

DUKKHA EXPERIENCE OF PATIENTS LIVING WITH CANCER IN PALLIATIVE CARE: A QUALITATIVE STUDY

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ABSTRACT:

Background: The study on the suffering experience of cancer patients under palliative treatment revealed the meanings of “suffering” as “hardship and struggling life, causing both physical and psychological ordeal.” However, there are few studies to uncover the suffering experiences of patients in the context of Buddhism or “Dukkha.” This study therefore aimed to explore the experience of cancer patients under palliative treatment.

Method: Participants included 8 cancer patients treated with palliative scheme (4 males, and 4 females). Data were collected with individual interviews before being analyzed with phenomenological qualitative methods.

Results: Findings revealed three main themes. The first theme is characteristics of suffering, including hardship, struggling lives causing physical and mental ordeals, and emotional suffering such as frustration, grievances, tensions, or pressure. The second theme is disease-related suffering experience, including a sudden encounter with changes, anxiety, doubts, and inquiry on the future upon learning of the disease, all of which differed from one patient to another. The third theme is encounter with death, including preparing oneself physically and mentally for cancer-induced death.

Conclusion: This study helps shed light on the suffering of the cancer patients under palliative medical treatment. The cancer patients reported that they face great physical and psychological suffering in various aspects. With moral support and attention from health-care professionals including people around them, the patients could muster their strong will power to fight against the maladies in hope that this would alleviate their illness.

Keywords: Dukkha experience; Patients living with cancer; Palliative care; Qualitative study

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INTRODUCTION

Cancer is a disease that causes both physical and mental changes in patients. The fact that this disease is uncontrollable, that its treatments are unpredictable, and that the relapse possibility is very high lead patients to greatly suffer physically, psychologically, and spiritually. Most cancer patients, especially those under palliative treatment scheme, are usually faced with pressures and tensions in various areas of their lives: guilt, reality denial, loss of trust in living with others, diffidence,

unstable temperament, despair and hopelessness, anxiety, and depression. These tend to intensify as patients' conditions deteriorate beyond their control [1-2]. Besides, cancer patients usually suffer from fear of pain, suffocation, abandonment, disgrace, powerlessness, self-loss, most importantly, parting with their families and loved ones, and death [3-4]. Pressure and tension caused by physical agony in cancer patients can be called “psychological distress” or “psychological suffering.”

It was recorded in Buddhist doctrines that psychological distress is part of “Dukkha” (suffering) categorized further into “inevitable suffering” and “miscellaneous suffering.” Inevitable

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suffering is unavoidable, while miscellaneous suffering is irregular or temporary in nature. Both types of suffering can be both physical and psychological. Diseases and death are corporeal Dukkha that leads to psychological Dukkha, which is termed “Dukkha Wetana” (suffering-inflicting sensations) meaning feelings, pain, hardship [5]. Another type of suffering is caused by changes, or “Dukkha in Three Marks of Existence”; that is, everything keeps changing depending on causes and factors whose states change continuously, moment by moment, without real self, arising and passing away naturally. When people do not understand these characteristics of nature and life as mentioned, living can't be devoid of attachment, expectation, and craving, all of which brings only tension, confusion, grief, fear, frustration, distress, anxiety, boredom, and despair. These are simply the characteristics of suffering mind because of its inability to accept undesirable changes [6, 7]. Besides, Roshi [8] also opined that sufferings arise from our encounter with changes of things in the form of loss and bereavement.

In the past several decades, psychologists and various healthcare professionals have tried to make sense of the terminal cancer patients' experience in order to find ways to alleviate their sufferings caused by the conditions and help them to live their final breaths worthwhile. Such efforts include mental preparation to live with the disease and get ready for imminent death without struggling panic, assisting the patients to view normality in sickness and death and pass their final moment peacefully and gracefully as a human could with the faith in their religions, cultures, and families. Such studies usually emphasize on education, stress, depression, anxiety, and such treatments like the hope intervention [9]. From the past literature and empirical studies in this topic, it is evident that most understanding on stress and psychological distress has been derived from the concepts of western psychology. Many empirical studies in psychology, however, also pay attention to psychological suffering as viewed from Thai context and society. This research article then presents suffering experience of cancer patients under palliative treatment with the qualitative method, aiming to shed the light on sufferings in every aspects possible as experienced by this group of patients. This understanding would be useful to further improve the psychological side of care for cancer patients in the future.

