

Living with suffering as voiced by Thai patients with terminal advanced cancer

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The ultimate goal of end-of-life care is to relieve suffering and promote the quality of life of patients and their families. Suffering, however, is difficult to define and appears, therefore, to be something about which little is known (Morse, 2001). Often the experience of suffering reported by patients is equated to pain or other symptoms by health-care providers. Cassell (1991) demonstrated that suffering is an experience of the whole person, while the focus of medicine is likely to be only on the diseased body. Understanding the experience of suffering in patients with terminal illness can provide essential information to develop patient-driven care strategies, which would contribute to ultimately improving the quality of life of patients and their families at the end of life.

During the last decade, there has been a substantial increase in the concern and attention given to the phenomenon of suffering in health-care literature. Using the method of concept analysis, Rodger and Cowles (1997) defined the concept of suffering as an individualized, subjective, and complex experience. Suffering entails the meaning that individuals attribute to a situation (Kahn and Steeves, 1986). In addition the suffering experience is complex in the way that it is historically, culturally, and socially constructed (Barton-Burke et al, 2008). Suffering is also conceptualized as a result of the threat to the integrity of one's own experience of personal identity (Kahn and Steeves, 1986) and a response to its loss (Morse, 2001; Ferrell and Coyle, 2008). The loss may be of a relationship, of some aspect of the physical body, of control, of certainty, of plans in life, or a significant loss of self (Chamaz, 1983; Ferrell and Coyle, 2008).

Suffering is part of a patient's illness narrative and encompasses the 'wounds' that are identified and told only by those who suffer them (Terry and Olson, 2004). The illness narrative provides listeners with access to subjective experiences and their meanings (R  holm, 2008). To gain a comprehensive view of suffering, Kahn and Steeves (1986) suggested that it is impor-

tant for a research study not to trivialize lived experiences into medical terms, or collective behaviours. Several authors have suggested that a qualitative approach may be appropriate for studying human suffering (Kleinman, 1995; Arman and Rehnfeldt, 2006).

Suffering is a common phenomenon experienced by patients with cancer, particularly advanced cancer. Cancer is one of the leading causes of death in Thailand (Bureau of Policy and Strategy, 2010). The most common cancers in men include liver, lung, colorectal and bladder cancers, and in women, cancers of the cervix, breast, liver, and lung (Ratanavichitshilp et al, 2005). Thai people with cancer often seek medical treatment once the disease has reached the advanced stage. There are deficiencies in the delivery of hospice and palliative care services in Thai health-care institutions; mostly to inpatients, while home care services are also limited. Most patients die at home (Bureau of Policy and Strategy, 2008). Based on literature and online database review, little research was located on

Abstract

Cancer is a leading cause of death in Thailand. Thai cancer patients often seek medical treatment while in advanced stages of the disease. This longitudinal qualitative study aimed to describe the suffering that patients with terminal advanced cancer experience in their everyday life. A series of interviews were conducted and patient observation performed with 15 patients with terminal advanced cancer. Thematic analysis was applied and the overriding theme of the end-of-life experiences was living with suffering. Five inter-related sub-themes regarding the experience of suffering were identified in the informants' accounts, including physical symptom distress, feeling of alienation, sense of worthlessness, sense of burden to others, and desire for hastened death. The findings of this study can be of value for health professionals in cancer care in Thailand. Comprehensive end-of-life care programmes are needed to alleviate suffering in this group of patients.

Key words: Suffering ● Terminal ● Advanced cancer
● Qualitative ● Thailand

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suffering among patients with advanced cancer in Thailand (Nilmanat, et al, 2010). The findings presented in this article are taken from a larger project, the aim of which was to explore the experience of patients living with terminal advanced cancer in southern, Thailand (Nilmanat et al, 2010). This article reports on one of the main themes under this study's investigation; living with suffering.

Method

Setting

This study was conducted in southern Thailand. The selected hospital was known as the large public health service provider for the treatment of cancer in Southern Thailand. The people with cancer from various provinces in the south receive cancer treatments at this hospital. The division of therapeutic radiology was selected as the place to establish rapport with informants and gain permission to visit patients at home.

Study design and participants

This was a longitudinal qualitative study, in which participants were followed through from the point of referral to home care until death. The qualitative method is an appropriate approach for exploring issues surrounding end of life (Koenig et al, 2003), while the longitudinal study offered the researchers an opportunity to gather information about changes in the experience through encounters with various situations during a period of time (Nakashima and Canda, 2005). The eligibility criteria for patient inclusion were: older than 17 years; diagnosed with terminal cancer with life expectancy of less than 6 months (predicted by the medical doctors who recruited patients using a palliative performance scale less than 50); aware of their prognosis; able to communicate verbally in Thai; mentally and physically able to participate in an interview; family caregivers agreed to participate in the study. The recruitment process took place in a tertiary care hospital.

