



Caring Experience for a Good Death at Home by Family Members of Terminally Ill Cancer Patients

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Abstract

This qualitative research aimed to explore the caring experience for a good death at home, as perceived by family members of terminally ill cancer patients. A purposive sampling method was employed to select 15 family members of terminally ill cancer patients, who had at least one month of caring experience at home, lived with the patients, and were either related by blood or legal relationship. Data were collected through in-depth interviews with family members and analyzed using the framework outlined by Cohen, Kahn, and Steeves. Heidegger's concept, which emphasizes that individuals derive meaning from phenomena based on their personal feelings and thoughts, was applied as the conceptual framework.

The findings demonstrated that the caring experience for a good death at home, as perceived by family members of terminally ill cancer patients, included the following: (1) caring for the patients to feel comfortable in their final stages of life and pass away peacefully, which involved maintaining daily routines, offering emotional support and encouragement to help the patients cope with the suffering caused by illness, providing compassionate and attentive care, alleviating pain and suffering, and facilitating a connection to religion to calm the mind and prepare for death; (2) family collaboration in caregiving, where family members collaborated in caring for the patients by collectively accepting the reality of death, making shared decisions about treatment, fulfilling the patients' wishes, sharing caregiving responsibilities, and providing emotional support to each other; (3) caring with love and attachment, which was an opportunity to give back and the key component of caring for a good death.

The research findings can be used as foundational information to explain the caring experience for a good death at home, as perceived by family members of terminally ill cancer patients, which will deepen the understanding of the family's role in such care. The findings can also contribute to the development of the Thai family service system for

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terminally ill cancer patients by coordinating with the healthcare team, including physicians, social workers, home care services and specialists in end-of-life care, to assess the needs of the patients and their families, provide information, as well as manage symptoms and other discomforts, along with offering psychological and spiritual care. Additionally, it can help promote the well-being of Thai families in caring for terminally ill cancer patients to ensure a good death at home.

Keywords: caring for a good death, comfort at the end of life, family collaboration, love and attachment, terminally ill cancer patients

=====**Background and Significance of the Study**=====

Cancer is currently the leading cause of death in many countries around the world. There were approximately 19.3 million new cancer patients worldwide and approximately 10 million deaths from cancer occurred in 2020¹. In Thailand, cancer remains the leading cause of death. In 2020, cancer deaths were 129.5 cases per 100,000 population². In addition, according to the 2020 hospital-level cancer registry of the National Cancer Institute, Department of Medical Services, Ministry of Public Health, the number of new cancer patients in the National Cancer Institute was reported to be 2,890, accounting for 29.4%. New cancer patients are also increasing and are expected to rise every year. More than half of new cancer patients are in the metastatic stage of the disease, accounting for 57.50%, while most new cancer patients by stage of the disease are in the terminal stage, accounting for 36%³. From this situation, it can be seen that cancer is becoming a major problem for the public health system in Thailand. Cancer can directly affect the well-being of patients in terms of physical, mental, emotional, social, and spiritual aspects. It also affects family members physically, mentally, emotionally, socially, occupationally, economically, and spiritually.

Cancer patients are often aware that the disease is incurable, and they experience pain both from the cancer itself and from treatments that cause further suffering until death. As the disease progresses, cancer patients face numerous challenges and changes in their lives. Particularly at the end of life, they often experience feelings of depression, sadness, fear of symptoms that may arise, and anxiety about separation from loved ones, which persist until death⁴. These feelings also have a direct impact on their family members⁵. Family members are the closest and most important people to patients, playing a crucial role in ensuring that patients experience a good death⁶. Studies showed that when family members realized that the patients were in the final stage of illness and death was approaching, they often experienced fear, anxiety, depression, and sadness, and might



attempt to prolong the patients' lives. However, when they come to terms with the inevitability of death, they wish for the patients to receive care that ensures a good death^{7,8,9}. This reflects the primary goal of palliative care, which is to support terminally ill patients and their families to get through this difficult time, ensuring quality of life both in the hospital and at home¹⁰.

Therefore, nurses play a crucial role in caring for terminally ill patients, ensuring they experience a good death, and supporting their families. Family members are not only important in helping patients achieve a good death¹¹, but also cope with the sorrow of watching loved ones gradually pass away with the helpless feeling in their inability to prevent it. Many studies highlighted that family members wished to be involved in end-of-life care to ensure that patients had a good death¹². A study also showed that family members of patients perceived a good death as a death that was peaceful and free from suffering⁶. However, there is still a lack of understanding regarding how to care for patients to achieve a good death, particularly in the home setting, which is often the place patients choose to return to in their final days¹³. Therefore, understanding the meaning of caring for terminally ill cancer patients to ensure a good death at home, as perceived by family members is important. This knowledge will enable nurses to better prepare family members to care for patients when they return home. However, the concept of "caring for a good death" remains unclear, as its definition can vary based on individual beliefs, attitudes, cultural backgrounds and personal experiences¹⁴.

A review of the literature revealed that studies on nursing care for a good death from the nurses' perspectives had been conducted^{11,15}. However, research on caring for a good death at home, as perceived by family members, particularly in the context of terminally ill cancer patients, is limited and varies across different cultural settings in Thai society¹⁶. Furthermore, research on end-of-life care indicated that medical professionals tended to focus more on patients than on family members¹⁷.

For these reasons, this study aimed to explore the care for terminally ill cancer patients for a good death at home, focusing on the perception of the patients' family members. The research findings will provide foundational information to explain the caring experience for a good death at home, as perceived by family members in the context of Thai culture. This knowledge can also contribute to the development of the family service system, enhance nursing practices to promote the well-being of Thai families, and serve as a basis for further research on how Thai families care for terminally ill cancer patients at home.

Research Objective

To explore the caring experience for a good death at home, as perceived by family members of terminally ill cancer patients.