METHODS

A phenomenological methodology was selected because it focuses on the full meaning of the key informants' experiences— their thoughts, feelings, beliefs, and other psychological perspectives as shared in their own words [10]. This study received the Ethics Review Committee for Research Involving Human Research Subjects from Siriraj Institutional Review Board (Protocol number 627/2554(EC3), COA No. Si 284/2012).

Key informants

Key informants were 8 cancer patients (4 males, 4 females) from a public hospital in Bangkok were selected through purposive sampling. All is a patient with palliative care who has been received chemotherapy for at least two months to several years. Their age was between 18-70 years old.

Instruments

The checklist and interview guideline on suffering experience of cancer. The checklist contains items such as being diagnosed as a cancer patient with palliative care, experiencing the things or situations related to their illness that make them feel distressed, uncomfortable, sad, depressed, hatred, exhausted, worried, and anxious, etc. The checklist and interview guideline developed by the researcher were checked by three experts on for content validity and corrected accordingly before application.

Procedures

After receiving the approval from the Ethics Review Committee, the researcher contacted the gatekeepers to recruit the qualified participants. Then, the appointments with the participants were made to provide information about the study and their rights to participate in the study. Those who were willing to participate in the study were asked to sign the consent form and completed the checklist. After that, the participants who passed all the criteria on the checklist were invited and interviewed once, each for about 1 hour. Three primary questions provided the framework and guiding direction for an interview. First question focused on a broad description of the patient's view on suffering or Dukkha experiences. Second question was to ask the patients to detail their reactions to life-threatening conditions due to illness as well as the treatments received. Last question was about supports available or difficulties as they encounter with experiences of palliative care when death is expected, etc.

Data analysis

As suggested by Rossman and Rallis [11], first verbatim transcription of the interview tapes were made. Then the scripts were analyzed by coding messages with similar meanings together. The next step was to find similar topics, and organize them into categories. Finally, those with the same themes were grouped into subcategories [11]. Trustworthiness of the validity of analysis on the findings, interpretation, and summary from supportive data were achieved through external auditing conducted by three experts on counseling psychology and two experts on qualitative research.

RESULTS

The suffering experience undergone by cancer patients under the palliative treatment can be divided into 3 major themes: 1) characteristics of sufferings; 2) the experience of disease-related sufferings; and 3) encounter with death.

1. Characteristics of sufferings

1.1 Definition of sufferings

The informants covered 3 main aspects, as follows.

1.1.1 Suffering as hardship

The informants defined “suffering” as hardship: struggling life leading to physical and psychological ordeal. Further data analysis also revealed that psychological ordeal manifested itself through grievances, frustration, and the pressed and tensed state of mind, as exemplified below.

“It was really hard to put up with, hard even to put this suffering in words. I got the runs as many as 30 times a day, could only drink Ensure milk and eat nothing as radiation was suffocating me. Even plain water could burn my throat. Too much to bear. Very cold to the bone. Patients with this cancer usually feel very cold and sudden dizziness. Then I cried out, ‘No more. I am done’.” (Informant 7)

1.1.2 Sufferings are things everyone experiences

All informants opined unanimously that sufferings are what everyone must face in life, only different in types and to each individual. It can be said that sufferings can occur to every person, every time, depending on interrelated elements. This is common in life.

“Each person has his own suffering. It depends on each, doesn't it?” (Informant 1)

“My kinsmen and relatives are all equally struggling in their lives. One of my sisters-in-law lost her husband when she was still so young. She has been trying hard to do little trading to feed her young.” (Informant 5)

1.1.3 Sufferings arise and pass by

The informants viewed that sufferings arise and pass by with time. The suffering that occurs will soon become a past when it is let on. If one doesn't pay much thought to it, when one passes that ordeal, his/her life will be happier.

“Suffering at heart. None. Suffering, and then it passes, no more suffering, left only the story of my mom and my past. Others can't make me suffer...I don't think much about it. Let it be. Thinking of it just comes and goes away. I don't think too hard about it.” (Informant 1)

1.2 Attachment is the cause of sufferings

Sufferings are caused by attachment to a person or an event, whether negative or positive. Positively, attachment leads to bonds, cravings, and care for the beloved, which brings sufferings. Negatively, unpleasant, disliked events cause unfinished business with bad memories in the past. Despite a long time passing, anger, hatred, and malice still persist with a disliked person or event. Besides, attachment and expectation in what one wants but can't get can also cause psychological sufferings.

