Abstract

Background: Family caregivers have a significant role in Thai healthcare, taking on responsibilities of health professionals. The purpose of this research was to explore Thai family caregivers’ experiences of providing palliative cancer care. Methods: This qualitative study took a phenomenological approach. In-depth interviews were conducted with 14 family caregivers aged 33–72 years in a regional hospital in the north of Thailand. The data was analysed using Colaizzi’s phenomenological approach. Rigour was established by following Lincoln and Guba’s guidelines for qualitative research. Findings: The experiences of Thai family caregivers providing palliative cancer care could be categorised into four themes: caring as a team; caring as supportive care; taking care to keep patients happy; and caring for the self while looking after a relative. Conclusion: Health professionals can support family caregivers to deliver the best care for cancer patients and to help them decrease their stress. This study discusses ways how this may be done.

Key words: ● Family ● Caregiver ● Palliative care ● Cancer

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Cancer is a serious health problem with a high mortality rate unless it is diagnosed and treated at an early stage (Wiseso et al, 2017; Taleghani et al, 2018). Palliative care can be provided at any point along the cancer care continuum, from diagnosis to the end of life (Aydogan et al, 2016). When a person receives palliative care, he or she may still be given cancer treatment. A cancer diagnosis is terrifying for Thai people because it is the leading cause of death in the Thai population (Kongswanan et al, 2012). Cancer and its treatment cause many symptoms and side effects, which can be a source of distress for patients and their families (Aydogan et al, 2016; Wiseso et al, 2017).

In Thailand, more than 95% of the population believes in Buddhism (Kongswanan et al, 2012), which affects every decision in their lives, including those on medical treatment, as well as their perception of disease. Relatives of Thais who have long-term conditions assist them by helping with medication and day-to-day expenses (Kongswanan et al, 2010). Family members take care of each other. Adult children are expected to support and to care for their elderly parents when they get sick. Elderly parents prefer to live with their children and fear living separately from them (Wiseso et al, 2017). Thai cultural beliefs and social and family structures are among the factors that form social support.

However, family caregivers also experience distress related to the burden of caregiving and their loved one’s physical pain or impending death (Rhondali et al, 2014).

Some studies have demonstrated the importance of family support in providing comfort and peace shortly after a love one’s cancer diagnosis (Adams et al, 2014; Aydogan et al, 2016). Family caregivers are important, especially in the countries where health personnel can be scarce. Thailand, which is in Southeast Asia, has a limited number of palliative and hospice care units (Krongyuth et al, 2014).

In palliative care, family caregivers address most of the patient’s problems and needs, and are the main communication bridge between patients and healthcare providers (Huang et al, 2012). Family caregivers need to know about holistic caring, acquire practical skills and be aware of what to expect and plan for as the relative’s health declines (Angelo et al, 2013).
Carers’ psychological distress is closely associated with that of the patient; a palliative approach generally considers the family to be the ‘unit of care’ because family members share caring to minimise their distress (Kim et al, 2014). The experiences of these caregivers are important for health personnel; they allow professionals to understand carers and use these experiences to improve how they look after family members.

For example, Huang et al (2012) found families frequently faced difficult decisions while caring for terminally ill loved ones. Families’ distress around palliative care is conceptualised as a multidimensional construct encompassing physical, cognitive, affective, behavioural and quality-of-life domains (Carolan et al, 2015). Healthcare staff need to pay close attention to the psychological health of caregivers, working closely with them and finding strategies to best support them and their individual coping styles in distressing situations (Kim et al, 2014).

However, family caregivers’ experiences when providing palliative cancer care are not well understood in Thai culture. The purpose of this article is to explore Thai family carer experiences of giving palliative cancer care using a qualitative approach to provide detailed explanations of their experiences. This data could be used to develop future interventions for Thai family caregivers to address their specific needs throughout the cancer care trajectory.

Methods

Study design

This study used a phenomenology qualitative research design. This approach can be used to explain and describe the ontological meaning and the lived experience of a particular group of people (Grossoehme, 2014; Sloan and Bowe, 2014; Gildersleevea, 2016).