Conceptual Framework

This research focused on understanding the meaning of a good death as perceived by the patients' family members. To frame this, we drew on Heidegger's concept, which is grounded in the philosophy of existentialism, emphasizing the inherent nature of human existence in specific situations, where individuals assign meaning to the phenomena they encounter based on their personal feelings and thoughts. These meanings will be different from others, as the experience is unique and true to their own perspectives and perception. The main concepts include: the person as having a world; the person as being for whom things have significance and value; the person as self-interpreting; the person as embodied; and the person in time¹⁸. In addition, Heidegger's concept emphasizes the importance of a person's background, including age, education, culture, beliefs, and values, which influences how a person perceives, understands, interprets, and gives meaning to his or her experiences. This background also influences how a person communicates these experiences, both verbally and non-verbally. Furthermore, this research focused on understanding family caregiving within the context of Thai sociocultural norms. This context is a unique aspect of Thai society, rooted in long-standing traditions that reflect interpersonal relationships, ways of life, values, and beliefs that influence caregiving practices within families. It also includes caregiving behaviors shaped by these beliefs and sociocultural contexts, which can serve as a framework to better comprehend the cultural influences that shape caregiving within Thai families.

Methods

This qualitative research aimed to explore the caring experience for a good death at home, as perceived by the family members of terminally ill cancer patients. The informants were purposively selected from the family members of terminally ill cancer patients receiving care at Chonburi Cancer Hospital. The eligible informants had at least one month of experience providing care at home, lived in the same household as the patient, were either related by blood or legal relationship, aged 20 years old or older, and were willing to participate in the research. Data collection venues included the Inpatient Ward of Chonburi Cancer Hospital, and various care settings, including the homes of families caring for terminally ill cancer patients.



Research Instruments

The research instruments included the researchers, a personal data record form for the patients, a personal data record form for the informants, and interview guidelines. These instruments were designed to allow the informants to share their caring experiences for a good death at home, in line with Heidegger's concept, which emphasizes that individuals assign meaning to phenomena based on their own feelings and thoughts.

Data Collection Procedures and Methods

The research project was submitted to the Research Ethics Committee of Chonburi Cancer Hospital, and permission to collect data was sought from the Dean of the Faculty of Nursing and was then presented to the hospital director for final approval. Coordination with the ward for data collection was then administered. Subsequently, the head of the ward was appointed as the coordinator. The consent was requested from the patients' family members who met the inclusion criteria. Once the family members agreed to participate in the research, the researchers met with them to make self-introduction, explain the research objective, data collection procedures, the protection of the informants' rights, and formally asked for their consent to participate in the research. After obtaining the consent, the interviews commenced when the informants were ready to share their experiences. Data were collected through in-depth interviews, which were audio-recorded, and observations were conducted. Each informant was interviewed approximately 2 - 3 times to ensure comprehensive and clear in-depth information. The first interview with audio recording, lasted approximately 60 - 90 minutes; the second interview lasted approximately 45 - 60 minutes, and the third interview lasted approximately 30 - 45 minutes. Examples of interview questions included: "Please tell me how your family found out that the patient had terminal cancer." "How did you feel when you found out that the patient had terminal cancer?" "What is your definition of a good death?" "In the past, how did you take care of your family member with terminal cancer to ensure a good death at home?" "In addition, who in the family was involved in caring for the patient to ensure a good death at home/how did you take care of him/her?" "What are your opinions/feelings about family members being involved in caring for the patient for a good death?" "What family factors do you think influenced caring for the patient with terminal cancer to ensure a good death at home? How did these factors affect patient care?" Additional questions were asked based on the responses provided, to gain further explanation and deeper insights in line with the qualitative research approach. These included prompts such as, "What happens next?" "Why do you think that?" and "Can you elaborate on that?" Data collection continued until saturation was reached after interviewing 15 participants, meaning no new themes or insights emerged. This sample size was considered adequate to reflect the variety of

perspectives within the study context and relevant to the study's objectives. At this point, data collection was concluded.

Protection of the Informants' Rights

The research proposal was approved by the Human Ethics Committee of Burapha University (No. Sci 044/2018), and the Academic and Research Ethics Committee of Chonburi Cancer Hospital, (No. 9/2018). Before collecting data, the researchers met with the informants to build rapport, make self-introduction, explain the research objective, duration, and procedures, and clarify the roles of both the researchers and the informants. The expected outcomes of the study were also outlined, which included completing a general information questionnaire, participating in interviews, and engaging in observations. The informants were allowed to ask questions and express any concerns until they fully understood. They were provided the freedom to decide whether or not to participate in the study. Refusal to participate in the study had no impact on their families or the patients' treatment at the hospital as well as at home. Once the informants agreed to take part in the study, they were asked for the permission to audio-record the conversations during the interviews and observations. In addition, the research ethics were strictly adhered to, ensuring respect for the privacy of the informants. Data were collected only with the informants' voluntary consent, ensuring that they did not feel anxious, and embarrassed. Their privacy was respected, and there were no negative effects on their physical, mental, or social well-being. The confidentiality of the informants was maintained throughout the research process, including in the audio recordings and transcriptions of the interviews, with no identifying information or names disclosed. All data obtained from the interviews, observations, and transcripts were stored in a locked cabinet, accessible only to the researchers. The identities of the informants were remained confidential. The research findings were presented as a summary. Any publication of the research findings were solely for academic and educational purposes.

Data Analysis

The interview recordings were transcribed immediately after each session, and data were analyzed using the six-step framework outlined by Cohen, Kahn, & Steeves¹⁹, as follows: (1) reading the transcript several times to fully understand the informants' overall experiences; (2) removing irrelevant data (data reduction) while maintaining the integrity of the information, using the researchers' judgment; (3) reviewing the remaining data to identify key meanings, coding both interview data and observational notes; (4) grouping related codes into subcategories and categories; (5) organizing the categories into themes based on shared meanings; and (6) validating the main points and themes by cross-checking them with the categories and confirming with the informants.