Twenty-one patients were approached and 15 participated in the period from January 2008 to August 2009. Six patients withdrew at the time of interview, with four being too sick to respond verbally, and the other two's families having enormous emotional distress due to the terminal diagnosis. Of the 15 patients, four were men and 11 women. The informants ranged in age from 30 to 72, with a mean age of 56.47 years. Five of them had been diagnosed with cervical cancer as the primary cancer type, four others with urogenital cancer, three with lung cancer, one with head and neck cancer, one with breast

cancer, and one with colon cancer. Religious affiliation was Buddhist ($n=14$) and Muslim ($n=1$). All of the patients lived with their families and were taken care of by various family members, including children ($n=10$), spouses ($n=4$) and parents ($n=1$).

Before initiation, the Health Research Ethics Board at the Faculty of Nursing, Prince of Songkla University approved the study and the Hospital Research Ethics Review Board of the selected hospital granted formal access to patients. The doctor approached the patients who met the inclusion criteria to seek their agreement to participate in the study. Patients received verbal information about the content and objectives of the study. They were reassured that they would not be disadvantaged from receiving normal care if they refused to be included in the study. Informed written consent was obtained from all of the patients before the interview. All of the patients were informed that their personal data would be kept confidential. Names used in presented findings are pseudonyms.

Multiple sources of data collection were pursued. Series interviews and participant observation were used as primary data collection methods. The principle investigator conducted all the interviews at the informants' home or place of care. The interviews generally began with, 'can you tell me of your experience of having this illness?' as an invitation for informants to share their stories. The questions included, for example: what are your health problems/concerns at present? How do these health problems/concerns affect your life? The participants were also encouraged to describe their daily experiences. Follow-up interviews focused on how their experiences had changed since the previous interview. The frequency of interview visits varied based on the health status of the informants and their willingness, ranging from weekly to monthly. During each visit, the interviews lasted about 60 minutes on average. Interviews were taped and then transcribed verbatim. A total of 116 interviews were completed and the mean number of interview visits per patient was 7.73, with a range of 4–14.

Participant observation focused on the informant's response to questions and when he or she experienced distress symptoms during the interaction between informants and their family members and their routines at home. Field notes were recorded to describe experiences and observations arising from the interviews and participant observation. A field journal of thoughts and feelings was also kept.

Data analysis

The data analysis followed the basic steps as guided by Patton (2002). The preliminary analysis was started and checked simultaneously during the data collection phase. The transcription and field notes were read and re-read several times, aiming to get the sense of the whole experience and to look for repetition of words and/or sentences that participants used to describe or express their experiences in a particular context. Comparative analyses within and across cases were performed to determine similarities and differences and common patterns were identified and grouped together. Several meetings among the research team were held. All investigators reviewed the significant statements and coding or emergent categories independently. The principle investigator drafted and redrafted the themes, statements, and illustrative quotes that were discussed in the research team and then revised them together with the other research team members to ensure agreement, and develop the final emerging themes. Lincoln and Guba's (1985) strategies for enhancing trustworthiness were adopted. These strategies included prolonged engagement, persistent observation, triangulation, reflexivity and a transparent audit trail.

Results

The overriding theme of the end-of-life experience was living with suffering. Five inter-related sub-themes regarding the experience of suffering were identified in the informants' accounts. The themes are described below, and illustrative quotes from interviews are used to identify and substantiate the thematic structure.

Physical symptom distress

All of the informants shared their experience of suffering related to distress symptoms. Most of them experienced more than one symptom at the end of life. The physical symptoms perceived as most burdensome and distressing were lack of energy, anorexia, pain and dry mouth, both when they were newly recruited to the study and in the last month before death. Some informants indicated that their suffering stemmed from their unbearable symptoms.

Jame, a 58-year-old man, spoke about his experience of living with metastatic lung cancer and concurrent symptoms.

'It is miserable. I feel very weak ... no energy to do things. After receiving chemotherapy, I lost my appetite ... did not want to eat ... could only have two or three spoonfuls per meal. I often woke up in the middle of the night

because I felt hungry and had gastric discomfort. I had to look for snacks and/or milk to fill my stomach. After that, it would be hard for me to go to sleep again. Then my mind would sink into anxiety; keeping on thinking and worrying about my unfinished business ... could not find the way out. I could not talk to my son and daughters about this. They are too young and very busy. In the morning I would not feel rested ... this [situation] made me weaker and weaker. It also made me feel blue ... why does it take so long to get better? It is not good to be like this ... (sigh).'

