a mother who cared for her son of one family described it in this way:

> *We never leave him alone... He will not feel stressed out because we never leave him... It's like living one minute at a time. It makes him feel loved.* (Family 3: 37-year-old wife)
>
> *....We do everything to make him feel that he has not been abandoned. We are together all day and night. He feels he is doing as he said, coming home in the bosom of his parents' arms ...it feels good to be together.* (Family 3: 69-year-old mother)

Families encouraged their loved one by talking, touching through warm embraces, as well as being with the family. Some families gave encouragement to their loved one by saying nice things and avoiding topics that caused stress and that might worsen the illness. They felt that they could provide mental support through hugging which communicated their love and let the loved one know that the family would always stay by his/her side, as this mother said:

> *...I hug her. ... This is like giving [daughter] some mental support, to make her feel loved and know that we are still here.* (Family 12: A 68-year-old mother)

The values of positive demonstrations of love were reiterated by another family member, the sister of the ill person said:

> *....We should avoid saying things that are not supposed to be said. We shouldn't cause any stress. She may get worse. We should say something nice.* (Family 12: 38- year-old younger sister)

Understanding death is a natural law in life

Families believed that talking with their ill family member about accepting death could help them to gain a calmer mind about their approaching death. This would then help the ill person die in peace when the time came. A wife and a mother in one family described their individual conversations that reflected similar values and beliefs about the inevitability of death and that it was not to be feared:

> *I tell him that no one can run away from death. We have to accept it. It's just a matter of time. I want him to accept what is going on here, so he won't be stressed out. ...He can accept it when the time comes. He has to be calm so he can go without suffering. He can go with peace.* (Family 3: 35-year-old wife)
>
> *....I tell him not to be afraid of death. Death is like a quick transfer to another dimension. It will be like once we die, we will be instantly reborn. I want to give him moral uplift.* (Family 3: 69-year-old mother)

Performing religious activities to compensate bad karma

Thai cultural norms and values around responsibilities to each other created a strong context for caregiving beliefs and practices. Family beliefs are traditional or cultural values that are passed on from generation to generation within Thai families. In context of Thai family, religion played an important role in caregiving practices. Buddhist beliefs meant that most families believed that their family member was suffering as the consequence of his or her past deeds and that the illness was caused by karma. In Buddhism, karma refers to good or bad luck resulting from past actions that determines future fate. Therefore, family members as individuals endeavored to "make merit" that served as offerings to the Buddha in order to seek forgiveness for their ill family member's past bad deeds and to counteract the offense caused by these bad deeds. The daughters of one family who cared for their father described:

> *...I believe that everything in our lives happens as a consequence of our karma, whether it's bad or good karma. So, what my father is facing now is caused by his own karma. I try to make*

> *merits for him by saving animals. He may have caused some suffering to some animals to make a living when he was younger.* (Family 11: 40-year-old daughter)

> *... I pray for whomever our father might have offended. I pray for our father because he has killed a lot of animals. He provided for his family by catching fish and crab. I believe in this.* (Family 11: 37-year-old daughter)

Arranging calm environment

Families arranged the environment to promote comfort by creating room for their ill family members. Research observations of the family home environment revealed that families strove to make the environment work for both caregiving activities and to ensure the comfort of their ill family member. Caregivers stayed near, preparing equipment for supporting care at home. Some families built an extra extension to the house for their loved one so that caregivers could stay nearby for helping each other in caring. In one family, the wife and daughter who cared for her father described:

> *...We built the additional room for him* [husband]. *... It is convenient to care for him during the nighttime.* (Family 7: 47-year-old wife)

> *... He [father] is very tired, so we moved to be closer to [father] by creating new room for staying near him. My mother can call me if she needs some help.* (Family 7: 25-year-old daughter)

Typically, the family ensured comfort for their loved one by providing a hospital bed and wheelchair to make caregiving activities and movement easier, as two daughters caring for their mother described:

> *We want her to feel comfort and can move easily. These make our mother feel comfortable and also make it convenient to care.* (Family 4: 39-year-old daughter)