Establishing Trustworthiness of the Research

The guidelines established by Lincoln & Guba²⁰ were followed:

1) Credibility. The informants with direct experience were selected and a strong rapport was built to foster trust and encourage the informants to openly share their experiences. After each interview, a summary was provided to the informants for confirmation, and they were asked to clarify or expand on any areas that were unclear or lacked detail (member checking). In addition, the researchers reflected on their own thoughts and feelings during data collection to minimize potential biases.

2) Transferability. The detailed descriptions of the informant selection process was clarified, enabling the readers to understand and apply the findings to the patients with similar characteristics and contexts. Thick description was employed to present the informants' experiences in detail, context, emotions, thoughts and perceptions in their natural setting which help to ensure transferability.

3) Dependability. The data collection processes, data analysis, and conclusion were outlined in detail to make them understandable and verifiable. To achieve dependability, the analysis was reviewed by a group of three experts, consisting of nursing faculty members with expertise in qualitative research and palliative care, and was approved by the research team. Reflection, journaling, and memoing were used throughout the data collection and analysis process.

4) Confirmability. This refers to the neutrality or impartiality of the research. Peer debriefing was conducted with two experienced colleagues in qualitative research and who were not involved in the study, to provide critical feedback and minimize researcher bias. This process was used to confirm the decision-making and check the consistency of the inferences and the development of codes during the analysis. Confirmability occurs through credibility, transferability, and dependability.

Results

Part 1: Personal information of the informants

The informants were 15 family members who provided care for terminally ill cancer patients. The majority of informants were from nuclear families (53.33%). Mostly, two family members (46.67%) were primarily involved in the patient's care. The majority of the informants were female (73.33%), with an age range of 51 – 60 years (40%). All informants identified as Buddhist (100%). In terms of their relationship with the patients, they were mostly daughters (33.33%), followed by wives (26.67%). Other relationships included father/mother, husband, son, and sibling. The duration of care was between 6 months and 1 year (80%). Most of them spent more than 12 hours per day providing care for the patients

(66.67%). Additionally, most informants were not employed (66.67%). The average monthly family income for most informants ranged between 10,000 and 20,000 baht (60%). All family income was derived from family members (100%). The family's monthly expenses for patient care ranged between 5,000 and 10,000 baht (60%).

Part 2: Caring experience for a good death at home, as perceived by family members of terminally ill cancer patients

The caring experience for a good death at home, as perceived by family members of terminally ill cancer patients within the Thai sociocultural context included the following: (1) Caring for the patients to feel comfortable in their final stages of life and pass away peacefully: This involved maintaining daily routines, offering emotional support and encouragement to help the patients cope with the suffering caused by illness, providing compassionate and attentive care, alleviating pain and suffering, and facilitating a connection to religion to calm the mind and prepare for death; (2) Family collaboration in caregiving: Family members collaborated in caring for the patients by collectively accepting the reality of death, making shared decisions about treatment, fulfilling the patients' wishes, sharing caregiving responsibilities, and providing emotional support to each other; (3) Caring with love and attachment: An opportunity to give back and the key component of caring for a good death. These are elaborated below.

1. Caring for the patients to feel comfortable in their final stages of life and pass away peacefully

1.1 Maintaining daily routines

This involves caring for the patients' physical cleanliness, ensuring proper nutrition and medication, and creating a clean, peaceful environment to enhance the patients' comfort, as demonstrated in the following statements obtained from the interviews:

"After performing the urinary catheterization, I'll wipe his face and eyes... and keep an eye on him because sometimes when he's lying down, he'll urinate a lot, and it'll soak the mattress. I have to keep changing the pad. After the urinary catheterization, sometimes he wants to pee again, and he'll sit up immediately and the urine will start dripping. I have to keep wiping it. I don't use a diaper. I just place a pad underneath him because wearing a diaper makes him feel uncomfortable because of the ostomy bag on his stomach. It's not very convenient, so I avoid using a diaper to help him feel more comfortable." (F02, wife, 57 years old).

"I take care of his food. I prepare food and drinking water for him from the morning, and give him his medicine... all of this at home. He mostly likes to eat fish, so I cook fish for him. I usually boil it because frying uses oil, which he avoids. He used to



emphasize this a lot. Before, he would be the one cooking... When he's in the hospital, I don't have to cook for him, but when we're at home, it's my responsibility to cook for him." (F7, daughter, 35 years old).

"I always make sure his bed is clean. I sweep the floor, and tidy up the room. Cleanliness is a top priority. The bed needs to be clean so he can sleep comfortably... I wash the bedsheet every week, and on sunny days, I dry it outside. If the bedsheet is damp, I'll change it... Additionally, I have arranged a new room for him with a partition to ensure he has privacy and is free from loud noises. During the day, I open the windows to let in fresh air, keeping the space cool and comfortable." (F10, mother, 52 years old).

1.2 Offering emotional support and encouragement to help the patients cope with the suffering caused by illness

1.2.1 Offering words of encouragement

It involves helping the patients relax and alleviate fear and pain, acknowledging that cancer is a source of great suffering. The patients may feel irritable, fatigued, and discouraged, so encouragement is essential in helping them endure, not just relying on medical treatment, as demonstrated in the following statements obtained from the interviews:

"Encouragement is like showing love - holding her hands, hugging her, and staying by her side... Sometimes, she calls out to me and says, "Oh, it hurts. I cannot take it anymore," I tell her to be patient just a little longer, that she'll get better soon... It is like giving her a small boost to keep going." (F06, daughter, 25 years old).

"It feels like this illness can be cured with encouragement. Maybe it's not just being stressed or anything like that. Medicine might be a part of it. But if we are not stressed and offer encouragement, it may be better... I hold his hand and talk to him. He usually does not say much, but I'll be by his side, hold his hands, and give him words of encouragement." (F03, younger sister, 54 years old).

"I think encouragement is needed, especially from family members... It plays an important role, right? Like I said, encouragement is important... It's to just act like everything is normal and stay home when things are okay. If his symptoms improve, we should give him even more encouragement... Simple things like talking to him, showing affection, holding hands, hugging, patting his head, body, arms, or legs are done to give him encouragement... These make him feel supported and warm. Giving him that encouragement... makes him feel better and realized that he is still taken good care of..." (F08, wife, 47 years old).