Pain was another cause of suffering for many informants. Ten of them experienced moderate-to-severe pain on a daily basis in the last month of life. Rose, a 41-year-old woman with cervical cancer and metastasis to the bones and abdomen, often complained of physical pain, throughout the course of her illness. It appeared that her suffering from persistent pain was significant. Rose described her experience of suffering caused by pain and its consequence as follows:

'I do not want to experience pain again. The pain gave me many sleepless nights. It also made me grumpy; not wanting to talk to anyone, because I wanted to avoid upsetting them. I felt grumpy, touchy, and I actually felt sorry for my husband and relatives. When I was not in pain, I did not feel so bad, but when I was in pain, I felt withdrawn ... (crying) ... the pain is the scariest thing. When I was not in pain, I could walk anywhere I wanted, but when I was in pain my life entered darkness ... [I] could not walk. I was suffering.'

This patient explained the experience of suffering as a result of physical pain in terms of its effects on daily activities and her emotions, rather than its aetiology. The pain would cause more emotional suffering to this patient if it affected her ability to perform daily activities.

Feeling of alienation

Distress symptoms such as lack of energy, pain and dyspnea limited the informants' functional activities. Additionally, those who received radiotherapy or chemotherapy were aware that they were susceptible to infection. Their body image was also altered, becoming skinny, weak, or losing hair. All the conditions mentioned led the participants to social isolation; they did not wish to be seen, thus, they kept themselves indoors. Concerning the change of body image, some informants were fearful of being discriminated or

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stigmatized by society, and of what other people would say about them behind their backs (rumors). One patient spoke of being talked about by people in her community:

'If people know, they will talk about me ... something like, "she got cancer, she is going to die soon". I do not want to hear their words. It upsets me.'

The informants separated themselves from their social network; hence, suffering from feelings of insecurity and humiliation when in contact with other people. In addition, isolating themselves from their social network created the sense of alienation in some informants. These people suffered because they perceived themselves as deviants in relation to others who are healthy. Jasmine, a 50-year-old woman with terminal lung cancer, recounted her feeling of alienation when asked about isolating herself at home:

'I fear going out ... [I am] not strong ... [I am afraid of] getting infected ... [I] just sit here (at the window), look at other people outside. Others are good [healthy] ... can walk about and work, but I hide in the house. I cannot do anything ... (sigh) ... and think why it has to be me who is in this condition.'

A sense of worthlessness

A sense of worthlessness was the most frequently mentioned concern among the informants, particularly the women. As the disease progressed, the concurrent unrelieved symptoms had an adverse effect on the informants' functional status. Some informants spoke of their fear of losing control of their body. Loss of ability to perform daily activities and an increased dependency triggers psychological and spiritual suffering. For some informants, loss of control over their body is regarded as losing the value of being a human. Many accounts revealed a sense of pressure and stress when the informants failed to balance the competing demands of their family and themselves. Thus, they felt depressed and worthless.

This feeling was prominent in Anne, a 49-year-old housewife living with her husband and 17-year-old son. She was diagnosed with breast cancer and underwent surgery followed by chemotherapy and radiation. She did well until 3 years later when she developed shoulder pain. She consulted her doctor and was hospitalized for investigation. During hospitalization she became paralyzed as the disease spread to her spine. At the first visit, after the researcher performed the Thai Wai (the traditional Thai greeting during

which hands are put together close to one's body resembling the lotus), and Anne was unable to return the greeting, she burst into tears and mumbled about how worthless she had become:

'There is nothing left for me to live for ... I lost the dignity as a human being ... I cannot [even] perform the greeting; arms and legs are completely weak. The disease has eaten my body up ... nothing is left. If it [cancer] only ate only one [affected] side [of the body], it would be better than losing all [function]. Nowadays, my life is worth nothing ... [I] cannot do anything.'

Later on, Anne spoke emotionally about a sense of worthlessness and her loss of dignity for having to depend on her son to assist her with her daily activities:

'I cannot come to terms with the changes in my life, from being a capable person to an incapable one. I cannot accept it. [I] have lost the value of being a human ... lost my dignity as a human being ... and as a mother, I feel sorry for my son. But as I am ill, and not having any other person to help me, I have to rely on my son ... Last night, I woke my son up because I was in pain, asking him to massage my legs ... asking him to do physical therapy exercises on me. When he woke up to massage me, his eyes remained closed ... that really made me feel deep pain. He is so young ... only 17 years old, still in the process of growing up, so he needs longer rest. Having to look after me, he has only 5 hours to rest at night, while other boys might have 8 hours. I feel sorry for my son that he has to wake up in the middle of the night to look after me, but what else could I do? I cannot control my body. I feel worthless. Nowadays, I feel like my life is worth nothing. I am suffering a lot [from the whole situation].'

