

# American Journal of Hospice and Palliative Medicine

<http://ajh.sagepub.com/>

---

## **The Experiences of Suffering of Palliative Care Patients in Malaysia: A Thematic Analysis**

Tan Seng Beng, Ng Chong Guan, Lim Kheng Seang, Subramaniam Pathmawathi, Moy Foong Ming, Lim Ee Jane, Loh Ee Chin and Lam Chee Loong

*AM J HOSP PALLIAT CARE* published online 5 September 2012

DOI: 10.1177/1049909112458721

The online version of this article can be found at:

<http://ajh.sagepub.com/content/early/2012/09/05/1049909112458721>

---

Published by:



<http://www.sagepublications.com>

Additional services and information for *American Journal of Hospice and Palliative Medicine* can be found at:

**Email Alerts:** <http://ajh.sagepub.com/cgi/alerts>

**Subscriptions:** <http://ajh.sagepub.com/subscriptions>

**Reprints:** <http://www.sagepub.com/journalsReprints.nav>

**Permissions:** <http://www.sagepub.com/journalsPermissions.nav>

>> [OnlineFirst Version of Record](#) - Sep 5, 2012

[What is This?](#)

# The Experiences of Suffering of Palliative Care Patients in Malaysia: A Thematic Analysis

American Journal of Hospice & Palliative Medicine®  
00(0) 1-12  
© The Author(s) 2012  
Reprints and permission:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1049909112458721  
http://ajhpm.sagepub.com



Tan Seng Beng, MRCP<sup>1</sup>, Ng Chong Guan, MPM<sup>2</sup>,  
Lim Kheng Seang, MRCP<sup>1</sup>, Subramaniam Pathmawathi, DHSci<sup>3</sup>,  
Moy Foong Ming, PhD<sup>4</sup>, Lim Ee Jane<sup>1</sup>, Loh Ee Chin, MRCP<sup>1</sup>, and  
Lam Chee Loong, MRCP<sup>1</sup>

## Abstract

A qualitative study was conducted with semi-structured interviews to explore the experiences of suffering in 20 adult palliative care inpatients of University Malaya Medical Centre. The results were thematically analyzed. Ten basic themes were generated (1) loss and change → differential suffering, (2) care dependence → dependent suffering, (3) family stress → empathic suffering, (4) disease and dying → terminal suffering, (5) health care staff encounters → interactional suffering, (6) hospital environment → environmental suffering, (7) physical symptoms → sensory suffering, (8) emotional reactions → emotional suffering, (9) cognitive reactions → cognitive suffering, and (10) spiritual reactions → spiritual suffering. An existential–experiential model of suffering was conceptualized from the analysis. This model may inform the development of interventions in the prevention and management of suffering.

## Keywords

suffering, distress, palliative care, Malaysia, thematic analysis, psychosocial issues

## Introduction

Suffering has a long-standing history that can be dated back as far as the beginning of sentient existence. It is a subject of great significance in various religions and schools of philosophy and also a subject of central importance in medicine. A widely accepted definition of suffering from Eric Cassell describes suffering as a state of severe distress associated with actual or perceived threat to the intactness, integrity, or existential continuity of a person.<sup>1,2</sup> This definition emphasizes the concept of personhood. Suffering is experienced by person, not bodies.<sup>1</sup> The person that suffers has a temporal dimension that includes the past, present, and perceived future of the person; a functional dimension that consists of multiple roles, actions, and behaviors; a sociocultural dimension that includes relationships and the cultural background; and a transcendental dimension. Comparably, Chapman and Gavrin defined suffering as a perceived threat or damage to the integrity of the self, helplessness in the face of the threat, and exhaustion of psychosocial and personal resources of coping.<sup>3,4</sup> This second definition emphasizes cognitive appraisal and exhaustion of coping resources in suffering. In addition to these 2 definitions, suffering has also been described as an aversive emotional experience characterized by the perception of personal distress that is generated by adverse factors that undermine the quality of

life,<sup>5</sup> and as an experience of distress or disharmony caused by loss or threatened loss of what we most cherish.<sup>6</sup>

Regarding types of suffering, the biopsychosocial–spiritual model offers a simple and practical classification of suffering based on the concept of “total pain.”<sup>7</sup> In this classification, suffering is divided into 4 dimensions—physical, psychological, social, and spiritual. Apart from these 4 dimensions, existential suffering is also commonly described in the literature either together with the spiritual dimension or as a stand-alone entity.<sup>8</sup> Existential suffering is a widely used but a poorly defined term.<sup>9,10</sup> The term existential suffering can be traced

<sup>1</sup> Department of Medicine, Faculty of Medicine, University Malaya Medical Center, Lembah Pantai, Kuala Lumpur, Malaysia

<sup>2</sup> Department of Psychological Medicine, Faculty of Medicine, University Malaya Medical Center, Kuala Lumpur, Malaysia

<sup>3</sup> Department of Nursing Science, Faculty of Medicine, University Malaya Medical Center, Kuala Lumpur, Malaysia

<sup>4</sup> Department of Social and Preventive Medicine, Faculty of Medicine, University Malaya Medical Center, Kuala Lumpur, Malaysia

## Corresponding Author:

Tan Seng Beng, MRCP, Department of Medicine, Faculty of Medicine, University Malaya Medical Center, Lembah Pantai, 59100 Kuala Lumpur, Malaysia  
Email: pramudita\_1@hotmail.com.

back to existential psychology, in which Yalom described 4 basic truths about existence: death, isolation, freedom, and meaning. Existential angst or anxiety is the inner conflict that arises from the experience of these existential realities.<sup>11</sup> In the modern context, Murata and Morita defined psychoexistential suffering as pain caused by loss of essential components that compose the being and the meaning of the self.<sup>12</sup> Types of existential suffering described in their study included relationship-related concerns, loss of control, burdening of others, loss of continuity of self, uncompleted life task, hope, and acceptance issues.<sup>13</sup> From a study of Blinderman, the following existential concerns were identified: autonomy, body image and dignity, guilt and past disappointment, social isolation, hope, meaning, coping issues, spiritual health, death, and dying.<sup>14</sup>

The intensity of suffering is best expressed by the term distress, which is defined as a multifactorial unpleasant emotional experience of a psychological, social, and spiritual nature that may interfere with the ability to cope effectively with the illness, its physical symptoms, and treatment.<sup>15</sup> The intensity of suffering can be severe and sometimes unbearable, leading to the request of hastening of death or the use of palliative sedation.<sup>16,17</sup> These patients with unbearable suffering exhibited features of the diagnosis of demoralization syndrome experienced as existential despair, hopelessness, helplessness, and loss of meaning and purpose in life.<sup>18,19</sup> Meaninglessness, dependence on others, death anxiety, the wish to control one's time of death, and isolation were reported as indications for palliative sedation in psychoexistential suffering.<sup>16</sup> Fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, pointlessness, and being tired of living were mentioned as unbearable suffering prompting the discussion of hastening of death.<sup>17</sup>