1.2.2 Providing compassionate and attentive care

Family members always stay close to the patients at all times, providing care both day and night. They have to wait until the patients fall asleep before they can rest themselves and keep a watchful eye because they are concerned about the patients.

“I’m really worried about him. He can barely get up or move around on his own, so I have to help him. He always asks me to pick things up for him. Especially at night, sometimes he wakes up in the middle of the night and calls out to me because he’s in pain and feels exhausted. That’s why I moved him to sleep in this room, right here... I stay with him all the time, both during the day and at night. I want him to be close because I’m worried about him, and he wants me to be near him, too.” (F08, wife, 47 years old).

“These days, I always stay up until 2 or 3 a.m. I don’t sleep well at night. I wait for my mother to fall asleep. Even when she goes to the bathroom, I worry. I fall asleep around 2 or 3 a.m.... I keep waking up to check on her, half-awake... I usually sleep deeply around 2 or 3 a.m., and I wake up when she calls me to give her medicine... It’s like this every day. I feel like I have to be closer to her than before, asking her questions and staying by her side all the time.” (F11, daughter, 24 years old).

1.2.3 Alleviating pain and suffering

Family members want to ensure that the patients experience as little pain and suffering as possible because they are afraid that the patients may pass away in pain. They may also express a desire for the doctor not to attempt resuscitation. When the time comes for the patients to pass away, the goal is for them to do so peacefully, without pain or distress, as illustrated in the following statements obtained from the interviews:

“...If he’s going to die, I don’t want him to be in pain or suffer any more. It’s like when we provide food for him-our priority is that he isn’t in pain, that he isn’t lying down suffering. We’re always thinking about how we can minimize his pain and make sure he suffers as little as possible.” (F04, wife, 52 years old).

“...Whatever happens, just let it happen. No need to help. If CPR or a breathing tube is necessary..., I’m worried he’ll be in pain, so just help him gently. If he’s unconscious, leave him that way. There’s no need to help. He doesn’t need to suffer or have broken ribs. Just let it be. If he’s knocked out, let him stay that way... If he’s already so sick, I don’t want him to feel pain from broken ribs. Let him rest peacefully. I don’t want him to hurt anymore. He’s already been through enough.” (F01, daughter, 52 years old).



1.3 Facilitating a connection to religion to calm the mind and prepare for death

1.3.1 Talking to the patients to accept their death

It is to encourage the patients not to focus on death because it only increases their suffering. Instead, they should accept it. It is important to tell them to let go of worries about those they leave behind. By finding peace, they can pass away calmly and without distress when the time comes. Additionally, the patients must be encouraged to overcome any fear of death, so they can face it with a sense of acceptance, as illustrated in the following statements obtained from the interviews:

“Sometimes she says he can’t take it anymore and doesn’t know when her time will come... I try to tell her, “How could you think like that? If you keep focusing on wanting to die, it won’t happen. It could even make things worse, causing more pain. Don’t think about it. As long as you’re still breathing, just keep going. Don’t dwell on it. It will only make you suffer more. Don’t think about it...” (F15, daughter, 30 years old).

“I advised him not to be afraid of death, as it is simply a rapid transmigration of the soul... I also encouraged him to pray that, in the next life, he will be reborn into a place where he can encounter Buddhism and good people. I told him these things to help calm his mind, keep him focused, and allow him to gradually accept what’s coming.” (F10, mother, 59 years old).

“Most of the time, I talk to him in a way that will help him accept it... I told him that no one can escape it. We all have to accept it... I told him not to worry about those left behind, not to worry about the children, just keep his mind calm... I want him to accept what is happening, so he won’t be so afraid. I reminded him that everyone has to face it eventually... He said he understands what is happening to him. He assures me that he will accept it when it is time... And when that time comes, he needs to keep his mind calm, so he won’t suffer too much. He can pass away peacefully, without pain.” (F02, wife, 57 years old).

1.3.2 Telling the patients not to worry anymore

Family members do not expect the patients to recover from the illness because they know that it is the final stage. They wish for the patients to pass away peacefully without worry, as shown in the following statements obtained from the interviews:

“I don’t want her to worry if the time comes for her to go. That’s how I think. I don’t want her to worry at all. If it’s her time, we just want her to go peacefully... I don’t expect my mother to get better. I know this is the final stage, and she knows it too.” (F06, daughter, 25 years old).

1.3.3 Engaging in religious practices at the end of life to bring peace of mind and to atone for the sins of past lives

Family members have assisted the patients to be close to their faith in the final moments of life by setting up a Buddha shelf in the patients' bedroom for prayer and worship. They have also invited monks to the home, so the patients could give alms. The religious prayers are also played for the patients to listen to, helping to calm the mind, foster understanding of the illness, and ease any worries. Additionally, family members usually make merit on the patients' behalf by bringing food for the patients to bless before making offerings. The merit is then dedicated to the patients' karmic creditors with the intention of relieving any negative karma, as shown in the following statements obtained from the interviews:

“His father set up a Buddha shelf in his bedroom so he can worship and pay homage... We want him to be drawn to the Buddha and find peace. Before going to bed, he usually prays to seek peace of mind.” (F10, mother, 59 years old).

“ . . . I invited the monks to the house and let him give alms...Sometimes, the monks come to collect alms outside the house, so I give alms on his behalf... I also taught him to observe the precepts and practice meditation, because if he keeps focusing on the pain and the time when he passes away, it will only make the suffering worse.” (F05, father, 70 years old).

“...My mother also enjoys listening to chanting. It helps calm her mind, like it keeps her from being distracted. She just keeps listening to the Dhamma, and chants, over and over...” (F01, daughter, 52 years old).

“...If I'm free, I'll take him to make merit. I'll take him there if he can go... I'll buy food for him, let him pray, and give alms on his behalf because he can't get up. It's the same at home. I'll buy the necessary items for merit-making for him, so he can pray for his karmic creditors, which is the most important thing. He'll pray to end any enmity between them, so there will be no more conflict or resentment.” (F08, wife, 47 years old).

