



Methodology Article

Suffering Among Patients with Cancer: A Concept Analysis and Implications for Oncology Nurses

Dhuha Youssef Wazqar

Medical Surgical Nursing Department, Faculty of Nursing, King Abdulaziz University, Jeddah, Kingdom of Saudi Arabia

Email address:

dwazger@kau.edu.sa

To cite this article:

Dhuha Youssef Wazqar. Suffering Among Patients with Cancer: A Concept Analysis and Implications for Oncology Nurses. *International Journal of Clinical Oncology and Cancer Research*. Vol. 2, No. 5, 2017, pp. 113-122. doi: 10.11648/j.ijcocr.20170205.14

Received: August 18, 2017; **Accepted:** September 9, 2017; **Published:** October 20, 2017

Abstract: The number of patients with cancer and cancer survivors have increased globally, due to the increase in the complexity and intensity of cancer treatment modalities. This increase in intensity cause suffering in patients with cancer who experience these kinds of treatment. The purpose of this article was to conduct a concept analysis on suffering through analyzing the existing literature. Suffering needs to be defined and examined by qualitative oncology nursing research to provide a precise, complete picture of the nature and possibility of suffering in patients with cancer. Knowledge of how these patients experience suffering would facilitate oncology nurses to create interventions to avoid or reduce this suffering. Overall, this concept is relevant to nursing and further studies should use this concept in generating knowledge about understanding and reducing suffering among patients with cancer. Cultural differences need to be examined in a large more diverse sample size to ensure the suffering concept applicability and validity cross culturally.

Keywords: Concept Analysis, Suffering, Pain, Symptom Distress, Patients with Cancer

1. Introduction

Cancer represents one of the major public health issues and one of the main causes of death in developing countries [1]. The number of patients with cancer has been continuously and noticeably increasing in many low and middle-income countries, such as Kingdom of Saudi Arabia (KSA) [2]. It has been estimated that more than 14,000 new cases of cancer were diagnosed in the KSA in 2013, and, regardless of advances in management, 8,900 patients with cancer died during the same year [2, 3]. However, advancements in treatment have led to a gradually increasing number of cancer survivors. A study conducted by the National Cancer Registry in the KSA, estimated the survival of patients diagnosed with cancer in 1994-1996, cases followed-up until 2001, to be 56%; for instance, localized breast cancer patient's survival is more than 70% [3]. However, more intensive cancer treatment modalities, such as chemotherapy and radiation therapy, have increased the adverse reactions that lead to suffering among patients with cancer [4]. But what is suffering in the context of patients with cancer? patients with cancer suffer from many physical, social, behavioral, and psychological problems that

affect the quality of their lives due to the intensive therapy and disease process [5]. Despite the importance of suffering in healthcare contexts, there is an unexpectedly small amount of substantive literature on this concept among patients with cancer.

As a concept that becomes widely used, suffering may be extended to the point where it becomes ambiguous and unclear. Clear concepts are essential if phenomena are to be recognized, situations and problems described, and proper interventions planned [4]. The concept of suffering in patients with cancer need to be defined and described. Oncology nurses cannot plan and examine interventions to help patients with cancer cope and adapt to the disease and treatment until they understand the experiences of these patients. Therefore, the development of suffering concept in oncology nursing has great implications.

Even though suffering has been explored in nursing literature since the late 1980s, a concept analysis of suffering has never been performed. For this reason, the author decided to critically analyze suffering with a concept analysis to identify its uses in nursing, especially oncology nursing. This will expose the concept of suffering's potential limitations and

redefine its attributes that have evolved over the last decade. Through reviewing oncology nursing literature, most researchers conducted their studies without clearly defining suffering. Because of this definition concern, and with the complexity of cancer problems that increase over the time, the use and understanding of the suffering concept by oncology nurses can help promote successful relevance to patients with cancer. Therefore, the purpose of this analysis was to define the concept of suffering among patients with cancer from a review of the professional and non-professional literature, and clarify the meaning of suffering in the nursing profession to advance oncology nursing knowledge base and practice.

2. Concept Analysis

A concept can be used to give various meanings; concept analysis can be defined as “a complex mental formulation of experience” [6]. In addition, a concept is a word or label used to explain a phenomenon or a group of phenomena [7]. Multiple methods can be used to analyze and when undertaking a concept analysis, the selected method should support the purpose of analysis [6]. Chin and Kramer’s [6] guidelines for concept analysis was chosen as the methodology for this analysis for several reasons. First, Chin and Kramer’s method is logically organized and straightforward. Second, this method has been used successfully by many authors to analyze concepts related to nursing and other healthcare professionals. Third, the purpose of their definition supports the purpose of this concept analysis of suffering, which it provides oncology nurses the mental image or picture of suffering among patients with cancer to advance nursing knowledge and practice. The method requires several steps: (1) selecting the concept, (2) clarifying purpose, (3) defining the concept from various sources, (4) formulating criteria for concept, (5) construction of a model, related, borderline and contrary cases, (6) identifying consequences, and (7) exploring contexts and values [6].