Setting and samples

Subjects were recruited from an oncology unit at a regional hospital in the lower north of Thailand, where the researcher worked as a student supervisor at the time. A nurse working in that unit helped to identify and contact participants.

Inclusion criteria included being a primary family caregiver aged 20–80 years who had been looking after patients with cancer for more than 6 months. In addition, participants had to be related to the clients as a parent, husband, wife, son, daughter, sister or brother.

The nurse chose participants who would be able to describe features of their lived experiences of palliative care in depth.

Data saturation was reached and no further participants recruited when: no new concepts were emerging; the subthemes contained detailed information; and all categories showed variety. Fourteen subjects were recruited.

Ethical considerations

The study was approved by the human research ethics committee of the university. Approval for this research involving human subjects was obtained from the regional hospital in line with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

All participants were fully informed about the purpose of the study and assured anonymity and confidentiality would be maintained. Alphabetical codes were used instead of participants’ names. The participants were told that anyone who wished to withdraw could do so at any time.

Data collection

The data was collected between May 2016 and September 2016 in a private room in the oncology unit. The interviews were conducted by the researcher, who has been a nurse instructor in the field of oncology for more than 20 years.

To obtain rich, complete data, each interview lasted 60–90 minutes. The researcher used the techniques of reflection, repeating the question, giving an example and asking unstructured questions until the data was saturated.

The interview guide, created by the researcher, included questions related to Thai family caregivers’ experiences of palliative cancer care. The guide and the questions’ content validity were approved by three people who were experts in both oncology and qualitative research.

A pilot study was carried out to test the reliability of the questions on five respondents, using similar inclusion criteria, in another district in Thailand.

The interviews started with questions including: ‘Can you describe your experiences of providing palliative care for your loved ones?’ and ‘How do you apply this method of caring in this situation? Why?’ The researcher encouraged participants to reflect on and talk about their experiences of providing palliative cancer care to get as individual a description as possible.

The researcher also asked participants to be explicit about the phenomenon, using questions such as: ‘How do you use this method for caring? Why?’ or ‘Can you give more details about that?’ The researcher tried to be sensitive and open minded toward the participants.
Data analysis
All interviews were recorded and transcribed verbatim. The researcher used frequency statistics to analyse personal data and content analysis for patient data.

Data analysis was carried out using Colaizzi’s content analysis method (Colaizzi, 1978). This has six procedures: read transcripts many times to find themes; extract as many sentences relevant to each theme as possible; group sentences by each theme; stop interviewing when data saturation is reached; classify information so all issues have major and minor themes; and check the accuracy of information by comparing it with the original field notes.

Finally, the researcher integrated the results into a comprehensive description of the topics and returned these to each participant so they could verify the results (Polit and Beck, 2012).

Rigour
Study rigour was achieved by following Lincoln and Guba’s criteria of 1985 of credibility (Lincoln and Guba, 1985; Polit and Beck, 2012; Cope, 2015). The researcher followed these guidelines by being professional, and ensuring intellectual rigour and methodological capability.

To provide dependability, all interviews were transcribed by the researcher. To provide confirmability, data, interpretation and findings of the research could be linked to their sources.

In addition, the results were integrated into an extensive description of the topics and returned to each participant to verify the results.

Finally, to provide transferability, the researcher provided a rich description of family caregivers’ experiences of palliative care.

Results
All of the participants were Buddhists and in the age range of 33–72 years (mean=46.57 years). Education levels ranged from no education to high school; half of the participants (50.0%) had completed only primary school. More people were in farming (42.9%) than in any other occupation. Most of the participants were wives and daughters of patients (85.8%); in Thai culture, women are the main caretakers and the men are often out working on farms, so may have less time for study participation (Lundberg and Rattanasuwan, 2007). Lymphoma accounted for the highest proportion of cancers (21.4%).

Four themes about the experience of Thai family carers on palliative cancer care were identified from the results:

- Caring as a team
- Caring as supportive care
- Taking care to keep patients happy
- Caring for the self while looking after the patient

These themes and their subthemes are outlined in Table 1.