2. Family collaboration in caregiving

2.1 Collaborating in caring for the patients by collectively accepting the reality of death

Family members have accepted the patients' illness and impending death, understanding that it is a natural part of life. They believe that when the patients pass away, both the patients and the family will be free from suffering, as illustrated in the following statements obtained from the interviews:



“Just accept the situation as it is; it has to be this way. Don’t be miserable. When the mind is calm, it brings peace and no longer causes suffering. Nowadays, I’m not really suffering. I believe that if he dies, it will be good for both of us. If he dies..., he won’t suffer anymore. He won’t feel pain or be hurt. I also won’t have to suffer, watching him in pain, unable to help. We all just have to accept it. People are born this way. If we live long, it means we have a lot of karma. If we die quickly, it means our karma is finished sooner... Accept it. Understand the truth of life: everyone is born, grows old, gets sick, and eventually dies.” (F10, mother, 59 years old).

2.2 Making shared decisions about treatment

2.2.1 Discontinuing resuscitation efforts in the event of cardiac arrest

Family members have discussed together and made a joint decision regarding resuscitation in the event of cardiac arrest, ultimately choosing not to resuscitate, as illustrated in the following statements obtained from the interviews:

“We discussed everything. I talked to his relatives and parents. Everyone agreed. They didn’t want him to undergo resuscitation either. His mother also said that there was no need for CPR. She felt sorry for her son and said that if it went that way, it would only cause him more pain.” (F08, wife, 47 years old).

“...We’ve already talked about it. If it’s his time, let him go. There’s no need for resuscitation or CPR, no need to let him suffer. Just let him pass away peacefully. If it’s his time, let him go... I don’t want him to be in pain. Let him rest comfortably. He’s already been through enough pain here.” (F01, daughter, 52 years old).

2.2.2 Receiving palliative care

Family members have discussed and made decisions together regarding the patients’ treatment options, as presented in the following statements obtained from the interviews:

“...From now on, I will continue to take him to doctor’s appointments and receive treatment until it becomes clear that it’s incurable. I will keep managing his symptoms. But when the time comes for him to pass away, I will let him go. We’ve already discussed it. I talked to my mother, and she said there’s no need to buy any more medicine for him. I’ll save that money for the doctor’s appointments instead...” (F06, daughter, 25 years old).

“We talk. We talk every day... We discuss what to do for her, whether she can be cured or not. We talk about everything... Right now, we’ve agreed to continue supporting her as best we can, until she can’t handle it anymore. My father said there’s nothing more we can do. If it’s her time, then we have to let her go.” (F07, daughter, 35 years old).

2.2.3 Seeking alternative treatments to help patients feel better

Family members have discussed and decided on the treatment plan for the patients, combining modern and traditional medicine. They have chosen modern medicine as the primary treatment, while also incorporating herbal remedies, hoping this may help the patients to get better, as presented in the following statements obtained from the interviews:

“ We discussed what kind of treatment to use, whether modern medicine or traditional remedies. We agreed that modern medicine would be the best option..., as it will bring us closer to the doctor. With today’s technology and available treatments, there’s hope. However, we have also tried some herbs, just in case they may help improve the symptoms. We still have hope...” (F15, daughter, 30 years old).

“ Someone suggested we try some herbal medicine, a monk’s remedy... They said it was very effective, so we got some, and hoped it would help. I talked to my daughter, and after she took it, she felt better. She seemed to be able to eat more... However, when the doctor scheduled her chemotherapy, we decided not to continue with the herbal medicine. We stopped taking it for now and focus on the treatment plan recommended by the doctor.” (F05, father, 70 years old).

“...Now, we’re using the Soursop leaf medicine... A friend of him used it and it worked, so he recommended it to us, hoping it will help. I want him to be able to sit up and eat... I’m waiting to see if it helps... but I always take him see the doctor. We never miss that.” (F04, wife, 52 years old).

2.3 Fulfilling the patients’ wishes

Providing close care to the patients at home is to fulfill their wish to be surrounded by family, in the comfort of their home environment. It offers them the warmth and support of loved ones, giving them the encouragement to live their final moments with their family, as illustrated in the following statements obtained from the interviews:

“...He felt that he had fulfilled his wish - wanting to go home and be with parents... We feel good. We are close to him, and he is close to us. It is better than leaving him in the hospital.” (F14, mother, 58 years old).

“...We tried to find a hospital-like bed for her so that she could sit up comfortably. But she refused. She doesn’t want to be in a hospital-like environment. She wants to sleep on the same bed she used to sleep on at home. If we put her in a hospital-like bed, it would feel like she was still in the hospital. So, we respect her wish.” (F13, husband, 50 years old).



“...She wants to come back home to be with her son. Her son is her source of inspiration. When she wakes up in the morning, she smiles. She’s happy that her son comes to see her and kisses her cheek. When we see that she is happy, we feel good too. Bringing her home has been the right decision because it gives her the encouragement. We want her to feel supported, so she can rest in peace.” (F14, father, 58 years old).

2.4 Sharing caregiving responsibilities

Family members have worked together to divide their time in caring for the patients, as they cannot all be present at once. One person is designated as the primary caregiver at home, while others take turns caring for the patients during hospital stays. Those with regular jobs contribute by earning income to support the family, as demonstrated in the following statements obtained from the interviews:

“We take turns caring for her. During her hospital stays, we rotate caregiving duties. I am the primary caregiver from Monday to Friday, and on weekends, my children will come to help. I get two days off. We take turns.” (F13, husband, 50 years old).

“... We cannot be there at the same time because we all have to work. When he is in the hospital, I am the one to take care of him. But when he is home, my younger sister takes on the main caregiving role. Because she works from home most of the time, she can take care of him. On Saturdays and Sundays, we will all come together to help each other. We have divided our time and done our best to care for him during his final moments.” (F03, younger sister, 54 years old).