Since concept development is a dynamic and ongoing process, the concept itself should be flexible enough to fit in different contexts and times [4]. For instance, suffering may be conceptualized in different disciplines such as, psychology and nursing. Suffering is different in children than in adults. It also means that suffering may be different in the same children or adults over time. An adult newly diagnosed with cancer may suffer much more from vomiting and nausea than an adult who has been receiving the same chemotherapy medications for one year, or vice versa.

3. General Applications of Suffering and Suffering in Other Disciplines

Suffering has many different definitions and synonyms in common usage. One literature search engine (www.google.com) reported 7,360,000 references with the keyword “suffering” [4]. A substantial proportion of the

general references related to suffering are from the disciplines of spirituality and religion. A Scopus literature search using the keyword of suffering yielded 445 references in medicine, 138 in social science, 125 in psychology, 19 in nursing and 12 in genetic and molecular biology. A PubMed literature search using the keywords “suffering and suffering and cancer” yielded 801 references. Many themes were related to family caregivers of patients with cancer, death, healthcare team reactions, quality of life, palliative care, end-of life care, patient’s symptoms, and symptom management. Through reviewing the literature in nursing, medicine, sociology, psychology, ethics, and religion, “suffering” was mostly used as an adjective or descriptive phrase and not as a concept. For instance, it relates to other words, as in “distress and suffering” or “suffering and pain,” or “the patient suffering from insomnia, chronic illnesses and cancer”.

The Oxford Canadian Dictionary of Current English defines “suffering” as to “undergo, put up with, experience, be subjected to “pain, loss, grief, defeat, change, punishment, wrong, etc.” [8]. The Japanese Kojien Dictionary defines “suffering” as “a pain, worry, psychical pain” [9]. Words that are approximately synonymic with suffering are pain, distress, misery, sorrow, displeasure, unpleasant, unhappiness, discomfort, ill, sadness and affliction.

Suffering in psychological literature involves agony, grief, sorrow, pain and conflict due to an inability of patients to find an answer to problems that altered their lives and the relationships with others. Viktor Frankl [10], a founder of existential psychology, stated “we can discover the meaning in life in three ways: by doing a deed; by experiencing a value; and by suffering”. He assumed that physical discomfort and deprivation are not the main causes of suffering, but suffering can happen due to an experienced loss of meaning and purpose. Therefore, suffering is connected to loss, it may be loss of relationship, of some portion of the self, or of some aspect of physical body. In another study conducted by Ronald [11], suffering was defined as a complex process involving physical, psychological, and social components strongly rooted in the moral area in such a way as to make the practice of psychotherapy certainly also the practice of ethics. Based on this, suffering has many dimensions that threat to integrity or continued existence of the whole person.

According to Arthur Kleinman [12], social suffering is a collective process connected to the life situations shaped by controlling social forces. In another study conducted about the themes of suffering in the end of life, the incomparability of suffering experiences relates to individual’s unique personal histories, feelings, and reason of suffering [13]. Social suffering is related to cultural and race conflict, and international economic trends, poverty, diseases, genocide, torture, and sexual abuse. Suffering happens when individuals feel voiceless; when individuals are an unable to provide words about their experiences or when the individuals’ screams are unheard.

Suffering plays a key role in many religions [14]. The Four Noble Truths of Buddhism are about dukkha, an expression usually translated as suffering. The Four Noble Truths say (1)

the nature of suffering, (2) its reason, (3) its termination, and (4) the way leading to its termination. Buddhism considers liberation from suffering as fundamental for leading a holy life and attaining nirvana [4]. Also, the thought of suffering in Islam is based on the fundamental notion of the imperfection of human life. Humans are on this earth so that their faith in God is tested. A test necessarily requires calamities and misfortunes [14]. Suffering in religions is used specially to increase spirituality, to compensate, to inspire compassion, to frighten, and to discipline. Moreover, in arts, people might use suffering for creation, for performance, or for pleasure [4]. Entertainment mainly also makes use of suffering in aggressive video games, blood sports and violence in media. Suffering is illustrated in art, for instance the painting by Edward Munch, "The Scream", painted in 1893 and in photography as in Ansel Adams's 1943 collection of photographs of Japanese Americans interned at Manzanar Relocation Camp, entitled "Suffering under a Great Injustice" [15].