Caring as a team
Caring as a team was the first theme in this study, and comprised merging family members into a care team, sharing the responsibility for caring and having unity in the family.

The emergence of managed care is the spontaneous response to a diagnosis of cancer in a relative. The process of illness and treatment of cancer takes a long time, so Thai family carers come together to provide care and take responsibility for their loved ones. Individuals did not deliver palliative cancer care in isolation; care was provided by a team of family members.

<table>
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<tr>
<th>Themes</th>
<th>Subthemes</th>
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<td>Caring as a team</td>
<td>Emergence of a family care team</td>
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<td>Sharing a responsibility for caring</td>
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<td>Having unity in the family</td>
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<td>Caring as a supportive care</td>
<td>Supporting the patient through crisis</td>
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<td>Supporting a patient to be treated holistically</td>
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<td>Providing care based on symptoms</td>
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<td>Taking care to keep patients happy</td>
<td>Focusing care on diet and stress management</td>
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<td>Making patients feel happy during the treatment</td>
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<td>Using religion as a source of encouragement for loved ones</td>
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<td>Spending more money to make patients happy</td>
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<td>Caring for the self while looking after the patient</td>
<td>Reducing their stress so not to discourage patients</td>
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<td>Trying to be strong to cheer patients</td>
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<td>Balance care between patient and themselves</td>
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Table 1. Themes and subthemes of Thai family caregivers’ experience of providing palliative cancer care
Thai family caregivers delivered supportive care so the patient was treated holistically.

‘We have a team of family carers. If we care alone, it is sometimes stressful and tiring. Moreover, if the patient continuously needs care, the caregiver will feel stress.’ (Participant 1)

‘My husband stays with me and my children. His sister and brother live far from us but they sent money to help me. His niece knew he was sick and she sent money to me too. Sometimes, his mother comes to care for him. My family have given good care to my husband.’ (Participant 5)

Family caregivers have to deal with the unpredictability of their loved one’s disease as well as the expense involved, and there was a sense of family unity among members over these issues.

‘I and my family get the best things [to help with] cancer. My family turn to unity. It seems to be encouraging that children take turns to work in harmony to give care. I was encouraged. Then the pain from chemotherapy treatment went. Feeling better, my mother said. This seems to be over.’ (Participant 8)

Caring as supportive care
Thai family caregivers noted that the meaning of caring was similar to giving supportive care. Caring as supportive care had three subthemes: supporting the patient through crisis; supporting a patient to be treated fully or holistically; and providing care depending on symptoms.

Cancer and its treatment have many symptoms and side effects, which can be a source of stress for patients and their families. The treatment step of the disease can be a time of crisis, especially for patients. Thai family caregivers take care of patients by supporting them through crisis.

‘I focused her mind on not being afraid, and not to be stressed. I must try to support her through this crisis.’ (Participant 13)

‘I give my mother palliative care. It is actually supportive care to go through the crisis each day.’ (Participant 6)

Palliative care involves treatment, and Thai family caregivers gave supportive care so the patient was treated holistically.

‘I encourage my mum. I just tell her that I am not stressed and fearful. The treatment will not take up much more time. It is nearly complete. I support her during the treatment and doctor appointments.’ (Participant 14)

‘The solution can be: try not to think ahead. I tried to hold her until she finished the treatment.’ (Participant 2)

Thai family caregivers take care of patients by supporting them through crises and to be treated holistically, and provide care depending on symptoms. Patients with cancer experience physical, psychological, spiritual and social distress during treatment. The predominant symptoms are nausea, vomiting, fatigue, weakness and loss of ability to participate in some activities.

‘I take care of my daughter. I take care of the symptoms. But I know that she will gradually need increasing care.’ (Participant 9)

‘I give supportive care to my mum with her symptoms. We take care of her to reduce the symptoms. At first, my mum could not eat, sometimes she eats less. We were trying to find food she likes. We try to help her to deal with the treatment.’ (Participant 12)

Taking care to keep patients happy
The third theme was taking care to keep patients happy. Thai family caregivers try to make their loved ones feel happy during the process of treatment by focusing their care on diet and stress management, using religion to encourage their relatives, and spending more money to make them happy.