> *...Our mother feels more comfortable on this bed when she sleeps or sits up.... The wheel chair makes it convenient to move her to see views out of the house.* (Family 4: 33-year-old daughter)

A comforting environment was one that also supported Buddhist spiritual bonds for a peaceful death. There was generally a Buddhist shrine in the ill family member's room. Families offered Buddhist spiritual bonds to promote a peaceful mind. Dharma in Buddhism refers to the teachings of Buddha about fundamental principles that are relied upon for lasting happiness. They offered their loved one dharma books to help their loved ones understand the sickness and to help them calm their minds in their last moments of life. The parents caring for their son each explained the role of dharma as follows:

> *It's the Buddha's image of his birthday. It's a spiritual belief. I want him to see the dharma and be calm in the last moments of life. So, there is peace in his mind.* (Family 3: 69-year-old mother)

> *...I show him some dharma books. I bring them to him to read or pray with...I want to let him know suffering and sickness.* (Family 3: 71-year-old father)

Mutually Managing Care

Families mutually managed caregiving based on common values and practices for their loved one by providing care wholeheartedly, reprioritizing their individual life plans, sharing responsibilities for caring, and managing family finances.

Providing care wholeheartedly

Families provided care for their loved one with wholeheartedness conceptualizes the a strong value of the loving bonds between family members based on cultural values of strong interdependence, duty and love, often known as filial piety. It was seen in the caring relationships of children caring for parents and parents caring for a dying child. Families consisting of son/daughter caregivers expressed that providing care for their parent was a time to be grateful to the parent. Parents were regarded as the "Buddha monk of the family". Children were taught that in Thai culture, parents should come before other people. This encouraged sons and daughters to wholeheartedly provide care for their parent, as two daughters of one family who cared for their mother described:

> *My parent has always taught me to be grateful to the parent first. They [parents] are regarded as the Buddha monk of the house ... I do everything with all my heart.* (Family 4: 33-year-old daughter)

> *...because we only have our parent and because we have been taught to take a good care of our parent. The most important thing is our parent. ... I try to take care as much as I can.* (Family 4: 20-year-old daughter)

Similarly families consisting of parents caring for their child universally believed strongly in care based on a strong value of a parent-child loving bond. They saw their child as their "heart and soul". They thought the love for each other within the family was unique to each family. Therefore, they had to do their best in caring for their child, as the parents who cared for their daughter described:

> *...My daughter is like my other life. ... I'll give her what she wants because she is my heart's love and soul.* (Family 10: 58-year-old father)

> *...because of my duty as I was her mother. I love her. Love depends on each person and each family. Each family is different. This is what our family does to best care for her.* (Family 10: 52-year-old mother)

Reprioritizing life plan

Caring was a personal, or individual devotion that contributed to the family as a whole. This devotion meant individual family members abandoned their educational and career opportunities to enable the family to care for their loved one and also survive financially. Some participants changed their future education and career goals in order to prioritize caring for their family member. They perceived this was temporary and they could return to their original plans later as a daughter caregiver in one family explained:

> *I had to put the plan to continue my study on hold. My goal changed, I don't know now about my future. I want to provide care for my mother first. I can go back to study whenever I want to.* (Family 13: 19-year-old daughter)

They rationalized it as the life of their loved one was finite but there would always be future opportunities to earn money. This is how a daughter caregiver explained:

> *I applied for positions at a factory, but I put everything on hold for my mother. This feels much better than making money because money is something we can always make, but we cannot remake lives.* (Family 5: 25-year-old daughter)

Sharing responsibilities for caring

Families shared responsibility for caring by switching care duties during the day and night and dividing responsibilities for caregiving activities, as a wife and the son of a man described:

> *Sometimes I need to take turns with [my son] so I can go to sleep. [Son] does the day shift. I do the night shift. Sometimes [daughter and son] help each other, so I can have a full rest in the daytime.* (Family 2: 52-year-old wife)

> *If he is in hospital for many days, my mother will come to take turn with me. We help each other take care of him, so I have time to rest.* (Family 2: 29-year-old son)