“Our heart captures just a small part of suffering. When my husband doesn't come, the heart lingers on that and overreacts to it, thinking with whom he might be now. He used to have lunch with me, but now with whom he is dining with.” (Informant 6)

1.3 Characteristics of sufferings

Characteristics of suffering can manifest in different ways: such emotional states that can be felt as hurt, indignation, fury, worry, loneliness, etc.; such cognitive states as stress, obsession, hesitation, wavering, confusion, among others; or even behavioral signs or actions such as weeping and shedding tears. Sometimes, sufferings are hidden

deep in the mind, so a person can appear suffering-free. But when that person is provoked or touched with concerned matters, those sufferings can surface and manifest as actions previously mentioned.

“Emotional suffering? I can’t actually tell, only knowing that it is uneasy, painful, thinking of these and those.”... “Why must I be hospitalized? At first, I was so stressed out, crying a lot when knowing my illness was cancer. But my friends supported me, telling me that doctors now are so good that many people can recover. Not a big deal.” (Informant 5)

1.4 Coping with sufferings

These include direct problem-oriented coping with the direct cause of a specific suffering, avoidance by isolation, or distraction from unpleasant events or sufferings, and repression - never letting their sufferings shown. Besides, Dhamma and Karma were also used to heal one’s spirit as all the informants in this study are Buddhists. The informants reported applying Buddha’s teachings to their living as the foundation to take care of their spirit and mind praying, meditation, breath observation, and contemplation on Karma in the past were used as tools to relieve their suffering mind, enabling the patients to heal their distress and live with the sufferings.

“I talked to my cancer, ‘don’t harm me, dear cancer. I don’t want to die. If you want to stay long with me, please let all my merits done help you and me to be happy. And please get out of my body. Let us not share the path. I still have loads of responsibilities to take care’.” (Informant 7)

2. Experience of disease-related sufferings

All the cancer patient subjects under palliative treatment started to suffer from the minute they knew they had a cancer owing to such a sudden change to which they could hardly adapt in time. This brought about worries, doubts, and questions on how their future lives would become. However, the intensity of suffering expression could be different from person to person. This experience can be represented through 5 aspects.

2.1 Defining and understanding cancer

The first time getting to know about cancer, the patients defined cancer similarly: an incurable

disease costing a lot money for treatment; the condition everyone can get inflicted with without rhyme or reason; and the disease that impacts the patients’ psychological state by evoking great fear toward the disease.

“For cancer, no matter how much treatment you take, you’ll die. No one can survive. Just think that so many people arriving here after me have already died. Another, a policeman with cancer too, I have just gone to his funeral.” ... “even though I am suffering from cancer, I have seen many dying; some came after me, some were younger than me. Only 46, some already passed away.” (Informant 1)

2.2 Knowing about the cancer condition for the first time

After experiencing painful symptoms, the informants got diagnosed and learned of their cancer. The report from the informants on the initial experience of learning from the doctors of their certainty to have cancer can be divided into 2 themes, as follows.

“I sulked why this disease must befall me. My life was going well. My children promised me when I got old, they would take me travel overseas, visiting these and those countries. At last, my dream crumbled. Other countries are colder. People suffering from this disease are not supposed to visit cold places. My condition needs to be regarded.” (Informant 7)

2.2.1 Doubts and questions about the occurrence

Knowing their positive diagnosis of cancer, the patient subjects had similar feelings: unprepared for the unexpected news, confused, hesitant, doubtful, and trying to question and explain about the cause of their predicaments. Some patients attributed their disease to their Karma in the past to explain why they had to suffer from the nefarious disease. Additionally, the informants tried to research about cancer to gain the deeper insight into their conditions; the most used method was inquiry from their physicians. This reflects the patients’ need to acquire as much information about their disease as possible in all aspects, from types, progression, stages, to treatment directions. Such information could relieve confusion and anxiety

among the patients, while enabling them to continue their lives.

“Sometimes I cried myself to sleep, for I didn’t want others to know. I was blue deep down, thinking why I had to suffer like this, why this disease, why not others.”
(Informant 8)

2.2.2 Worries about the impacts on families

Besides the psychological distress on their cancer, the patients were also worried about their families getting affected in various ways. Therefore, disease-related sufferings plagued not only the patients but also their families and relatives, who also suffered emotionally, socially, and financially, especially from the expenses. All the informants agreed expensive treatment made them worried that their children couldn’t bear the high-cost burden of medical care. Thus, the patients couldn’t help worrying about the living condition of their families during their hospitalization.