‘I take care of him in the best way for patients. Most of the care is focused on food, which is not stressful to patients.’ (Participant 3)

‘Most of the care is focused on food and stress management. My dad lost weight. I am trying to find supplementary food, refreshments, juice to offer him. I buy soft-boiled rice for him too. I also tell him not to stress.’ (Participant 10)

The other aspect of taking care to keep patients happy was encouraging them during treatment. All the Thai family caregivers focused on encouraging patients because they believe stress is a cause of cancer.

‘He was afraid, but I told him not to be afraid. His uncle had cancer and the doctor said his uncle would live more than three months. But his uncle is still alive 30 years later and only recently died. We must greatly encourage patients. He will be with us for long time.’ (Participant 11)
I told him that all of us will get ill. Don’t be afraid of it. I take him to the temple to pray. To make himself peaceful. Everything is based on karma.’ (Participant 4)

One aspect of taking care to keep patients happy was spending more money. Thai family caregivers spent money to modify the home environment, buy food and pay for treatment.

‘Sometimes we are not busy—sometimes we hire someone to be a friend with my sister at the hospital. We also buy special food that she likes. We pay for the VIP room. We are ready to support her. We have the money to hire someone to take care her when I am busy.’ (Participant 2)

‘I pay more money for air conditioning and modified my house. He feels so hot. He must sleep in an air-conditioned room. I spent money too on food for when he cannot eat [normally]. Sometimes, I buy canned fruit. I take care of him by making him as happy as possible.’ (Participant 7)

Caring for self during patient care

While Thai family caregivers looked after the patients, they also cared for themselves. The cancer process is traumatic for both patients and their caregivers.

This study found that Thai family caregivers engage in self-care while looking after their relatives to reduce their stress and to be in a position to give better cares. Thai family caregivers try to reduce their stress so as not to discourage their ill relatives.

‘It must not be stressful because if we are serious, patients decline. I tried to take the best care of him and take care of myself too. I must be strong, not ill. If I get sick, I cannot care for him.’ (Participant 3)

‘My husband is the master of the family. When he got sick, I was worried and stressed. But I don’t want him to know this. I pretend to be strong to encourage him.’ (Participant 11)

Some Thai family caregivers have personal health problems and have to strike the right balance between caring for themselves and looking after their loved ones.

‘I have to find a balance between my dad and me. In particular, I was sick from lupus [systemic lupus erythematosus]. I have to take care of my illness while I care for my dad.’ (Participant 1)

This study showed that the experiences of Thai family caregivers with palliative cancer care had many aspects within caring as a team, caring as supportive care, taking care to keep patients in good frame of mind and as happy as possible, and self-care while looking after their relatives. Although the care involved with the treatment of cancer can be daunting, all family caregivers tried to deliver the best care for their loved ones.

Discussion

As noted above, there were 14 participants in this study. All were Buddhists; more than 95% of Thai people believe in Buddhism (Kongsuwan et al, 2012). Ages were in the range of 33–72 years (mean=46.57 year). The largest occupational group was farming (42.9%) and most participants were female, since in Thai culture the women are the main caretakers and the men are often out working in the farm so may have less time to take part in studies (Lundberg and Rattanasuwan, 2007). The most common type of cancers was lymphoma (21.4%).

Haematological malignancies are rare (Taylor et al, 2017). The patients with hematological malignancies are more likely to die in the hospital compare with those with solid tumours (Hui et al, 2014). However, specimens of malignant cells can be obtained easily from blood. Therefore, clinicians in general practice may be more frequently exposed to haematological malignancies than solid tumours.

Palliative cancer care is not a normal process in families. It is a crisis situation for both family caregivers and patients. Cancer is a stressful experience not only for patients but also for their family caregivers who assist with care or medical tasks, offer information or provide emotional or financial support (Adams et al, 2014).

Most Thais have an extended family, and many rely on Buddhist values to guide them when they deal with family health issues, especially those affecting their parents (Lundberg and Rattanasuwan, 2007). This culture is important for Thai people's health.