“...We discussed things like this among siblings. My brother covers expenses like gas, food, and other costs during that time. I take care of my mother... Sometimes, my father pays for his own expenses, so does my mother. We all share the burden... Those who have more money contribute more. We support each other.” (F11, daughter, 24 years old).

2.5 Providing emotional support to each other

Family members have supported each other in caring for the patients to ease the caregiving burden by expressing concern for each other’s health, inquiring about their needs, offering comfort, or buying things for them. These actions create a sense of warmth and joy, as presented in the following statements obtained from the interviews:

“It helps a lot. When someone gives us encouragement, we feel better, happy and warm. It’s nice. It’s like having family members asking how we’re doing, making sure we’re taking care of ourselves, worrying about us, and asking if we need anything. When they offer to get something for us, it makes us feel comforted. It’s like they’re giving us encouragement, and that lifts our spirits because taking care of the patient is really tiring.” (F03, younger sister, 54 years old).

“We also need encouragement. Sometimes we get tired, and in those moments, other people don’t matter, except for the support from our family... Their encouragement means the most to us. I don’t care about what others say, just as long as my family is there for me. I’ve told them before, and later on, they have helped with things and lightened my burden. It feels like they are giving me the encouragement. I’m really grateful for that.” (F12, wife, 37 years old).

“She (older sister) helps take care of our mother as much as she can. Sometimes, she gets tired, so we give her encouragement because she also has a child to look after. Her child is studying, and she has to find time to visit our mother as well. She does her best, and we try to support her by giving her encouragement and buying her things. This makes her happy.” (F07, daughter, 35 years old).

3. Caring with love and attachment—an opportunity to give back and the key component of caring for a good death

3.1 Caring with love

Family members have provided care for the patients with love and dedication, never abandoning them. So, the patients have the strength to live their final days with peace, as illustrated in the following statements obtained from the interviews:

“Our family helps take care of him (the patient), and that gives him a lot of encouragement. It motivates him to keep fighting. I think if it were someone else, they might not have been able to care for him as much as we do. It’s all about love... because our father raised us and was tired of us back then, now it’s our turn to take care of him.” (F06, daughter, 25 years old).

“It is because of love. Because she’s our mother, we can’t abandon her, no matter what. Just like how she never abandoned us, no matter how good or bad we were. I know she won’t be with us for much longer. Sometimes she gets cranky or irritated because of the pain, and sometimes she gets angry. But no matter what, we have to take care of her. She is our mother.” (F09, son, 21 years old).

3.2 Family attachment

Because of the strong bond between family members, which existed even before the patients’ illness, they have always been close to one another. This deep connection drives them to provide the best possible care for the patients in their final moments, as demonstrated in the following statements obtained from the interviews:

“Before she got sick, we were always together, wherever we went. We did everything together..., so it is normal to be together all the time. It is a bond that has been there for years. She took care of everything for me until she became ill. In her final moments, I just want to give her the best possible care.” (F13, husband, 50 years old).



“...We’ve been together for more than twenty years - almost thirty, and we’re very close. Of course, we argue sometimes and face problems, but he’s always been good to me and helps with everything. I feel sad seeing him sick like this. It is more of a bond, and now, in the final stage of his life, I just want to give him the best possible care.” (F02, wife, 57 years old).

“...Because we have raised him, when he gets sick, it’s our responsibility to take care of him, just like how he took care of me when I was sick. It’s our duty. It’s the bond between a child and parents, something like that. It’s what makes us care for each other until the end of life.” (F05, father, 70 years old).

3.3 An opportunity to give back

Family members have come together to care for the patients by performing good deeds for them, as a way of repaying the care and support the patients have given them. They believe that the merit gained from these acts will help the patients pass away peacefully and find a good place after death, as illustrated in the following statements obtained from the interviews:

“I thought about how I could repay him. For the wrongs I’ve done, I’ve apologized to him... I’ve tried to do everything I can for him. There were times when I did bad things to him, but now it’s my time to do good and make up for those things. It feels like it’s time to repay the debt. When he leaves, we won’t have to worry about each other anymore. He’ll be able to rest in peace.” (F04, wife, 52 years old).

“At this time, I think that ordaining would be a way to repay his kindness... so that my father can cling to the saffron robe (gain the merit from the son’s ordination) and find his way to heaven, to a good place. I think like this... Sometimes, I believe it’s a way of making merit, and my father will also gain merit from it. I’ve never had the chance to ordain for him before..., but I think it will make him feel good too.” (F09, son, 21 years old).

“...Making merit with parents is never a waste... It’s like making merit with the monks in your home... As they say, the monks in your home are your parents... It’s comforting because, as I mentioned, taking care of the monks in our home (parents) is a way of giving back to them while they are still alive. They won’t be with us forever. It’s better to do good for them now, rather than regret not doing so later.” (F15, 30-year-old daughter).

However, an important finding of this study is the predominantly positive points of view reflected by family caregivers. It is worth noting that challenging or negative experiences may not be entirely negative in nature—as family caregivers may have already adapted or shifted their perspectives. These challenges encountered by family caregivers

can offer valuable insights. Some of the family caregivers described feeling burdened by their overwhelming care responsibilities. Their physical health deteriorated and they experienced social deprivation. Although it was a demanding task, they were willing to care for their loved ones with compassion, and they described their caregiving experiences as a devotion of personal life.

Discussion

The caring experience for a good death at home, as perceived by family members of terminally ill cancer patients consisted of: (1) Caring for the patients to feel comfortable in their final stages of life and pass away peacefully: This involved maintaining daily routines, offering emotional support and encouragement to help the patients cope with the suffering caused by illness, providing compassionate and attentive care, alleviating pain and suffering, and facilitating a connection to religion to calm the mind and prepare for death; (2) Family collaboration in caregiving: Family members collaborated in caring for the patients by collectively accepting the reality of death, making shared decisions about treatment, fulfilling the patients' wishes, sharing caregiving responsibilities, and providing emotional support to each other; and (3) Caring with love and attachment: An opportunity to give back and the key component of caring for a good death.