Existential issues were found to occur at all stages of cancer.<sup>20</sup> However, these issues do not necessarily lead to existential suffering.<sup>14</sup> The perception of existential suffering was described as experiencing groundlessness or as "being shaken to the core." Three reactions to existential suffering were noted, which included engaging groundlessness, in which people turn toward the issues and learn to let go; taking refuge in the habitual, in which people turn away from the issues and seek security by holding on to the familiar; or living in between, in which people create a balance between the two.<sup>21</sup> As the coping resources are exhausted, the person suffers. When the person suffers, a collective suffering of family and health care providers may ensue.<sup>22</sup>

Suffering is a subjective experience unique to the person who experiences it. Most of the studies on the literature of suffering have focused mainly on types of suffering rather than the experiences of it. To explore the experiences of suffering, qualitative research has been proposed as the methodology of choice.<sup>23</sup> A majority of studies on suffering are quantitative studies. Therefore, we conducted this qualitative study to explore the subjective experiences of suffering in palliative care patients in Malaysia. This is one of the studies from our research looking into suffering, causes of suffering, and

**Table 1.** Questions in the Semi-structured Interviews

---

Can you tell me about your experience of suffering?
How has this illness affected you emotionally?
How have your family been throughout your illness?
What about your friends?
How do you find the doctors and nurses here?
How is it like staying in the hospital?
How about your religion?
Is there anything else that you would like to share with me about your suffering?

---

well-being and causes of well-being in the palliative care settings, with regard to patients, families, and health care providers.

## Methods

The research was approved by the Ethics Committee in University Malaya and was conducted in University Malaya Medical Centre in Malaysia from November 2010 to May 2012. Informed consent was taken from the patients who participated in the study. Convenience sampling was used to collect qualitative data from adult palliative care inpatients  $\geq 18$  years, who were admitted to University Malaya Medical Centre and were referred to the palliative care team. From the palliative care assessment, patients who were deemed distressed by the palliative care team were included in the study. Data collection was carried out with semi-structured interviews of the patients by a trained research assistant with a voice recorder. The questions were listed in Table 1. The total number of patients interviewed was 20. The average interview time for each patient was 24 minutes. Most of the patients were comfortable with discussing their suffering or sounded relieved after expressing their thoughts on suffering. One patient became more distressed during the interview and had to stop the conversation to calm down. Another patient ended the conversation early due to a request from a family member because of the patient's fatigue. These patients continued to receive psychosocial support from the palliative care team after the interviews. A total of 14 interviews in English were transcribed verbatim. A total of 4 Chinese transcripts and 2 Malay transcripts were translated into English. The transcription and translation were done by the principal investigator and a trained research assistant who were both proficient in the 3 languages.

The 6 phases of thematic analysis based on Braun and Clarke were used to analyze the qualitative data.<sup>24</sup> To begin with, the transcripts were imported into data management software called NVIVO9. In phase 1, familiarization of the data was done by repetitive reading through the entire data set. Then, initial coding was conducted in phase 2 to organize segments of data from the entire data set into meaningful codes. After coding all the transcripts, the codes were then sorted into potential themes in phase 3 by recognizing meaningful repeated patterns across the data. The initial 3 phases were conducted by the principal investigator, a palliative care physician. In phase 4, these themes were independently reviewed and

**Table 2.** Patient Characteristics

Patient characteristics	Number of patients (%)
Total number of patients	20 (100%)
Sex	
Male	6 (30%)
Female	14 (70%)
Age in years	
< 50	4 (20%)
50-59	9 (45%)
60-69	5 (25%)
≥ 70	2 (10%)
Marital status	
Single/divorced	8 (40%)
Married	12 (60%)
Ethnicity	
Malay	3 (15%)
Chinese	14 (70%)
Indian	3 (15%)
Religion	
Islam	3 (15%)
Buddhism/Taoism/Confucianism	7 (35%)
Christianity	7 (35%)
Hinduism	2 (10%)
Atheism	1 (5%)
Disease	
Breast cancer	7 (35%)
Lung cancer	3 (15%)
Stomach cancer	3 (15%)
Acute leukemia	3 (15%)
Renal cell carcinoma	1 (5%)
Ovarian cancer	1 (5%)
Bladder cancer	1 (5%)
Spine cancer	1 (5%)

revised by 2 other palliative care physicians, 1 psychiatrist, and 1 neurologist. This independent review and revision of themes involved reexamining the original data for relevant incidents of data for each potential theme; expanding, collapsing, or discarding of initial themes; generation of new themes; and rediscussion of themes. The concepts of thematic networks were applied in phase 4 to facilitate the structuring of themes, in which the basic themes derived from textual data were grouped into the organizing themes which were then linked to form global themes that captured the principal tenet. These were presented as a model depicting the multiple levels of themes and their relationship.<sup>25</sup> Next, in phase 5, the themes and networks were defined and named. Literature review was done to be woven into the final write-up of phase 6.