“All through the past I have been thinking why I have to be like this, why I have to suffer from cancer. Think that my children have to waste a great deal of money for their mom. This is also painful.” “Even now I sometimes still think why my children need to lose lots of money on me. They have their own burden of paying for their children’s tuition fees.” (Informant 5)

2.3 Awareness of physical pains

The patients were aware of their physical pains due to their disease by observing physical changes: each passing day increased deterioration, not to mention that the disease progress also obstructed their normal living and required most time for treatment. The patients, therefore, had to inevitably adjust their lifestyles.

“The last time was the worst: such great stomach pain and coughing that I could barely eat. I got bored with everything and did not want to eat. So, I lost 8 kilograms. I tried to keep my weight, but it dropped.” ... “my bowel release was irregular and got less until it has become like small thread and finally blood mucus.”
(Informant 1)

2.4 Physical sufferings lead to psychological distress

All the cancer patients had to face physical pains due to atrophy of organs as the disease progressed rapidly. All the symptoms manifesting caused great sufferings to the patients. Despite different types of cancers, the patients suffered somewhat similarly. Such physical pains were caused by the disease and treatment procedure including operations, aspirations, chemotherapy, and medication allergy. This led to psychological distress, such as depression, melancholy, and sorrow due to disease exacerbation. Such distress was also caused by the patients’ own thought as they kept worrying about various matters, be it work, families, expenses, among others.

“It was really hard to put up with, hard even to put this suffering in words. I got the runs as many as 30 times a day, could only drink Ensure milk and eat nothing as radiation was suffocating me. Even plain water could burn my throat. Too much to bear. Patients with this cancer usually feel very cold and sudden dizziness, and then cried out, ‘No more. I am done.’ I didn’t know whether I would be happy or not after death, but if that meant I could get away from this suffering, then fine.” (Informant 7)

2.5 Fighting against cancer

Fighting against cancer here means facing physical pains and sufferings that would lead to psychological distress, focusing on morale support the patients received in resisting and taking care of themselves as instructed by their doctors. Three main themes could be identified in this topic as follows.

2.5.1 Will-power to take care of oneself

Despite great physical and psychological sufferings, the informants relied on their will-power, in addition to the hope to recover from cancer, to fight against their illness and enable them to put up with sufferings. All the informants reported they knew cancer would stay with them until the end and couldn’t be totally cured, but with good self-care, medication, regular visit to doctor, and symptom-based treatment, their illness could be improved and they could live longer. Their will power was the drive behind their strength and ability to take care of themselves and live with the disease.

“The second relapse was harder than the first time, but never mind, I will keep fighting. At least I am still living for 5 years after he retired. We stay together.” ... “No one can help me. I have to help myself, be it treatment, medication, or meditation to let things go.” (Informant 6)

2.5.2 Morale support from people in the close circle

Care, attention, and frequent inquiries of their conditions from their families, relatives and friends empowered the patients to live and fight against the disease. Having relatives visit and attend or friends ask about the patients' whereabouts could relieve the patients' loneliness and burden of resisting the disease on their own.

“Sufferings come from time to time, but my children support me so well, saying that money can be earned, but mom can't.” ... “I still wish to see my grandchildren grow up. If I can live longer, I will feel motivated to see grandchildren grow and graduate. My eldest grandchild is 18. I am also worried about him. It's like love that passes on from my children to grandchildren. And my grandchild is also cute, talkative. I am motivated to live on because I want to see him grow up with a bright future.” (Informant 5)

2.5.3 Care from the medical team

The medical team, from the personal doctors, therapists, nurses, to the hospital staff, had a great influence on the will power of the cancer patients to fight against and cure the disease. The subjects reported having faith in their doctors. Experiencing the good care and attention from doctors and nurses, the patients felt impressed and trusting. Even the modern medical equipment could make them confident in the treatment they receive and motivated to continue taking care of themselves and resisting the disease.

“Doctors here at the hospital are good. They won't let patients go without diagnosing the cause, so I received colonoscopy. A clinic would have just sent me home. That is why I am sleeping here now. This might be luck. Had I been unfortunate, I would have received medicine and gone home. Then, in the next

5 or 10 years, my condition would be too severe to treat.” I have to do whatever my doctor sees fit. I must have faith in my doctor.” (Informant 3)

3. Encounter with death

The informants reported the issue of encounter with death in terms of physical and psychological preparation to die from cancer in the future. Two main themes emerged here.