From the findings, it can be discussed that good death in the cultural dimension of Thai society aims to let those in the final stages of life see good things, know love and feel valued by providing care that is consistent with religion, and beliefs that are aligned with the feelings and faith of the religion they believe in. A good death from the perspective of Thai people is considered natural, being in a peaceful environment, showing faith in sacred things that they respect, and being in a place that they like, which are essential elements that can lead to a good death²¹.

However, a good death depends on the perception and perspective of the individual. A good death perspective reflects the characteristics of a person's view of a good death, which can affect behavior or expression. A good death, according to the patient's perception focuses on being free from suffering physically and mentally in order to die peacefully, and the family is the person that the patient wants to be with before, during and after death^{6,8}. If the family can accept the death, it will play an important role in helping the patient to have a good death⁸. In addition, Gurdogan et al²² studied the concept of a good death from the perspectives of family caregivers of advanced cancer patients. The results revealed that family caregivers of advanced cancer patients obtained high scores from the good death scale and they considered a good death as very important in all dimensions. They also want their patients to achieve a good death. Moreover, a systematic



literature review on the family's experience with end-of-life care by Yoo, Lee & Chang²³ found that one of the needs of the family regarding end-of-life care is preparation for the patient's death. Therefore, the concept of a “good death” is multifaceted, encompassing various elements that contribute to a dignified and peaceful end-of-life experience. Family caregivers play a pivotal role in facilitating this process.

The perspective of a good death of caregivers, as well as family members, is that they want to be involved in caring for patients in their final moments to ensure a good death. They place a lot of importance on the place where the death will occur. Most of the time, they want the place to be familiar to the patient or where they have expressed their wishes, which is to be able to go back home to die. They have responded to the patient's wishes, made the patient feel that life is valuable, created happiness for the patient until the final moment, and helped reduce physical suffering. In addition, family members also have a good death perspective towards themselves, seeing that having a good death is something that can be managed or controlled. They also want a good death to occur. Therefore, a good death is something that can be achieved effectively²⁴. This is consistent with the study of Ailshire et al.²⁵ which highlighted that family caregiving is associated with reduced odds of dying in a hospital or nursing home, indicating a preference for home deaths when family support is present. A study conducted by Kinoshita et al.²⁶ with family caregivers of cancer patients also determined that caregivers consider the dying process at home as an important component of a good death. It was found that the dying process at home allows individuals to spend time with the loved ones, maintain hope, experience environmental comfort and preserve their self-esteem. This is compatible to the traditional beliefs of Thai people, shaped by their Buddhist faith that home death is associated with a better rebirth and receiving better care from family than death in the hospitals²⁷.

Caring for the patients to feel comfortable in their final stages of life and pass away peacefully, emphasizes the importance of maintaining daily routines, offering emotional support, helping the patients cope with the suffering caused by illness, providing compassionate care and alleviating pain and suffering. These aspects play a critical role in ensuring comfort and providing a sense of normalcy for both patients and caregivers. Maintaining daily routines is seen as a vital part of providing compassionate care, fostering emotional stability, and honoring the dignity of terminally ill patients during their final days at home²⁸. In addition, daily routines provide opportunities for meaningful interactions between caregivers and patients as caregiver-patient bonding, reinforcing emotional connections and creating moments of shared intimacy. Moreover, adhering to daily routines

helps patients feel more in control and comfortable, mitigating the disruptions caused by illness. Family caregivers play a crucial role in sustaining these routines to support the patient's emotional well-being. Engaging in regular activities can help alleviate pain and suffering in patients, providing a comforting structure. Caregivers often facilitate these routines to enhance the patient's quality of life in the final stages of life²⁹.

Facilitating a connection to religion or spirituality is a significant aspect of providing end-of-life care at home for terminally ill cancer patients, as perceived by their family members. This practice offers emotional comfort, aids in coping mechanisms, and prepares both patients and caregivers for the approaching end of life. Engaging in religious or spiritual practices provides family caregivers with the strength to manage caregiving challenges, overcome fears, and enhance decision-making skills. Such practices offer a sense of peace and acceptance during the end-of-life phase³⁰. In addition, spirituality serves as a coping mechanism for caregivers, helping them deal with the emotional and psychological demands of caregiving. It enables them to find meaning and purpose in their role, which can alleviate feelings of distress. Moreover, facilitating spiritual connections helps both patients and caregivers prepare for death, addressing existential concerns and fostering a sense of readiness for the end-of-life transition³¹.

Family members play a crucial role in providing end-of-life care at home for terminally ill cancer patients. Their involvement encompasses accepting the reality of impending death, making joint decisions about treatment, fulfilling the patient's wishes, and sharing caregiving responsibilities. Family caregivers often undergo a process of coming to terms with the patient's terminal condition, which is essential for effective caregiving and emotional preparedness. This acceptance enables them to support the patient through the end-of-life journey. Consistent with the study of Upasen & Thanasilp³², four major themes related to death acceptance from a Thai Buddhist perspective were identified: perceiving death as a natural part of life, perceiving that death cannot be controlled, understanding that death can come at any time, and letting everything go before dying. Religious and spiritual beliefs in Thailand are deeply rooted in Theravada Buddhism which is the dominant religion in Thailand. Buddhists believe in the inevitability of death. One goal of life is to psychologically prepare to accept one's impending death. Moreover, Buddhists consider death with a peaceful and pure mind to be a good death that can lead to a good rebirth³³.