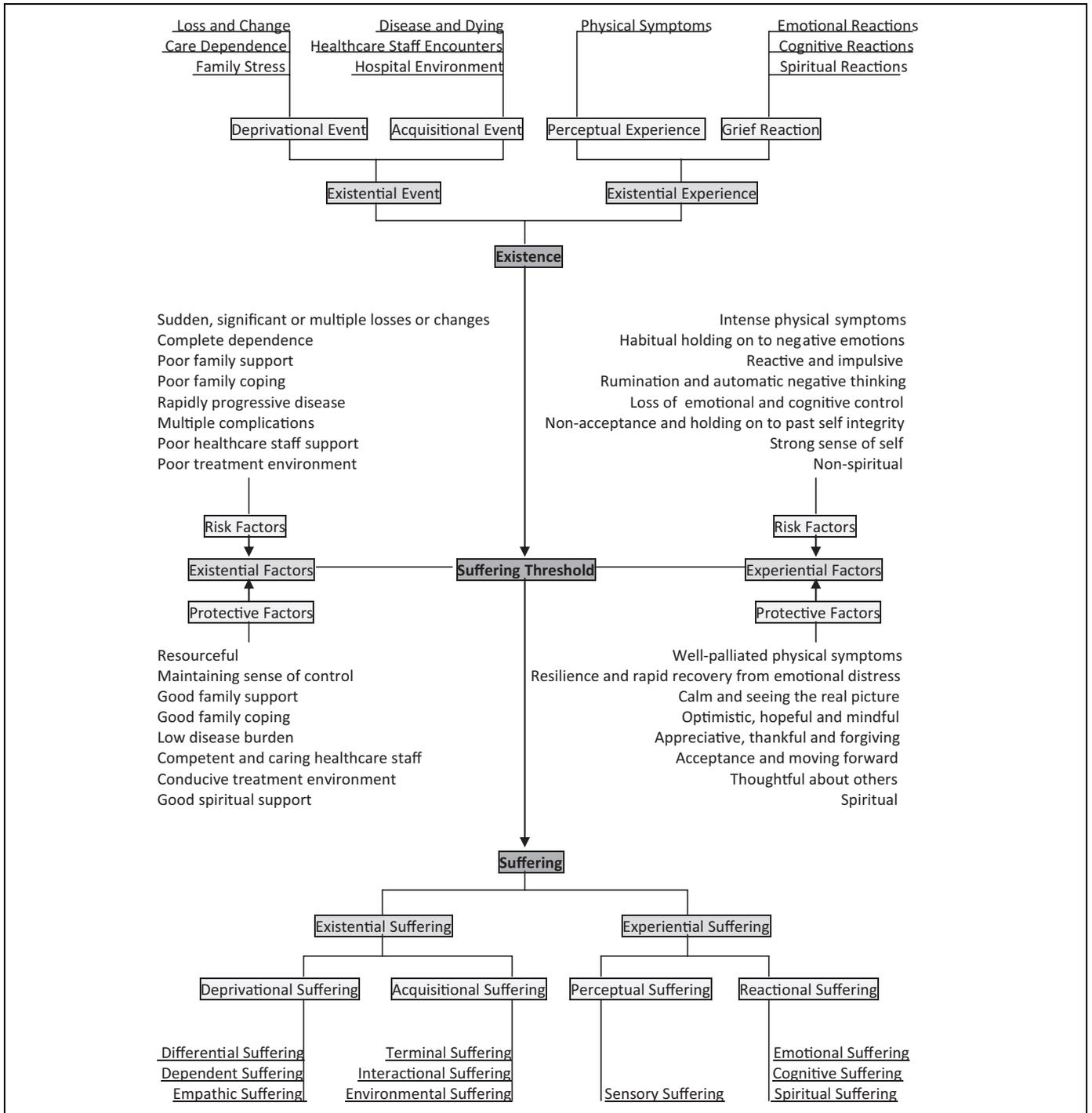
## Results

A total of 20 patients were interviewed with their characteristics presented in Table 2. After repetitive reading of all the transcripts, coding was done by screening all the data for experiences of suffering. Some of the data were double coded if the same segment of transcript carried 2 experiences of suffering. A total of 456 codes were generated. These codes were then categorized into 10 basic themes, with each of the themes

composed of a threat and its corresponding suffering: (1) loss and change → differential suffering, (2) care dependence → dependent suffering, (3) family stress → empathic suffering, (4) disease and dying → terminal suffering, (5) healthcare staff encounters → interactional suffering, (6) hospital environment → environmental suffering, (7) physical symptoms → sensory suffering, (8) emotional reactions → emotional suffering, (9) cognitive reactions → cognitive suffering, and (10) spiritual reactions → spiritual suffering. These composite themes were conceptualized because of the intrinsic difficulty in distinguishing the experiences of threats from suffering by reading the description of patients. Regarding data saturation, all 10 basic themes were represented within the first 4 interviews. The final theme of spiritual reactions → spiritual suffering was generated during the fourth interview. Data saturation was identified from revisiting the interview transcripts.

Using thematic network analysis, 4 first-level organizing themes were extracted from the 10 basic themes, including (1) deprivational event → deprivational suffering, (2) acquisitional event → acquisitional suffering, (3) perceptual experience → perceptual suffering, and (4) grief reaction → reactional suffering. From the 4 organizing themes, 2 second-level organizing themes were formed to further summarize the principal assumptions of the group of first-level organizing themes. These second-level organizing themes were (1) existential event → existential suffering and (2) existential experience → experiential suffering. The second-level organizing themes were then linked to form 2 global themes, namely (1) existence and (2) suffering. Formed from an inductive approach, these data-grounded themes were represented as web-like maps depicting the multiple levels of themes and the relationships between them in 2 networks—the existence network and the suffering network, as in Figure 1.

During thematic network analysis, the concept of a suffering threshold was deduced from the fact that a beginning point of suffering might exist where a threat just began to be experienced as suffering. This threshold concept was supported by 2 findings in the study. First, our patients who experienced similar existential events might or might not suffer. Second, most experiences of suffering of our patients changed from none to present or vice versa during the course of their illnesses. It is speculated that this threshold is a unique, subjective, and dynamic point modulated by various risk factors that reduce it and protective factors that increase it. Drawing from the existential and experiential data, multiple losses, complete dependence, poor support, intense symptoms, excessive rumination, and nonacceptance are proposed as examples of risk factors; whereas good support, well-palliated symptoms, resilience, optimism, appreciation, and acceptance can be protective factors that elevate the suffering threshold. Hence, the threshold network was constructed from this top-down approach and linked with the existence and suffering networks, which were formed from a bottom-up approach, to develop an existential-experiential model of suffering as illustrated in Figure 1, with different shades representing different levels of themes.



**Figure 1.** Existential-experiential model of suffering in palliative care patients.

After constructing the model of suffering with thematic network analysis, the networks and themes were named and defined. For the existence network, existence is defined as the state of being. It is characterized by existential events, or life events that occurred during one’s existence; and existential experiences, the first person experiences of such events. These events and experiences lead to suffering when the suffering threshold is exceeded. The suffering threshold is defined as a unique, subjective, and dynamic point of the beginning of

suffering, where the events and experiences are perceived as suffering. This suffering threshold is modulated by various risk factors that reduce the threshold and protective factors that increase it. When the suffering threshold is exceeded, existential events become existential suffering, and existential experiences become experiential suffering. Existential suffering and experiential suffering are 2 different perspectives of suffering. Existential suffering is the view of suffering from the perspective of existential realities, which include loss-related events,

named as deprivational events in the study; and gain-related events, named as acquisitional events. Experiential suffering is the view of suffering from the perspective of the inner experiences of the person, the unique, direct, first person experiences. It encompasses perceptual suffering that involves the experiences of suffering through the senses and reactional suffering that embraces all the unpleasant reactions triggered by perceptual suffering. Due to the self-explanatory nature of the threat component, the 10 basic themes were only defined for the component of its corresponding suffering. These definitions of basic themes are elaborated below, followed by selected transcripts from interviews that represent each theme. Due to the interrelated nature of the codes and our intent to preserve the flow of patients' description, some of the selected transcripts may carry codes from a different theme.

### *Loss and Change → Differential Suffering*

Differential suffering is the suffering related to change and loss. Patients experience losses in many ways at the end of their lives. This includes loss of physical function such as the ability to perform activities of daily living and instrumental activities. In this aspect, patients expressed their concerns over the inability to feed, stand, walk, move, cook, drive, do laundry, shop for groceries, and take care of children. In addition, patients also expressed their frustration of being bedridden, with loss of independence, freedom, and the sense of control over their bodies. Patients perceived changes from a normal life, from having the ability to carry out routines, social and spiritual activities to a life of suffering coupled with the loss of their job, income, role, normality, and quality of life. Many women with advanced breast cancer mentioned their distress resulting from a change in their body image. Some patients were devastated after illnesses ruined their long-term plans in life. Psychologically, patients experienced the loss of hope, happiness, confidence, and fighting spirit due to the awareness of their eventuality despite all efforts and treatment. Apart from the actual losses, expected losses bothered patients too, like the anticipated loss of function, anticipated separation with the family and anticipated loss of all things in the end, including their own existence.