Family members also collaboratively decided who should hold main responsibility for earning money to support the family while others took primary responsibility for caregiving. Two daughters of one family who cared for their father explained how they decided on caregiving and employment roles:

> *We have planned to allow my older sister to concentrate on her work. I can stay with my father every day. I take turn with my older sister who comes to help me on her day off.... When my sister is around, I go to work.* (Family 11: 37-year-old daughter)

> *....My younger sister has not full-time job so she is the one with the biggest responsibility to care for father. On my day off, I always come, so that my younger sister can go to work.* (Family 11: 40-year-old daughter)

Managing family finances

Families mutually managed finances by dividing earning and caregiving tasks. This allowed them to save the costs of hiring professional caregivers, as a wife and daughter caregiver in one family explained:

> *We can't afford to hire anyone to do it. It's expensive. So, we take turns to help each other.* (Family 2: 52-year-old wife)

> *... If we hired someone else, it would cost us money. We can do this on our own.* (Family 2: 23-year-old daughter)

Participants indicated they solved financial problems cooperating and sharing caregiving responsibilities within the family. For example, one family decided that only one family member should stay at the hospital to take care of their loved one and other members would take their turns on the non-work days as this wife and daughter caregiver described:

> *I decided to stay here [hospital] to save the cost within my family. If I decide to go back and forth, the cost will be increased. If someone else came here with me, then we would have to pay more. We have to lower our expenses.* (Family 6: 60-year-old wife)

> *...We decided to let only my mother to stay here to take care of my father and I will take my turn on Saturday and Sunday. That helps save some money.* (Family 6: 35-year-old daughter)

Participants stated that within their families, it was understood that members who had left their jobs planned return to work in order to be able to support the family financially in the future:

> *...My youngest daughter says that if she doesn't work, how can we get the money? So she will go to work* [after the ill person's death] *and she can send money back to me.* (Family 12: 68-year-old mother)

> *...I am thinking about going back to work. Therefore, I will be able to support the family financially.* (Family 12: 38-year-old younger sister)

Discussion

In this study, individual members in families perceived and agreed upon how the family as a unit held particular beliefs and values that guided their caregiving roles and responsibilities. These beliefs were strongly situated within Buddhist philosophy and reflected strong norms of filial piety and family responsibility for the well-being of each other. When a family member becomes ill, the individuals cooperate to find ways to manage caring in order to support their loved one as they moved toward a peaceful death. Even while they dealt with the physical and emotional dimensions of dying, the values of traditional culture and religion helped the family as a whole to promote comfort and prepare for a peaceful death in the dying process of one of their members.

Family members provide care wholeheartedly and reprioritizing their life plans because of their values and practices that reflected their devotion of their personal lives to caring their loved one. It reflects the loving bonds between parents and children. This is congruent with previous cultural studies in Thailand that indicate that providing care for a person with terminally ill cancer may generate positive aspects including a sense of obligation, gratitude, and humanity.[5] This study illuminated that the unique of context of Thai family caregiving is intimately based on the concept of filial piety: being grateful to parents who are regarded as the "Buddha monk" of the family. Filial piety is rooted in the Thai cultural concept of *bunkhun* which is "a deeply ingrained relational pattern with ancient roots in Thai society".[25, p.90] This strong cultural value influences the nature of intergenerational relationships in Thai culture. Filial piety is characterized by respect, honor, fidelity, devotion, dutifulness, and sacrifice on the part of child which motivates children to take care of their parents.[26] Filial piety is a key cultural concept in understanding how intergenerational relationships influence attitudes and behaviors of family caregivers.