These narratives show that the patient was affected by events. She moved between two positions; on the one hand, as a nurturing mother she would like to look after her son, yet; as an ill person, on the other hand, she needs to be cared for. These two positions put a lot of stress on her. This narrative also reveals the conflict between the competing demands of the patient and her son. Although she wished to nurture her son, she was unable to do so; consequently, believing that she had failed to act as a 'nurturing mother.' She had not nurtured her son as fully as she should and this caused her to feel ashamed and guilty that she could not fulfill her responsibilities to her family, especially to her son.

A sense of burden to others

The feeling of being a burden to others was expressed by most of the informants. The progression of cancer was accompanied by a loss of independence and an increased dependency on others in their everyday life. All informants were aware that their caregivers also had other roles and responsibilities in the family. Some patients frequently mentioned their concern of being a burden to their family. Lily, a 53-year-old Buddhist woman with breast cancer and brain metastasis, suffered nausea and vomiting, and dizziness. She expressed her concern as follows:

'I keep vomiting. If I did not have the urge to vomit, I would be able to walk without having to ask for help from others ... [I] just wish that I would not need to vomit, so I could walk and care for myself. If I could walk, I could clean up when I vomit. My husband therefore would not have to take leave from work to take care of me. I do not want him to be worried about me ... the only thing I hope for is to be able to take care of myself. I do not want to bother my family.'

Similarly, Rose described her emotional entrapment and suffering as follows:

'I was worried if I was going to be disabled, afraid that I would become paralyzed; unable to walk ... worried that I was going to be a burden to others. When I was in pain, I could not do anything. I felt depressed as it was hard to cope with the fear ... wished for the pain to go away by any means. Since I have been ill, my husband has been unable to do anything else. He has to look after me, carry me here and there. I am worried ... [crying] ... [pause] ... I do not want to be his burden. I do not want him to be faced with further burdens. I feel sorry for him. I do not want him to carry [such] an excessive load of burden, and I do not want to be his burden. He has been taking care of me for several years.'

Most of the informants struggled with a sense of being a burden to their family. Hence, they tried to look after themselves as much as they could. Some patients asked their caregivers to put all medications and other caring aids such as cold packs or electric kettles by their bedside, so that they would not bother them at nighttime if they were in pain. Another patient, who had severe cancer pain, concealed his physical suffering to his caregivers by enduring the pain and waiting until the next routine dose of pain relief medication.

Desire for hastened death

Of the 15 informants, four spoke of a desire to hasten death. Suffering from severe pain and a sense of being a burden to others generated a desire for death among these patients. The pain not only prevented them from their normal activities, but it also affected the wholeness of their beings, which then led them to experience unbearable suffering, due to them being unaware that they would be a burden to their family. These informants, therefore, saw death as an escape from pain and suffering. As one patient put it:

'When I know that my life has become a burden to my loved ones, I would rather die. I think of death as a way to release me from this frustration.'

The desire for hastened death was in the mind of Lotus, a 58-year-old Buddhist female diagnosed with stomach cancer that spread to the lungs and abdomen, and whose pain was unbearable.

'When I was in excruciating pain ... sometimes, I wanted to grab a knife and stab myself, and cut it [pain/cancer] out. I felt angry ... why I am suffering so? I did not know what to do or how to deal with it. I could not work, so my life was no longer worth living. Continuing to live would only bring more suffering ... I could not look after myself. I made [Buddhist] merits in the morning, offered food to monks. I prayed every day. I prayed to have the day, during which I was no longer able to perform my daily activities, as my last day of life ... I prayed to die so that my suffering could end. I did not want to be fed by my children and grandchildren. Just let me die.'

Nevertheless, the wish for death was not constant. When the informants were not in pain, the desire to hasten death was not present. However, when they were unable to control the pain, their desire to die returned. Lotus elaborated further:

'It is torturous ... thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones. Actually, I do not want to be parted [die] ... when I do not experience any symptom. But when I suffer the symptoms, I again wish to die to escape the suffering.'