Last time I could go to work, came back and looked after my children. I cooked by myself. I ate. It's a happy life. Now, I come to stay in the hospital. I have pain all the time. The doctors come and inject me here and there. They want to give me a drip but they cannot see my veins. It's a life of suffering! (Patient 6)

What is my worst suffering? I cannot walk, cannot drink, cannot eat, cannot sleep, cannot do this, cannot do that. This is my worst suffering. (Patient 17)

I am lying on the bed all the time, like a living corpse. I am very alert but I cannot do anything. I cannot even stand up. (Patient 14)

Now I cannot do anything. I want to do but I cannot do. I get breathless. Last time I could do tough work. I drove a car. I even drove a lorry. I sent cargo. (Patient 16)

I enjoyed my life. I went hiking, diving. I always went out with my friends, but now, I can't even go out to do the grocery shopping. So, I felt it took away my life one hundred percent. (Patient 12)

Friends might not be coming to you. You cannot join them socially anymore. I am afraid they will transmit things to me. So socially I feel I'm out. Even if you go there, you will never enjoy it. (Patient 4)

First, you lose your hope. Then you lose your confidence. Then you feel like you have lost everything. You feel like you have lost everything because when you get this thing, maybe you will die one day. (Patient 1)

### *Care Dependence → Dependent Suffering*

Dependent suffering is suffering secondary to depending on others. The various losses experienced by patients make them dependent on others. Patients depend on their family for assistance in performing activities of daily living and instrumental activities. In the hospital, patients need assistance from the health care staff. This dependence on others was mentioned as being a stressor for many patients. These stresses included the perceived burdening of others, the perceived uselessness of oneself, and the embarrassment that resulted from the dependence on others. One patient expressed the loss of self-esteem and embarrassment from depending on others to assist in toileting. Some mentioned the reluctance of relying on people due to self-image. At one extreme end of the spectrum, the distress from actual or anticipated dependence was severe enough to cause patients to voice their desire to die faster. At another end, there were patients who had no caregiver. Their worries were mainly due to the lack of caregivers and the possibility of discharge as a result of hospital overcrowding.

The worst thing I feel is that I'm burdening a lot of people, giving them extra work. They have to spend extra time to come here. Everything that I need, I need them to do for me. (Patient 13)

I think I am burdening my family members. My father has to take leave to send me to the hospital. My mother has to take care of me. By right, I should be the person who is working and earning money for the family. But I cannot do anything because of my current condition. And I need others to take care of me. It shouldn't be this way and I cannot accept this. (Patient 19)

I stressed a lot on my personal hygiene, but now I have no choice but to depend on others. I feel like I am a useless person. (Patient 14)

It is like nobody can help me. It is really suffering. I do not know how to explain it. Lying down here, I need others to help me. Besides, accepting help from others is a stress too. (Patient 14)

I don't want others to take care of me until the end. I hope I can get better and I can deal with these problems myself. If one day I really cannot handle these problems, I wish doctors can help to relieve my suffering. That means to end my life. (Patient 17)

### *Family Stress → Empathic Suffering*

Empathic suffering is the suffering caused by feeling others' suffering. Caring and journeying with patients at their end of

lives poses great challenges to the caregivers. In this study, these challenges included physical assistance in carrying, turning, and cleansing the patients; the strain of running to and fro from the hospital while trying to take care of one's own work and routine at the same time; night vigils in the hospital and emotional ups and downs. These caused physical and mental exhaustion in the family, which in turn resulted in empathic suffering for the patients witnessing the exhaustion. To make things worse, some dedicated family members who lacked self-concern might fall ill due to exhaustion, heightening the worry of patients. Apart from these, patients also described their difficulties witnessing the feeling of helplessness and the grief of the family. Patients expressed their concerns about the lives of their spouses, children, and parents in the future with the absence of patient.

The effect of my sickness is mostly on my family. They need to take care of me and cook for me. I always feel sorry for them. They are busy and tired but they still need to take care of me. (Patient 1)

I told my wife I have leukemia. Her tears dropped because every time when we went and did things, we held hands and we went out together. I never let a day go by without telling her that I love her. So these are the things that you feel devastated about. (Patient 4)

I told my wife to go home and rest. She has not gotten enough sleep. I said, "you must take care of yourself. Don't get sick because of me. You are still okay. You know what you are supposed to do. Don't go to the extreme of murdering yourself." (Patient 4)

When the day comes, I'm not scared but I feel sad. I feel sad for my family. I hope my family won't be so sad. (Patient 19)

My son is still studying. He is not working yet. He still needs to wait until July before he graduates. Definitely I am worried about him. It is not possible not to worry. (Patient 14)

I vomited and nearly collapsed. My husband was so scared. He was alone because the children were not around. He has only the children and me. And I can see that he's stressed out. (Patient 20)

### *Disease and Dying* → *Terminal Suffering*

Terminal suffering is the suffering related to a terminal disease. Being diagnosed with a terminal disease is a shock to most patients. Furthermore, the progressive nature of their illnesses, the multiple recurrences and complications from the disease or treatment, and the incurability of their illness, caused a great deal of distress in patients. The majority of patients were not ready to die. They expressed fear of dying, fear of suffering during dying, and fear of the unknown after death. These fears were aggravated by near-death experiences in some; and in others, by the exact prediction of life span given by some doctors. Young patients expressed their dissatisfaction and grief of having to die early before experiencing many things in life such as working, earning a living, getting married, having children, and supporting their parents.

When I was diagnosed with cancer, I was very sad. I didn't know where to turn. I didn't know what to do. I was feeling angry and unfair. (Patient 13)

I cannot accept the disease. Why is this happening to me? It is terminal as soon as it is diagnosed. I don't have any clue before that. (Patient 14)

Honestly speaking everybody is scared of dying. Who can remain fearless when they reach the end of their lives? I am speaking honestly. Everybody is scared of dying. (Patient 14)

I kept on losing bit by bit. Firstly I lost my left arm. Then, I couldn't walk far. I needed to lie down. Pain was everywhere for the whole day. It came suddenly. Everything came, non-stop. One by one, it's attacking me. I know I am going to die, but I just don't want to die like this. (Patient 3)

I am not afraid of dying but I am afraid of suffering. I don't want to suffer. If my pain cannot be relieved or if it gets worse, I'd rather die. (Patient 12)

### *Health Care Staff Encounters* → *Interactional Suffering*

Interactional suffering is the suffering that arises from interactions with the health care staff. Even though most patients expressed their satisfaction and appreciation toward doctors and nurses, some weaknesses were pointed out. These deficiencies included the lack of information and full attention from the doctors because of rushed encounter, different information from different teams, poor communication, and lack of empathy from some health care staff members, lack of efficiency and immediate attention from nurses during bell calling, and perceived lack of competency of general health care staff in handling palliative care issues. Poor communication was illustrated by the fact that patients occasionally mentioned hearing "nothing more can be done" from doctors. One patient described the lack of coordination in different teams prior to the referral to specialist palliative care service. In addition to health care personnel, some patients expressed dissatisfaction related to medical students, such as being disturbed during sleep, being disturbed during pain, too large a group, and being treated like an experiment.