This study also illuminated how families oriented their caregiving based on their mutually held religious values that a peaceful death was important. Families found ways to promote comfort and prepare their loved one for a peaceful death. While some processes and strategies, such as respecting the ill person's, demonstrating how valued and loved the person is universal across cultures, Thai and Buddhist values strongly reinforced norms that dying was a natural law in life so there was little need for drastic life prolonging measures, and that there was need to perform religious activities to compensate for their loved one's bad karma. Valuing a peaceful death was also why these families wanted to transfer their loved ones home so that they could provide care in an environment that would contribute to a peaceful death. This finding supports previous studies where Thai Buddhist families decide to forgo life-sustaining treatment because of a fear of suffering from treatment. In Buddhist belief systems, death is a fact of life and is inevitable.[27] A good death is a peaceful death, in which all members are able to accept the impending death. A good death is characterized by being with family members, dying at home, using religion as a refuge, and caring with a heart.[28] Caring based on the dying person's needs and wishes and family participation in care are core factors to enhance caring toward a peaceful death.[29] Thai family members gain a sense of accomplishment in fulfilling the final wishes of their loved one.[30] Families perceived that spending time with family at home, maintaining hope and enjoyment, and environmental comfort would contribute to achieving good death in terminally ill people.[31] Family members were the best people to provide emotional support through their presence.[32] As with previous research, our study found that families relied on their religious and spiritual beliefs and practices and used them as coping resources to transcend suffering which helped them can find a new balance in dying experiences and harmonized their plan of care with their belief systems.[33]

The findings of this study explored how individuals in families mutually managed their caring by sharing responsibilities for caring and managing family finances. Individual roles and commitments, particularly around working and pursuing education were negotiated and frequently, individual goals and needs were foresworn in order to prioritize caregiving.[34] As a result, caregiving was coordinated and caregiving responsibilities were shared to balance burdens and provide the best care possible. Unfortunately, as is commonly found, there are consequences for individual health and wellness and financial security.[35] Our study demonstrated how individuals reflect the valuing of family over individual needs in the organization of caregiving. Thai culture, being more oriented toward family than more individualistic Western cultures means that health care providers need to support both individual caregivers and the family as a whole.

In summary, by virtue of their shared values and expectations, the participants in this study showed how they were able to work together in providing care for their loved ones. They mutually managed care situations and helped to maintain the balance of the family by negotiating roles and expectations. Ultimately, finding a new homeostasis helped their loved one to die peacefully.

Limitations

The findings of this study were based upon 13 families. While every effort to include all family members in the study was made, this was not always possible, and it is possible that family members not included in the study may have alternate perceptions of the family caregiving values, norms, roles and behaviors. Future studies based on family group interviews would help fill this gap. Moreover, this research needs to be conducted in other Thai social and religious contexts to determine how cultural and religious belief systems may vary and how this variation my impact family roles and expectations and thus values, expectations, coordination and practices of caregiving.

Conclusion

Families are constructed by individuals, and there will always be a mixture of uniquely individual and common family values and practices. Accessing family level data and interpretations is challenging in context of dying and imminent death. This focused ethnographic study sought to illuminate how Thai Buddhist families cooperated in caring for terminally ill persons with cancer based on shared values, expectations and practices. While some values and practices such as promoting comfort, respecting the person's wishes, loving and showing devotion, as well as coordinating care may be universal across cultures, Buddhist beliefs and culturally located values of filial piety were major sources of meaning for families and acted as a source of motivation to care and to share varying responsibilities to both ensure effective caregiving and the support of the family as a whole in particular ways.

Implications for nursing practice and research

Focusing on the context of family as a unit encourages nurses to assess patterns of family functioning in Thai Buddhist families caring for people with terminal cancer. Nurses need to understand the context of caring in each family to tailor interventions to promote family health and help their patients to achieve a peaceful death. Of particular importance in Thai nursing are cultural values around filial piety, family closeness in spirit and in person as well as peaceful death. Nurses need to find ways to facilitate family participation in care. They need to facilitate family conversations that foster family decision-making about ways to coordinate care and that helps the dying person achieve a peaceful death. Conversely, while family engagement and commitment is culturally important, nurses also need to assess the extent to which individual members experience negative consequences of their caregiving, including social isolation, and financial difficulties. Importantly, nurses can identify the roles and commitments of each individual family members in order to understand how the family is functioning as a whole.