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Discussion

The findings of this study support and add to previous research addressing the suffering experiences among patients living with advanced cancer. The suffering is a result of the physical ill-health caused by cancer, and the adverse effects of its treatment, coupled with psychological suffering caused by the loss of the ability to perform daily activities and becoming dependant. The study informants expressed their concern at having to rely on family members, and of suffering socially because of feeling different from other people and, consequently, wanting to isolate themselves. People living with cancer also experienced spiritual suffering, as they felt their life was of no value and fell into depression after realizing that they were going to depart from their loved ones. This study supports other works, which have noted that suffering encompasses all aspects of life (Schroeffer, 2007; Carnevale, 2009).

The informants of this study spent their terminal period of life at home and were taken care of by their family. During the course of their death trajectory, they reported several distress symptoms at the end of life, including lack of energy, pain, and anorexia. This physical suffering lead cancer patients to other dimensions of suffering. Pain and other distress symptoms are the reasons for the patients' loss of ability to perform daily activities. Consequently, they become dependent on their family, which then leads them to develop psychological suffering. The concern of being a burden to the family was often mentioned by the informants, especially when their health deteriorated and their ability to care for themselves decreased. The findings of this study support previous work reporting that patients at the end of life were most concerned about their loss of body functions, level of dependency, and being a burden to others (Hickman et al, 2004; Chochinov, et al, 2007; McPherson et al, 2007).

Loss of autonomy with increased dependency led to a sense of worthlessness and generated suffering. The increasing dependency forced patients with terminal advanced cancer to redefine themselves and to develop a new and undesirable image of themselves as a 'worthless' and 'unhealthy' person, by comparing themselves to other 'healthy' people. This new ill self and the old one also created an emotional battle between what they were and what people would see (Charmaz, 1983). Eventually, this emotional battering led them to feelings of disintegration (Frank, 1995), alienation (Sontag, 1990), and isolation (Rydahl-Hansen, 2005).

Chochinov et al (2007) found that perceiving the self as being a burden to others is associated with feeling fatigued, hopeless, concerned about changes in the physical image, perceived value and dignity of being human, and a will to live or die. In addition, self-perceived burden negatively affected a person's sense of self-worth (McPherson et al, 2007). In this study, many patients expressed the feeling of worthlessness. One of the participants perceived that she 'had lost the quality of being human' because of losing her mobility and becoming dependent on her son. All these feelings developed as the patients perceived themselves as worthless based on social norms, attitudes and models of human beings. The feeling of worthlessness leads people to trust no one, including themselves, and feel victimized, ashamed, and guilty (Strandmark, 2004). As a consequence, the inability to fulfill their life goals causes them to experience spiritual suffering (Chio, et al, 2008).

Four informants expressed the desire for death and loss of the will to live. Persistent severe pain, fear of future pain, and a concern about being a burden to others contributed to the wish for death among these patients. These findings are consistent with those recorded in previous studies (McPherson et al, 2007; Nissim et al, 2009), noting the effects of pain and other physical suffering, emotional distress such as depression and hopelessness, the level of physical functionality, the sense of burden to others on the desire for hastened death. In addition, the expression of a desire for hastened death is fluctuating. In the present study, the desire for hastened death was triggered by uncontrollable pain and/or other distress symptoms and intensified by an overwhelming feeling of worthlessness and a sense of being a burden to others. However, when symptoms were well managed and patients felt in control, the wish for death disappeared.

Limitations

Limitations of this study include its small sample size. The informants of this study were predominantly Buddhist, with a high proportion of female patients. Readers should be cautious in making generalizations beyond this study affecting patients with diverse demographic characteristics from those of our informants. The authors maintain that the generalizability of these findings should be limited to patients with terminal advanced cancer, living and dying at home in Southern, Thailand. Generalization of these results to terminally ill patients with other life-threatening illnesses and in other settings requires additional research.

Conclusion

Suffering is a common phenomenon experienced by patients with cancer, particularly advanced cancer. The findings of this study can be of value to health professionals in cancer care in Thailand. This study has demonstrated that patients with terminal advanced cancer suffer from uncontrollable multiple symptoms during the dying phase. Health-care providers can reduce the patients' suffering experiences and prevent the desire to hasten death by developing proactive intervention programmes to manage and control distress symptoms. Better symptom recognition and implementation of pharmacological and non-pharmacological interventions are needed. In addition, the majority of patients with advanced cancer in Thailand live at home during the last stage of their illness. Palliative home care programmes, therefore, are needed. The study at hand also highlights the importance of psychospiritual interventions to alleviate suffering among the dying patients with advanced cancer. Suffering arises when personal integrity is threatened. Attentive, non-judgmental listening is a necessary basic skill for health professionals to understand personal suffering. Furthermore, listening to a patient's story provides opportunities for effective intervention to alleviate suffering. Health professionals therefore must be trained to recognize the personal experience of their patients. ^{UPN}

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