Sometimes I asked the doctors about my condition, but then they didn't tell me clearly. They just told me roughly, "something like that, like that." (Patient 1)

Doctors being doctors, they have a short period of time. So, you are only going to get what is at the forefront of their mind. You are not going to get the entire picture. (Patient 11)

I didn't have a chance to be followed up by one particular doctor, really followed up by one particular doctor. The doctors always changed from one to another. (Patient 17)

I argued with the doctor. She said, "I have seen worse cases than yours." You have seen many cases, but you haven't tried. Try not to eat one week and see what happens. (Patient 10)

The services of nurses here are quite slow. You don't expect them to be like private hospital. They take some time to come. You don't expect them to come immediately because they have so many patients. (Patient 15)

The doctors and nurses helped me a lot. But the waiting time to see the doctors was very long. The time wasted in waiting made me suffer. (Patient 19)

The nurses are quite nice. I only met one nasty one. I was pressing the bell a few times because I needed something. So she came and said, "what do you want? Tell me. Don't call me again and again." (Patient 13)

Many of the medical students came at the wrong time. It's like when you wanted to rest, or when you were suffering, they came to ask you questions. Sometimes the doctors brought a lot of students. It was like being treated as their experiment. (Patient 1)

### *Hospital Environment* → *Environmental Suffering*

Environmental suffering is the suffering caused by hospital stays. Contrary to the belief of the healing environment of the hospital, none of the interviewed patients enjoyed their hospital stays. Patients uttered dissatisfaction about having to stay in bed most of the time, and this was made worse by the fact that their mobility was greatly restricted by the surrounding lines and tubes. They also expressed boredom and loneliness, having nothing to do in the hospital, watching people walking up and down, watching the 4 walls for those in single-bedded rooms, lack of appropriate entertainment, and the difficulty of passing time. Other issues mentioned were noises from neighboring patients and families that affected their sleep and rest and unpalatable hospital food. Some of them described their experiences in witnessing the groaning and suffering of other patients, as well as the death of neighboring patients.

I am sitting here watching people walking up and down. I wake up early in the morning and wait until evening. You cannot do anything. You feel depressed. You feel sleepy. Every morning, I just feel like I have nothing to do. I feel like I'm being trapped in the hospital. (Patient 2)

Staying here in the hospital? I cannot come down from the bed and go anywhere. Look! Left, right, and in front there are lines. Behind there are lines too. It's hanging here and there. I cannot come down and walk around. (Patient 9)

The food here doesn't do the patient any good. It doesn't have any nutrients at all. And, I wouldn't recommend the patient eat it. To cut a long story short, go and get a copy of the menu and the answer is there. (Patient 11)

She just came in. I always heard her breathing sound. Then she became quiet. I thought she's asleep. In the morning, my son came and told me that she has passed away. Then someone came with a big trolley to carry her body. (Patient 9)

### *Physical Symptoms* → *Sensory Suffering*

Sensory suffering is the suffering due to physical symptoms. Various physical symptoms were described in the study, like pain, breathlessness, vomiting, diarrhea, constipation, fatigue, sleeplessness, drowsiness, and body swelling. These physical symptoms were related to the disease or treatment such as chemotherapy, radiotherapy, surgery, and procedures such as

blood taking, pleural tapping, wound dressing, and so on. Unrelieved physical symptoms reduced patients' quality of life via impact on physical function, mental function, routines, social activities, and employment. Patients described the inability to do anything, the inability to stay still, and the inability to think clearly during pain. Mobility and sleep were affected. Family shared the suffering when seeing patients in pain. In severe cases, patients felt a sense of impending death during the exacerbation of symptoms, such as pain and breathlessness. Some expressed their wishes to expedite death due to unbearable pain. Some did not fear death itself but rather the pain and suffering associated with it.

I do not know how to express it. It was terrible. I had never felt such pain in my whole life before. (Patient 18)

At night, I can feel the leg pain all of a sudden and it wakes me up. The rest of the night I can barely go back to sleep. This pain causes me to take slow and small steps. Whenever I step on the ground, it hurts. I feel very terrible because of this. (Patient 19)

The second most difficult thing about being sick is the side effects of chemotherapy. That causes a lot of suffering such as vomiting, diarrhea, fainting, shortness of breath and everything else from the chemotherapy. (Patient 1)

I had six rounds of chemotherapy. This is my second time. I have vomiting. I feel sleepy. I have diarrhea. Once in a while you feel pain. You cannot go out. It's so painful. (Patient 2)

Sometimes when the pain is there I can't do anything about it. I can't even sit for ten minutes, walk for ten minutes or stay still for ten minutes. Even if I lie down for ten minutes, it's like I have to wake up again. I just don't know what I have to do and don't even know what I'm doing. (Patient 8)

I am no longer the same anymore. And it's not easy to live with it because the physical discomfort and the other things are a twenty-four-seven reminder. It's always there. You cannot even forget that you are sick. So that affects a lot. (Patient 11)

### *Emotional Reactions* → *Emotional Suffering*

Emotional suffering is the suffering related to emotions. A total of 5 common emotional reactions were noted, namely shock, anger, fear, worry, and sadness. Shock or surprise occurred at the beginning, right after the realization of the diagnosis. It could also occur during unexpected scans or blood results. Anger and frustration were observed when patients could not accept their losses or after unpleasant experiences with the family or the health care team. Examples of these experiences were the loss of function, the inability to do anything, dependence on others, progression of disease, poor communication from health care staff, and recurrent hospital admission. Boredom was expressed by a few patients as frustration of having nothing to do in the hospital or at home. Fear was another common emotion. Patients demonstrated fear of loss, burdening of others, morphine, dying, suffering, hospital admission, pain, and bleeding. One patient panicked with the fear of multiple losses, the fear of not having a caregiver, the fear of injections,

and the fear of dying. Worry was linked with anxiety, fear, sadness, and repetitive thinking. Complaints of worry included issues about health and recovery, disease progression, time of death, income, family, and competence of health care staff. Sadness, hopelessness, helplessness, uselessness, worthlessness, loneliness, and loss of will to live were all mentioned. These experiences were related to the disease, unsuccessful treatment, and the pressure of facing dying and multiple losses. Some described collective sadness shared with the family. With regard to loneliness, patients felt lonely not only from being literally alone but also from the perceived loneliness of experiencing the pain and suffering alone. The patients also mentioned regret over the past.