Acknowledgements

The authors give special thanks to Graduate School, Chiang Mai University for providing a scholarship for this study. The authors also are truly grateful to all participants for their sharing valuable experiences.

References

1. Given, B. A., Given, C. & Sherwood, P. R. Family and caregiver needs over the course of the cancer trajectory. J Support Oncol. 2012; 10(2): 57-64. doi: 10.1016/j.suponc.2011.10.003.
2. Glajchen, M. Physical well-being of oncology caregivers: An important quality-of-life domain. Semin Oncol Nurs. 2012; 28(4): 226-235.
3. Mehta, A., Cohen, R. & Chan, L.S. Palliative care: A need for a family systems approach. Palliat Support Care. 2009; 7: 235-243.
4. Corà, A., Partinico, M., Munafò, M. & Palomba, D. Health risk factors in caregivers of terminal cancer patients: A pilot study. Cancer Nurs. 2012; 35: 38-47.
5. Kang, J., Shin, D. W., Choi, J. E., Sanjo, M., Yoon, S. J., Kim, H. K., et al. Factors associated with positive consequences of serving as a family caregiver for a terminal cancer patient. Psychooncology. 2013; 22(3): 564-571.
6. Ling, S.F., Chen, M.L., Li, C.Y., Chang, W.C., Shen, W.C., & Tang, S.T. Trajectory and influencing factors of depressive symptoms in family caregivers before and after the death of terminally ill patients with cancer. Oncol Nurs Forum. 2013; 40: 32-40.
7. Tang, S.T., Chang, W.C., Chen, J.S. Wang, H.M., Shen, W.C., Li, C.Y., et al. Course and predictors of depressive symptoms among family caregivers of terminally ill cancer patients until their death. Psychooncology. 2013; 22: 1312-1318.
8. Delgado-Guay, M.O., Parsons, H.A., Hui, D., Cruz, M.G., Thorney, S., Bruera, E. Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. Am J Hosp Palliat Care. 2013; 30(5): 455-461.
9. Otis-Green, S. & Juarez, G. Enhancing the social well-being of family caregivers. Semin Oncol Nurs. 2012; 28(4): 246-255.
10. Son, K.Y., Lee, C.H., Park, S.M., Lee, C.H., Oh, S.I., Oh, B., et al. The factors associated with the quality of life of the spouse caregivers of patients with cancer: a cross-sectional study. J Palliat Med. 2012; 15(1): 216-224.
11. LeSeure, P. & Chongkham-ang, S. The experience of caregivers living with cancer patients: A systematic review and meta-synthesis. J Pers Med. 2015; 5: 406-439.
12. Reczek, C. Conducting a multi family member interview study. Fam Process. 2014; 53(2): 3178-335.
13. Matchim, Y. Hospice care: A cross-cultural comparison between the United States and Thailand. J Hosp Palliat Nurs. 2009; 11(5): 262 – 268.
14. Chan , C.L.W., Ho, A.H.Y., Leung, P.P.Y., Chochinov, H.M., Neimeyer, Pang, S.M.C. & Tse, D.M.W. The blessings and the curses of filial piety on dignity at the end of life: Lived experience of Hong Kong Chinese adult children caregivers. J Ethn Cult Divers Soc Work. 2012; 21(4): 277-296.
15. McCleary, L. & Blain, J. Cultural values and family caregiving for persons with dementia. J Gerontol. 2013; 27(1): 178-201.
16. Lin, J. & Yi, C. A comparative analysis of intergenerational relations in East Asia. International Sociology. 2013; 28(3): 297-315.
17. Funk, L., Chappell, N.L. & Liu, G. Associations between filial responsibility and caregiver well-being: Are there differences by cultural group?. ROA. 2013; 35(1): 78-95.
18. Kongsuwan, W., Chaipetch, O., & Matchim, Y. Thai Buddhist families' perspective of a peaceful death in ICUs. Nurs Crit Care. 2012; 17(3): 151-159.
19. Cruz, E.V., & Higginbottom, G. The use of focused ethnography in nursing research. Nurse Res. 2013; 20(4): 36-43.
20. Wall, S. Focused ethnography: A methodological adaptation for social research in emerging contexts. Forum Qual Soc Res. 2015; 16(1). http://nbn-resolving.de/urn:nbn:de: 0114-fqs150111
21. Eggenberger, S.K. & Nelms, T.P. Family interviews as a method for family research. J Adv Nurs. 2007; 58(3): 282-92.
22. Braun, V. & Clarke, V. Using thematic analysis in psychology. Qual Res Psychol. 2006; 3: 77-101.
23. Lincoln, Y.S. & Guba, E.G. Naturalistic inquiry. Newbury Park, CA: Sage Publications; 1985.