3.1 Fear of sufferings are greater than fear of death

The informants described their suffering from cancer as “the physical suffering that leads to psychological distress.” They said that they weren't afraid of the impending death, but disease-related sufferings. If the pain becomes so intolerable, they might wish to end their lives to free themselves from the sufferings, as professed in the following excerpts.

“Enough for my life. I don't want to treat my disease any more, want to finally leave (sobbing).” (Informant 1)

“I am not afraid of leaving this world. Living a painful life is what I fear. If I can be freed from pain, leaving is better than putting up with the pain. It's so painful, really painful.” ... “Never mind if I die. So painful. I think it's alright to end here. I can be released from this pain.” (Informant 5)

3.2 Preparing oneself to cope with death

Preparing oneself to cope with death includes mental and physical preparation to die and planning ahead for the future when one is no longer. The most important thing that assists the preparation procedure is acceptance of things arising, letting go of attachment to and worries about things in life, such as families, children, money, jobs, etc. The freedom from attachment enabled the patients to live each day lightly and fight the disease to their full potential despite imminent death.

“Nothing to worry now. If anything happens to me, I won't be sorry. I have been living for 70 years. Only not too painful. Pains are great sufferings. If there's anything, just let me sleep and go. I am ready. I don't worry about anyone now as all my children have settled down nicely.” ... “If now something happens to

me and I fall asleep forever, I won't be sad. Living for 70 years, I have nothing to lament, and no more worrying about my children and grandchildren.” (Informant 5)

DISCUSSION

The study on the suffering experience of cancer patients under palliative treatment revealed the meanings of “suffering” as “hardship and struggling life, causing both physical and psychological ordeal.” The characteristics of sufferings as reported by the cancer patients under palliative treatment included negative feelings which similar to the concept of “Dukkha Wetana” - such as upset, indignation, anger, worry, loneliness, among others- and such undesirable thoughts and behaviors as obsessions, hesitations, distractions, confusions, sobbing, and shedding tears [6, 7]. Moreover, the sufferings were hidden in the mind, so there seemed to be no sufferings on the surface. However, with the right provocation or reminding of related issues, those sufferings would automatically float to the surface. From a Buddhist psychology perspective, Avijja (ignorance) is the root of suffering mind because of its inability to accept undesirable changes leads to delusion, which is the initiation of mental defilement that prevents the human mind from seeing reality as it is. It is the cause of attachment, desire, and resentment [12].

The interesting point in their suffering experience is that the patients were aware of their disease-related physical sufferings by observing changes in their bodies that seemed to deteriorate in accordance with the disease progression. Given the atrophying conditions hindering daily living and most time spent on treatment, the patients had to inevitably adjust their lifestyles. The cancer patients pointed out that they were to face physical agony due to organ impairments, symptoms caused by rapid spread of cancer. In fact, their sufferings stemmed from both the disease itself and treatment procedure such as operation, aspirations, chemotherapy, and allergy to medications. Physical sufferings led to psychological distress, including depression, sorrow, or grief due to the exacerbating disease. These sufferings arise from impotent mind that cannot tolerate external events that come in contact [7, 13]. This is supported by Roshi [8] who explained that sufferings arise from changes we find in things, leading to loss and bereavement. Another issue stated by the cancer patients about suffering

experience is physical and mental preparation for death by letting go of attachment feeling, dissolving all worries about things in lives, such as families, children, wealth, occupations, etc. It can be said that the informants relied on the concept of “contemplation on death” in their coping with suffering experience: to live without carelessness and fear of death, to get constantly well-prepared to encounter death any time it comes, and to know commonness of impermanence, all of which will liberate the mind, extinguish craving and aversion, and end suffering (or reaching “nirvana”) [7].

CONCLUSION

It can be concluded from this study that, despite the fact that the cancer patients under palliative treatment had to face great physical and psychological sufferings in various aspects, they could muster their strong will power to fight against the maladies in hope that they would alleviate their illness, together with morale support and attention from people around, which helped relieve the patients' sufferings. Besides, the patients used various methods to cope with sufferings, including fighting, avoidance, and repression, together with reliance on faith, religious explanations, and belief in karma for their spiritual coping. This study helps shed the light on the sufferings of the cancer patients under palliative medical treatment for psychologists and health-care professionals to understand and lead to more effective psychological support for this group of patients.

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