The most difficult thing about being sick is the feeling. It is very hard to describe it with words. It is very painful. It is full of suffering. (Patient 1)

The initial reaction was more of, sort of surprising. Oh! How is this possible? After that, when things get more confirmed, you get angry, frustrated. You get scared, because nobody can tell you how long you have left to live. Like for my case, all I know is, it is terminal. (Patient 11)

Emotionally when he told me it's probably cancer, it was like a knife, the stab of a knife. I said not now, because my sons still need me. They couldn't live without me. I was fearful, because I knew what it was. (Patient 20)

I am scared of a lot of things. I am scared of dying, scared of nobody going to take care of me because I am not married, scared of troubling people for taking care of me. So many things I am scared of. I am scared of needles. They are going to poke me. I don't know. I know this is the end of me. So, I hope it is fast, so that I don't have to suffer anymore. I don't want to suffer anymore. That's all. (Patient 3)

Of course I am worried. I worry about my future. If I cannot walk, then what can I do? How about my children? How long do I still need to depend on others? (Patient 5)

I feel hopeless. I don't want to take medication. Sometimes I feel lonely. No one knows my pain. Maybe they can see, they know, or see something, but they can't hundred percent understand what is happening inside me. (Patient 12)

### **Cognitive Reactions → Cognitive Suffering**

Cognitive suffering is the suffering related to thinking. The cognitive experiences of patients facing life-limiting illnesses are complex and diverse. It involves many thoughts and various beliefs. It also includes hope, desire, and the expectations of patients. However, acceptance and hope were seen to emerge as cognitive subthemes in the study. These 2 subthemes occurred in spectrums: from nonacceptance to acceptance and from hopelessness to unrelenting hope. Regarding acceptance, patients exhibited complete nonacceptance, partial acceptance with the common expression of "hard to accept" or "I can accept but . . .," to complete acceptance. Furthermore, the acceptance experiences were event specific and dynamic. The events mentioned were the diagnosis of cancer or terminal illness, nonrecovery, poor prognosis, dying, loss, and suffering.

Some patients changed from nonacceptance in the beginning to complete acceptance. Hope and bargaining were closely related to acceptance. It ranged from hoping for a cure or a miracle; to hoping to live longer, to be independent, to be free from suffering, to have quality of life such as traveling and celebration of festivities, and to have peace of mind. On one end of the spectrum, patients described their hopes for a cure; at the other end, patients hoped for a sooner death because of nonrecovery and suffering. In some cases, patients described their ambiguous hopes for both ends.

At the moment, with the current technology, they don't have the medication to cure the cancer. What they have is only to control it, or maybe to help me to live a little bit longer, but not really to cure it, to cure one hundred percent. This makes me very sad. (Patient 12)

The doctor will come and tell you this thing. The prognosis is three months, four months. But the prognosis may not be correct. When you go for your blood test, the figure does seem very nice. So this is the thing that you find hard to accept. (Patient 4)

Actually, I am not scared of dying. How to say? It's like I haven't done many things, then I have to die. Do you understand this feeling? It's like I haven't done many things and I haven't tried many things in my life, then suddenly I have to die. (Patient 1)

I can't accept it but I have no choice. Who wants to die at such a young age? I studied for so many years but I haven't done many "normal" things in life. I want to work, earn money and support my parents. I want to have my own family. These are the basic things in life. (Patient 19)

I know my disease is terminal. My situation is hopeless. But I hope my life can be prolonged a bit. I hope if my life can be prolonged for one day then I will have one extra day to live. I hope I can see more people. I can see the world. I hope I can extend my life one day at a time. (Patient 14)

Of course the disease cannot be cured. But we can talk about prolonging. And then, prolonging, not just prolonging by hanging on drips and lying on hospital beds, but prolonging by making sure that there is still quality of life. (Patient 11)

There is no hope for recovery. And it is very painful. Is there a reason to continue to prolong this suffering? I would rather end these days of suffering. (Patient 17)

### **Spiritual Reactions → Spiritual Suffering**

Spiritual suffering is the suffering related to unmet spiritual needs. Toward the end of their lives, questions about suffering and dying were raised by patients. These included "why me?" "why now?" "what have I done wrong?" "why do I need to suffer?" and "what will happen to me after I die?" Without answers, patients not only expressed loss of faith but also developed doubtful thoughts about God as they did not know what God's plan was and where God was. They felt a kind of spiritual loneliness, likened to a state of being abandoned by God, and felt unfairly treated by God. Besides these, patients also communicated other various beliefs. Some believed that

their illnesses were a punishment from God; some thought that their illnesses were caused by the devil and some said that their conditions were retribution from past life. One patient described the hospital as a haunted place. Another patient refused to be transferred to the palliative care ward because of prior experiences of witnessing multiple deaths in that ward.

Sometimes I feel life is unfair. Why should I be the person who got this? (Patient 5)

Certain days can be very bad to you. You think that life is not worth it. What have you done wrong? It's like God has abandoned you. (Patient 4)

Sometimes I lose my faith. Because when I go through all of this, all the pain, sometimes I feel lonely. I don't know where God is. So, it's just like I've lost Him. (Patient 12)

I have leukemia. It's a disease. It is not mine. It is planted by the devils. I don't invite them in to stay in my body, and eventually, you see, they are going to kill me. (Patient 4)

Since I got the disease, I thought about dying all the time. When I was young, I made so many mistakes and I enjoyed too much. Now I am scared. I have to answer back to God. (Patient 18)

Some people said that suffering is due to actions of past life. It is like retribution. We can say that. I just listen to what people say. (Patient 14)

## Discussion

From the study, suffering is broadly categorized into existential and experiential sufferings. Existential suffering emphasizes the existential events that patients go through. It is further categorized into deprivational suffering or loss-related suffering and acquisitional suffering or gain-related suffering. The 3 types of deprivational sufferings are differential, dependent, and empathic sufferings. These 3 types of loss-related suffering have been described in the literature with different terms. For example, patients experience many types of losses at the end of their lives, such as loss of function, control, role, interpersonal relationships, safety, identity, and loss of life in the previous literature.<sup>26,27</sup> Suffering from being a burden to others and feeling the suffering of family members have also been mentioned.<sup>22,28-30</sup> The findings from this study consolidate the fact that suffering brought by a disease is more than a disease. The common biomedical approach to disease is inadequate to address the various suffering brought by the disease, such as loss, dependence, and family stress. This can be made worse by the development of more and more subspecialties in medicine. To counter this, a more holistic approach to suffering that takes into account these deprivational events triggered by the disease is required parallel to the development of the many subspecialties.

The 3 types of acquisitional sufferings are terminal, interactional, and environmental sufferings. These 3 types of gain-related sufferings have also been described in the literature. Terminal suffering resulting from the impact of a terminal

disease and dying has been described in studies on cancer experiences<sup>31-34</sup> and death anxiety.<sup>35-37</sup> As for interactional suffering and environmental suffering, though the terms may have a broader meaning, we defined them specifically related to the health care settings. Research in health care-related suffering was found to be scarce after our literature review. In addition to not being treated as a whole person and the feeling of abandonment in the failure of cure,<sup>38,39</sup> unpleasant encounters with health care professionals and the unpleasantness of being in a hospital environment were observed in this study. These findings lead us to put forward our argument that the conventional biomedical approach to disease is not only inadequate in treating suffering but is ironically contributing to suffering in many instances. Hence, apart from the disease, acquisitional events like attitude, behavior and communication of health care staff, and the hospital environment, should be taken into consideration in the management of suffering.