24. Morse, J., Barrett, M., Mayan, M., Olson, K. & Spiers, J. Verification strategies for establishing reliability and validity in qualitative research. Int J Qual Methods. 2002; 1(2): 1–19.
25. Crawford, C.F. Duty, obligation and prostitution: How family matters in entry into and exit from prostitution in Thailand. In P.H. De Neui (Eds.), Family and faith in Asia: The missional impact of social networks. Pasadena: William Carey Library; 2010, pp.77-99.
26. Meyer, O.L., Nguyen, K.H., Dao, T.N., Vu, P., Arean, P. & Hinton, L. The sociocultural context of caregiving experiences for vietnamese dementia family caregivers. Asian Am J Psychol. 2015; 6(3): 263–272.
27. Rukchart, N., Chaowalit, A., Suttharangsee, W. & Parker, M.E. End-of-life decisions among Thai Buddhist adults with chronic illness. Songklanagarind Journal of Nursing. 2014; 34: 44-544.
28. Kunsongkeit, W. Good death as perceived by the patients' family members. The Journal of Faculty of Nursing Burapha University. 2015; 23(3): 41-55.
29. Somanusorn, S., Hatthakit, U. & Nilmanat, K. Caring for a relative at the end of life to die peacefully in the Thai Buddhist culture. The Journal of Faculty of Nursing Burapha University. 2011; 19(2): 28-41.
30. Stajduhar, K.I. Burdens of family caregiving at the end of life. Clin Invest Med. 2013; 36(3): E121-E126.
31. Kinoshita, H., Maeda, I., Morita, T., Miyashita, M., Yamagishi, A., Shirahige, Y., et al. Place of death and the differences in patient quality of death and dying and caregiver burden. J Clin Oncol. 2015; 33(4): 357-363.
32. Bekkema, N., de Veer, A.J., Hertogh, C.M. & Francke, A.L. Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study. J Palliat Med. 2016; 30(7): 625-33.
33. Nilmanat, K., Chailungka, P., Phungrassami, T., Promnoi, C., Tulathamkit, K., Noo-urai, P., et al. Living with suffering as voiced by Thai patients with terminal advanced cancer. Int J Palliat Nurs. 2010; 16(8): 393-399.
34. Senden, C., Vandecasteele, T., Vandenberghe, E., Versluys, K., Piers, R., Grypdonck, M., et al. The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: A qualitative study. Int J Nurs Stud. 2015; *52*: 197–206.
35. Fletcher, B.S., Miaskowski, C., Given, B. & Schumacher, K. The cancer family caregiving experience: An updated and expanded conceptual model. Eur J Oncol Nurs. 2012; 16(4): 387-98.