In addition, collaborative decision-making of family members is vital. This ensures that treatment choices align with the patient's preferences and values, enhancing the quality of end-of-life care³⁴. Moreover, understanding and honoring the patient's end-of-life wishes, including advance directives and preferred care settings, are central to family



caregiving. Effective communication about these wishes is crucial for providing care that respects the patient's autonomy³⁵. The experience of caregiving for a good death at home, as perceived by family members of terminally ill cancer patients, often involves sharing caregiving responsibilities. Family caregivers often divide responsibilities such as personal care, medical management, and emotional support to provide holistic care for the patient. This collaborative approach helps in balancing the caregiving load and prevents burnout²⁸. Effective caregiving often requires teamwork, where each family member contributes based on their strengths, availability, and comfort levels. This collaboration helps prevent caregiver burnout and ensures continuity of care. In addition, sharing caregiving duties allows family members to support each other emotionally, enhancing their preparedness for the patient's eventual passing. This mutual support system is vital for coping with anticipatory grief and stress associated with end-of-life care³⁶. Most importantly, sharing caregiving duties can strengthen familial bonds as members come together to support the patient. Therefore, sharing responsibilities contributes significantly to the quality of the patient's final days.

Providing end-of-life care at home for terminally ill cancer patients is perceived by family members as an act of love and attachment, offering a meaningful opportunity to give back to their loved ones. This caregiving experience is considered a key component in facilitating a "good death." Strong emotional bonds between patients and family members can influence coping strategies during palliative care. Providing care allows family members to express love and attachment, offering a sense of purpose and fulfillment during a challenging time. This emotional engagement is integral to the caregiving experience. In addition, secure attachments may facilitate better emotional adjustment and resilience in facing the challenges of terminal illness. Family members often associate a "good death" with the fulfillment of the patient's wishes, effective symptom management, and the provision of compassionate care. Their involvement, driven by love and attachment, is crucial in achieving these aspects³⁷. Consistent with the results of the study of Lai et al³⁸, family caregivers' attachment styles and home care setting were found to be associated with psychological effects in caregivers of patients with terminal cancer. Moreover, family cohesion can reduce social burden, facilitate patient's awareness of their terminal condition, and help prevent pre-loss grief symptoms in the family caregivers.

Moreover, in Thai culture, family members often perceive caregiving for terminally ill patients as an opportunity to reciprocate care, which is integral to achieving a "good death." The concept of a good death in Thailand encompasses acceptance of death, social support, and faith. Family involvement, driven by a sense of duty and reciprocity, is crucial in fulfilling these cultural and religious expectations, thereby facilitating a good death³⁷. In addition, the Thai cultural context emphasizes family unity and collective responsibility in

caregiving. Family members perceive their caregiving role as a way to honor their loved ones, reflecting deep-seated cultural values of filial piety and reciprocity³⁹. At the same time, Thai family caregivers view their role as a chance to reciprocate care, aligning with Buddhist beliefs in karma. Providing compassionate care is seen as a way to promote a peaceful death for their loved ones and accrue merit for both the caregiver and the patient⁴⁰. Furthermore, it is also perceived as a meaningful way to return the care and affection received from the patient, strengthening familial bonds during the end-of-life phase. This reciprocal relationship enhances the emotional well-being of both the caregiver and the patient²⁷. In summary, within the Thai context, family members view caregiving as an opportunity to reciprocate care, deeply rooted in cultural and religious values. This reciprocal act is considered a key component in facilitating a good death, underscoring the importance of familial involvement in end-of-life care.

However, some family caregivers described feeling burdened by the overwhelming responsibility of caregiving. This sense of burden manifested in both physical and psychosocial dimensions, including deteriorating health and social isolation. These findings are consistent with previous studies that highlight the cumulative impact of long-term caregiving on family members' well-being^{41,42}. Despite these challenges, family caregivers in this study expressed a strong sense of willingness and emotional commitment to providing care, which they described as an act of love and a devotion of personal life. This paradox—between burden and willingness—reflects the complexity of caregiving within the Thai sociocultural context, where familial duty, compassion, and spiritual values deeply influence caregivers' attitudes. Understanding this dynamic is crucial for nurses and palliative care teams in developing culturally sensitive interventions that not only support family caregivers' physical health, but also acknowledge their holistic dimensions.

===== Conclusion =====

In conclusion, the findings of this study illuminate the uniqueness of Thai culture. Cultural belief systems are an important aspect of family members' perception and experience of family caregiving for a good death of terminally ill cancer patients at home. However, a clear understanding of family members' meaning of good death is required due to individualized needs and perceptions. Nurses should strive to understand and respond more effectively to the needs of family members, enabling them to support patients in achieving a good death, to be present during the final moments, and to experience satisfaction as a result. The concept of a good death is complex and interconnected with social and cultural contexts, experiences, and the mutual relationship between the needs of patients and their family members. It also depends on the ability of those involved to



meet the needs of both the patient and the family, as well as on their individual perceptions and experiences. Understanding the meaning of a good death as perceived by each individual within the cultural context and value systems that influence caregiving experiences is essential.

Recommendations for the Implication of the Research Findings

The research findings provide foundational information that explains the caring experience for a good death at home from the perspectives of family members of terminally ill cancer patients. These findings can contribute to the development of the Thai family service system aimed at supporting the care of terminally ill cancer patients for a good death at home. Additionally, the results can inform nursing practices to promote the well-being of Thai families involved in this case. This study also serves as a basis for further research on the caring experiences of Thai family caregivers of terminally ill cancer patients at home. Educational institutions can also incorporate these findings into their curricula, across undergraduate education and short-term training programs, to enhance nurses' competencies in this area.

Recommendations for Future Research

The findings from this study highlight the culturally embedded nature of caregiving for a good death at home among family members of terminally ill cancer patients in Thai sociocultural context. Future research could expand upon these insights in several directions:

1. Exploration of diverse sociocultural contexts: As this study focused on Thai sociocultural norms, future research could explore how caregiving experiences vary across different regions of Thailand or among families from diverse religious and ethnic backgrounds. This would help to uncover nuanced cultural factors that shape end-of-life care practices.
2. Longitudinal studies on family adaptation: Given the emotional complexity involved in caring with love and attachment, longitudinal qualitative studies may help to understand how family members adapt over time—from diagnosis through bereavement—and how caregiving impacts their long-term well-being.
3. Development of interventions: Based on the components identified—such as maintaining routine, emotional support, religious practices, and family collaboration—future research could focus on developing and testing culturally tailored interventions or educational programs to support family caregivers in providing holistic end-of-life care at home.

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