While existential suffering has its focus on the existential aspects of suffering, experiential suffering highlights the direct inner experiences of patients. Experiential suffering is classified into perceptual and reactional sufferings. In the study, sensory suffering is classified as perceptual suffering. Emotional, cognitive, and spiritual sufferings are categorized as reactional suffering. In sensory suffering, pain is one of the most common symptoms. Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage.<sup>40</sup> Contrary to most literature, which excluded pain and physical symptoms from existential suffering,<sup>5,10,12-14,26</sup> physical symptoms were seen as existential experiences in this study. Pain and physical symptoms were experienced as existential realities that were inseparable from the various emotional, cognitive, and spiritual reactions triggered by the perception. This inclusion helps us to clarify the definition of existential suffering,<sup>9,10</sup> but the controversy of palliative sedation in nonphysical existential suffering remains.<sup>9,41-43</sup> As for grief reactions, in comparison to the classical description of denial, anger, bargaining, depression, and acceptance in the Kubler-Ross model,<sup>44</sup> we noted shock, anger, fear, worry, and sadness as the 5 common nonsequential emotional reactions; hope-hopelessness and acceptance-denial as the 2 common spectrums of cognitive responses; and various spiritual questions that arose in the midst of terminal illnesses. From these findings, the interconnection of physical symptoms and the various reactions triggered by perception are emphasized. Therefore, apart from dealing with the multiple existential aspects of suffering, the experiential aspects of suffering like sensation, emotion, cognition, and spirituality cannot be ignored.

In this study, a 2-dimensional view of suffering is conceptualized—the existential-experiential model of suffering (Figure 1). This model of suffering can be divided into a horizontal component and a vertical component. While the horizontal component offers a broad classification of suffering based on existential and experiential dimensions, the vertical component presents a theory of formation of suffering with emphasis on the concept of a suffering threshold that is

modulated by the same existential and experiential factors. In the existing literature, suffering is commonly presented as a multidimensional experience comprising of physical, psychological, social, and spiritual or existential domains,<sup>26,45-47</sup> the so-called biopsychosocial-spiritual model.<sup>48</sup> This model can be complemented by the 10 types of suffering in our model, which are separated into an existential dimension that emphasizes the existential realities faced by the patients and an experiential dimension that focuses on the direct inner experiences of these realities. Our model can be a different approach in understanding suffering. It enables the separation of the often unchangeable existential realities in terminal disease and the dynamic inner experiences of these realities.

The vertical component of the model that presents the theory of formation of suffering by introducing the concept of suffering threshold and its modulating factors explains Blinerman finding that existential issues do not necessarily lead to suffering.<sup>14</sup> Comparing and contrasting the existential-experiential model of suffering with various theories of stress and illness, our model emphasizes the complex interplay of various existential and experiential factors that influences the formation of suffering. In the transactional model of stress by Lazarus and Folkman, the emphasis is on cognitive appraisal and coping.<sup>49</sup> In Leventhal's commonsense model of illness representation, the emphasis is on commonsense of patients in terms of identity, cause, time line, consequences, and curability or controllability of the illness; coping responses and appraisal.<sup>50</sup> In Helman folk model of health and illness, the emphasis is on the lay concepts of illness derived from within the individual, from the social world, from the natural world, and the supernatural world.<sup>51</sup> These 3 models emphasize cognitive factors as the main determinant of patient's stress and illness—namely appraisal (Lazarus and Folkman), commonsense (Leventhal), and lay beliefs (Helman). However, in our model, other than cognitive factors that are represented by the hope-hopelessness and acceptance-denial spectrums, other experiential and existential factors contribute to the formation of suffering too.

Based on the horizontal component of the existential-experiential model, we can tailor our assessment and management of suffering according to the existential and experiential dimensions of suffering. If the existential dimension of suffering is irremediable, then greater emphasis and effort can be put on the experiential dimension. If the perceptual suffering of the experiential dimension is refractory to treatment, then greater emphasis can be put on reactional suffering. Furthermore, the tailoring can be enhanced by using the 10 basic themes of suffering as a guide. Hence, a mechanism-based approach to assessment and management of suffering can be developed in the future. As for the vertical component of the model, it can be beneficial in the prevention of suffering because a mechanism-based approach can be developed based on the various existential and experiential factors that modulate the suffering threshold.

The main limitation of the study is caused by convenience sampling, in which the patients included do not represent the

population in Malaysia in terms of age, sex, ethnicity, and religion. Furthermore, the finding is limited by the scope of the 8 questions asked in the interviews. Questions about ethnicity, culture, beliefs, and home care are not included. Future studies focusing on the sociocultural aspects of suffering can be performed to address cultural differences between the various ethnic groups in Malaysia. Additionally, subtle description of experiences of suffering of the 6 non-English interviews may be inaccurately transcribed or translated in the process. In studying suffering, there is an intrinsic difficulty in getting an accurate description of patients' direct experiences. For example, some of our patients expressed the difficulty in describing their suffering in words. One of our patients mentioned that nobody could understand her experience of suffering. Her family and friends might know that she was suffering, but they could not understand completely the direct, first hand experience of her suffering. In addition, patients with impaired levels of consciousness and those who could not communicate could not be included in the study. Other than these factors, the absence of non-cancer palliative care patients in the study is also a limitation.

In conclusion, suffering can be defined as an unpleasant existential experience that occurs when the individual suffering threshold is exceeded. In the palliative care setting, in addition to treating unpleasant existential events, interventions that modulate the experiential dimension of suffering can enhance the relief of suffering. Finally, we would like to quote the aspiration of a compassionate scholar Shantideva in relation to suffering.<sup>52</sup>

For as long as space endures  
And for as long as living beings remain,  
Until then, may I, too, abide  
To dispel the misery of the world.

### Acknowledgment

We would like to express our heartfelt gratitude to all our patients who have participated in the study.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

### References

1. Cassell EJ. *The Nature of Suffering and the Goals of Medicine*. Oxford, UK: Oxford University Press; 1991:3-33.
2. Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;307(12):758-760.
3. Chapman CR, Gavrin J. Suffering and its relationship to pain. *J Palliat Care*. 1993;9(2):5-13.