This study found that Thai family caregivers experienced caring as a team. Uniting to form a care team is not a normal situation for a family. Teams emerged from a common goal of caring for their loved ones, and family members shared a responsibility for caring. The study found that, regardless of the amount of care provided, the emotional distress that the caregiver experienced when providing care limited their ability to participate in typical daily activities such as work, recreation and social events (McGuire et al, 2012). Sharing responsibility for caring
between Thai family caregivers emerged in this study, as did having unity in the family.

Palliative care focuses on relieving symptoms caused by serious cancer. It can be given at any point during a person’s illness to help them feel more comfortable. Caring as supportive care is one of the experiences of Thai family caregiver. Patients experienced pain and distress from the cancer as well as from the treatment for it. Thai family caregivers support their loved ones in many ways, including helping them through a crisis, supporting them to be treated holistically and providing care based on symptoms.

Family caregivers are deeply affected by the cancer patient’s illness and the side effects of treatments (Carolan et al, 2015). Moreover, Thai family caregivers took care to keep patients happy by focusing care on diet and stress management, making patients feel as positive as possible during the process of treatment, using religion to encourage their loved ones and spending more money to make patients happy.

Family caregivers have to monitor their ill relative and manage symptoms related to the illness. These caregiving responsibilities must be carried out while having to respond to emergency care needs, make care decisions and provide emotional care and support (Janze and Henriksson, 2014).

Thai family caregivers had to strike a balance in caring for patients and themselves. Family members frequently reported feeling ill prepared to assume care responsibilities for patients with advanced disease (Perrin and Kazanowski, 2015). Moreover, family caregivers experience levels of depression similar to patients and greater than the general population (Carolan et al, 2015). In palliative care, family caregivers experienced stress and anxiety and had to reduce their stress so as not to discourage patients, to try to be strong to cheer patients and to balance caring for the patient with caring for themselves.

Limitations

Limitations of the study are that respondents may have answered the questions in a manner that would be viewed favourably by others. Another limitation was that most participants were female. Future studies could recruit a sample where participants’ sex reflects the disease prevalence pattern. Future researchers could consider methods of data collection that be used to recruit male participants more easily, perhaps by going to where they work or live to collect data.

Conclusion

A knowledge of palliative cancer care is important for caregivers. These findings add to a small body of evidence suggesting that, while engaging in the highly stressful act of palliative cancer care, Thai family caregivers hide their feelings of stress and pretend to be healthy so as not to discourage patients. They provide support by giving assistance for medication and daily expenses of people who have long-term conditions (Wiseso et al, 2017), try to keep patients to be happy with supportive care, and care as a team.

It is recommended that nurses increase their knowledge of palliative cancer care to encourage the family care team to continue palliative cancer care and monitor the symptoms of patients in the best way they can. To cope with these demands, family caregivers require psychological support from healthcare providers.

Declaration of interests: none


Kongsuwan W, Keller K, Touhy T, Schoenhofer S. Thai Buddhist

• Most Thais have an extended family, and many rely on Buddhist values to guide them when they deal with family health issues. This culture is important for Thai people’s health •

Key points
- In Thailand, there is a strong culture of family members caring for relatives with long-term illness
- Families work in unity to care for their relatives as a team
- It is important for Thai family carers to understand palliative care
- Thai family carers require psychological support from healthcare providers
- Interventions for Thai family caregivers to address specific needs throughout the cancer care trajectory should be developed

Continuing professional development: reflective questions
1. Reflect on the role of the nurse working at an oncology unit on their responsibilities to patients who need palliative care.
2. How can nurses be sure they are aware of psychological distress of caregivers who are looking after patients approaching the end of life?
3. Consider the four themes healthcare providers have to consider to understand palliative care in a cultural perspective

Short reports
International Journal of Palliative Nursing now publishes short reports, and invites submissions for consideration. Short reports are intended to provide the international palliative care community with the opportunity for concise communication of work that will be of interest to nurses working in palliative care. Submissions are invited on:
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