การดูแลผู้ที่เป็นมะเร็งระยะสุดท้าย:ประสบการณ์ของผู้ดูแลในครอบครัวไทย

วิภา วิเสโส วารุณี ฟองแก้ว นิตยา ภิญโญคำ Jude Spiers*

บทคัดย่อ: การศึกษาที่ผ่านมาส่วนใหญ่มุ่งเน้นการศึกษาผู้ดูแลหลักในครอบครัวที่เป็นรายบุคคลในการดูแลผู้ที่เป็นมะเร็งระยะสุดท้าย ซึ่งประสบการณ์ที่มาจากผู้ดูแลคนใดคนหนึ่งในครอบครัวยังไม่เพียงพอที่จะอธิบายประสบการณ์การดูแลของครอบครัวได้ ดังนั้น จึงจำเป็นต้องศึกษามุมมองของผู้ดูแลในครอบครัวภายใต้บริบทของครอบครัว เพื่อส่งเสริมให้เกิดความผาสุกในครอบครัว การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อให้เกิดความเข้าใจประสบการณ์ของผู้ดูแลในครอบครัวในการดูแลผู้ที่เป็นมะเร็งระยะสุดท้ายในบริบทของวัฒนธรรมไทย โดยใช้ระเบียบวิธีการวิจัยเชิงชาติพันธุ์วรรณา คัดเลือกผู้ให้ข้อมูลแบบวิธีเฉพาะเจาะจง ซึ่งประกอบด้วยผู้ดูแลในครอบครัวทั้งหมด 30 คนจาก 13 ครอบครัว รวบรวมข้อมูลโดยวิธีการสังเกตแบบมีส่วนร่วมและการสัมภาษณ์แบบเจาะลึกสมาชิกในครอบครัว และวิเคราะห์โดยใช้การวิเคราะห์แก่นสาระ

ประสบการณ์การดูแลของครอบครัวไทยในการดูแลผู้ที่เป็นมะเร็งระยะสุดท้ายประกอบด้วย 1) ส่งเสริมความสุขสบายและเตรียมผู้ป่วยให้เสียชีวิตอย่างสงบ โดยเคารพในสิ่งปรารถนาสุดท้ายของผู้ป่วย ให้คุณค่ากับผู้ป่วยที่เป็นบุคคลอันเป็นที่รัก ทำความเข้าใจว่าความตายเป็นกฎธรรมชาติของชีวิต ปฏิบัติกิจกรรมทางศาสนาเพื่อลบล้างกรรม และจัดสภาพแวดล้อมที่เงียบสงบ และ 2) ร่วมกันจัดการการดูแล โดยดูแลด้วยความเต็มใจ จัดลำดับความสำคัญของแผนในชีวิตใหม่ แบ่งหน้าที่ความรับผิดชอบในการดูแลผู้ป่วย และบริหารจัดการด้านการเงินของครอบครัว

ผลการศึกษา สามารถนำไปใช้เป็นข้อมูลที่เป็นประโยชน์ เพื่อความเข้าใจการดูแลโดยสมาชิกครอบครัวในบริบทของวัฒนธรรมไทย ความเข้าใจในประสบการณ์ของผู้ดูแลในครอบครัวดังกล่าว สามารถนำไปใช้ในการพัฒนาระบบบริการสุขภาพเพื่อส่งเสริมความผาสุกของครอบครัวที่ดูแลผู้ที่เป็นมะเร็งระยะสุดท้าย

Pacific Rim Int J Nurs Res 2017; 21(4) 317-330

คำสำคัญ : การดูแล การศึกษาเชิงชาติพันธุ์วรรณา ผู้ที่เป็นมะเร็งระยะสุดท้าย ครอบครัวไทย

ติดต่อที่ : วิภา วิเสโส,* *RN, PhD (Candidate), คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทวโรรส ตำบลศรีภูมิ อำเภอเมือง จังหวัดเชียงใหม่ 50200*

วารุณี ฟองแก้ว *RN, PhD, ศาสตราจารย์ กลุ่มวิชาการพยาบาลอายุรศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทวโรรส ตำบลศรีภูมิ อำเภอเมือง จังหวัดเชียงใหม่ 50200*

นิตยา ภิญโญคำ *RN, PhD, ผู้ช่วยศาสตราจารย์ กลุ่มวิชาการพยาบาลอายุรศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่ 110 ถนนอินทวโรรส ตำบลศรีภูมิ อำเภอเมือง จังหวัดเชียงใหม่ 50200*

Jude Spiers, *RN, PhD, Associate Professor, Faculty of Nursing, University of Alberta, 11405-87 Avenue, Edmonton, Alberta, T6G 1C9 Canada.*