4. Chapman CR, Gavrin J. Suffering: the contributions of persistent pain. *Lancet*. 1999;353(9171):2233-2237.
5. Cherny NI, Coyle N, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care*. 1994;10(2):57-70.
6. Coulehan J. Suffering, hope and healing. In: Moore RJ, ed. *Handbook of Pain and Palliative Care*. New York, NY: Springer. 2012; 7:717-731.
7. Saunders C, Baines M. *Living with Dying: The Management of Terminal Disease*. 1st ed. Oxford, UK: Oxford University Press; 1983:74.
8. Boston P, Bruce A, Schreiber R. Existential suffering in the palliative care setting: an integrated literature review. *J Pain Symptom Manage*. 2011;41(3):604-618.
9. Bruce A, Boston P. Relieving existential suffering through palliative sedation: discussion of an uneasy practice. *J Adv Nurs*. 2011;67(12):2732-2740.
10. Strang P, Strang S, Hultborn R, Arner S. Existential pain – an entity, a provocation, or a challenge? *J Pain Symptom Manage*. 2004;27(3):241-250.
11. Yalom ID. *Existential Psychotherapy*. New York, NY: Basic Books; 1980.
12. Murata H, Morita T. Conceptualization of psycho-existential suffering by the Japanese Task Force: the first step of a nationwide project. *Palliat Support Care*. 2006;4(3):279-285.
13. Morita T. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. *Support Care Cancer*. 2004;12(2):137-140.
14. Blinderman CD, Cherny NI. Existential issues do not necessarily result in existential suffering: lesson from cancer patients in Israel. *Palliat Med*. 2005;19(5):371-380.
15. NCCN. The National Comprehensive Cancer Network. *Distress Management Guidelines*. <http://www.nccn.org>. Accessed May 2010.
16. Morita T. Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients. *J Pain Symptom Manage*. 2004; 28(5):445-450.
17. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C. 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics*. 2001;37(12):727-734.
18. Kissane DW, Clarke DM, Street AF. Demoralization syndrome – a relevant psychiatric diagnosis for palliative care. *J Palliat Care*. 2001;17(1):12-21.
19. Clarke DM, Kissane DW. Demoralization: its phenomenology and importance. *Aust N Z J Psychiatry*. 2002;36(6):733-742.
20. Vehling S, Lehmann C, Oechsle K, et al. Is advanced cancer associated with demoralization and lower global meaning? The role of tumor stage and physical problems in explaining existential distress in cancer patients. *Psychooncology*. 2010;doi:10.1002/pon.1866.
21. Bruce A, Schreiber R, Petrovskaya O, Boston P. Longing for ground in a ground(less) world: a qualitative inquiry of existential suffering. *BMC Nurs*. 2011;doi:10.1186/1472-6955-10-2.
22. Cherny NI, Coyle N, Foley KM. Suffering in the advanced cancer patient: a definition and taxonomy. *J Palliat Care*. 1994;10(2):57-70.
23. Boston P, Mount BM, Orenstein S, Freedman O. Spirituality, religion and health: the need for qualitative research. *Annales CRMCC*. 2001;34(6):368-374.
24. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101.
25. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qual Res*. 2001;1(3):385-405.
26. Wilson KG, Chochinov HM, McPherson CJ, et al. Suffering with advanced cancer. *J Clin Oncol*. 2007;25(13):1691-1697.
27. Lobb EA, Clayton JM, Price MA. Suffering, loss and grief in palliative care. *Aust Fam Physician*. 2006;35(10):772-775.
28. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden to others: a systematic review focusing on the end of life. *Palliat Med*. 2007;21(2):115-128.
29. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden to others: exploring the perspectives of patients at the end of life. *Soc Sci Med*. 2007;64(2):417-427.
30. Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Burden to others and the terminally ill. *J Pain Symptom Manage*. 2007;34(5):463-471.
31. Lee V, Loiselle CG. The salience of existential concerns across the cancer control continuum. *Palliat Support Care*. 2012;30:1-11.
32. Krause K. Contracting cancer and coping with it. Patients' experiences. *Cancer Nurs*. 1991;14(5):240-245.
33. Bertero C, Vanhanen M, Appelin G. Receiving a diagnosis of inoperable lung cancer: patients' perspectives of how it affects their life situation and quality of life. *Acta Oncol*. 2008;47(5):862-869.
34. Khatri S, Whiteley I, Gullick J, Wildbore C. Marking time: the temporal experience of gastrointestinal cancer. *Comtemp Nurse*. 2012;41(2):146-159.
35. Lehto RH, Stein KF. Death anxiety: an analysis of an evolving concept. *Res Theory Nurs Pract*. 2009;23(1):23-41.
36. Tomer A, Eliason G. Toward a comprehensive model of death anxiety. *Death Stud*. 1996;20(4):343-365.
37. Sherman DW, Norman R, McSherry CB. A comparison of death anxiety and quality of life of patients with advanced cancer or AIDS and their family caregivers. *J Assoc Nurses AIDS Care*. 2010;21(2):99-112.
38. Daneault S, Lussier V, Mongeau S, et al. Primum non nocere: could the healthcare system contribute to suffering? In-depth study from the perspective of terminally ill cancer patients. *Can Fam Physician*. 2006;52(12):1574-1575.
39. Arman M, Rehnsfeldt A, Lindholm L, Hamrin E, Eriksson K. Suffering related to healthcare: a study of breast cancer patients' experiences. *Int J Nurs Pract*. 2004;10(6):248-256.
40. Merskey H, Bogduk N. Part III: pain terms, a current list with definitions and notes on usage. In: Merskey H, Bogduk N, eds. *Classification of Chronic Pain*. Seattle, WA: IASP Task Force on Taxonomy Press; 1994:209-214.
41. Zittoun R. Distress during end-of-life: ethical questions about sedation. *Presse Med*. 2011;40(5):486-492.
42. Cassell EJ, Rich BA. Intractable end-of-life suffering and the ethics of palliative sedation. *Pain Med*. 2010;11(3):435-438.

43. Jansen LA. Intractable end-of-life suffering and the ethics of palliative sedation: a commentary on Cassell and Rich. *Pain Med.* 2010;11(3):440-441.
44. Kubler-Ross E. *On Death and Dying: What the Dying have to Teach Doctors, Nurses, Clergy, and their Own Families.* Scribner. 1997.
45. Krikorian A, Limonero JT, Mate J. Suffering and distress at the end-of-life. *Psychooncology.* 2011;doi:10.1002/pon.2087.
46. Kuuppelomaki M, Lauri S. Cancer patients' reported experiences of suffering. *Cancer Nurs.* 1998;21(5):364-369.
47. Thompson GN, Chochinov HM. Reducing the potential for suffering in older adults with advanced cancer. *Palliat Support Care.* 2010;8(1):83-93.
48. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist.* 2002;42(3):24-33.
49. Lazarus RS, Folkman S. *Stress, Appraisal and Coping.* New York, NY: Springer; 1984.
50. Leventhal H, Brisette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In: Cameron L, Leventhal H, eds. *The Self-Regulation of Health and Illness Behavior.* London, UK: Routledge; 2003:42-65.
51. Helman CG. Disease versus illness in general practice. *J R Coll Gen Pract.* 1981;31(230):548-552.
52. Shantideva. Dedication. In: *Guide to the Bodhisattva's Way of Life.* New York, NY: Tharpa; 2002.