Suffering in healthcare is related to illnesses and injuries in humans. Healthcare addresses this suffering in many ways, in medicine, clinical psychology, psychotherapy, complementary medicine, nursing, public health, and through various healthcare providers. Cassell [16] defines suffering as "the state of severe distress associated with events that threaten the intactness of the person". Suffering encompasses a complete set of physical and mental distress, discomfort, symptoms and problems. According to the medical literature, there is a strong difference between physical pain and suffering, but more attention goes to the treatment of physical pain.

Many studies examined suffering in patients with cancer. Researchers indicate that suffering of patients with cancer is a negative pain sometimes experienced in greater than the categories of sense of control of oneself [17]. Patients with cancer suffer pain by thinking negatively about problems that might occur during medical treatment [18]. Also, suffering among these patients can be due to being in an insensitive state, denying reality and the inability to rationalize [9]. Suffering may be a conflict between a spiritual feeling and reality. In addition, patients with cancer can suffer from the serious symptoms of the disease process and the intensive treatment [5]. Despite the importance of suffering in healthcare contexts, little is known about this concept within healthcare and oncology nursing in developing countries.

4. Historical Conceptual Development

The Hastings Centre, an organization devoted to research and teaching about ethical dilemmas created by biomedical advances, conducted two years project on death, suffering and well-being [16]. However, the project did not increase the oncology nurses' understanding of suffering. Based on this, Cassell [16], a medical doctor, published a decisive paper about suffering in healthcare sittings. He defined suffering as "a state of severe distress associated with events that threaten the intactness of the person" [16]. Here the concept of "distress" is included in the Cassell's definition of suffering.

In 1999, this definition of suffering was advanced: "Suffering involves some process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future" [19]. According to his definition, suffering may include non-physical sources. Rowe [20] described the sources of suffering in the healer and how they responded to their suffering by using Cassell's definition of suffering. According to Rowe [20]:

The suffering of the healer can be defined as severe distress associated with events that threaten the intactness of the healer in the role of healer. Here, the threat to the self is a threat to one's identity as a healing person, these are threats one would not encounter if one were not in the role of healer. Here, the concept of "distress" is mentioned again in the Rowe's definition, suggesting that "distress" is a related concept for suffering or a criterion of suffering.

Through reviewing the literature on suffering in oncology nursing, some research studies have been conducted without clearly defining suffering. One study evaluated healthcare providers' understanding of the principle of treating pain and suffering at the end of life of patients with cancer in the hospital [21]. The authors used the concept of suffering at least 26 times in the article without providing a clear definition of suffering. In the article, they just connected suffering with pain and mentioned suffering as a symptom usually occurring with terminally ill patients with cancer at the end of their lives in the hospital with the focus of discuss the solutions to reduce suffering. Also, another study conducted about the emotional pain and distress of borderline personality disorder, researchers found that distress and suffering have been described as two different concepts, but in the study the participants described their distress as suffering [22].

Some researchers use a very broad definition of suffering that could obstruct the actual definition of the suffering. In one study conducted by a group of researchers to describe the suffering experiences among women with breast cancer [23], it is not clear what is the researchers' definition of suffering. They state, "the suffering experience is the patient's spiritual (or emotional) answer to an event or a situation that is evil and undesirable, threatening and unavoidable" [23]. It is unclear for the author, if they created this definition or an explanation of another researcher's definition. Even though, Ferrell and Coyle's article [17] is rich in multiple definitions and descriptions of suffering, but the author thinks it is difficult to find an effective definition.

Moreover, some researchers have tried to advance the theoretical development of the concept of suffering. "When it came down to discussion of actual practice and human beings, the tendency was to consider suffering as a degree of pain or some other kind of distress, instead of a distinct experience that took place on the level of the whole person" [24]. Nevertheless, pain may happen without suffering, and suffering may happen without pain. Ferrell [25] states "For suffering to occur the individual must perceive the situation as distressing, although the judgment of distress may occur after the immediate situation is over". In another study, Travelbee [26] differentiated physical pain from mental distress and

recommended that they joined to produce suffering. Again, Kahn and Steeves [24] advanced the theoretical definition of the concept of suffering as “an individual’s experience of threat to self, a meaning given to events such as pain or loss”. Based on this work, Spross [27] approved that “suffering is not essentially a perception or sensation but an evaluation of the significance or meaning of pain or other source of suffering”.

Dr. Janice Morse, a nursing professor, developed a model about the response of patients to chronic diseases that included suffering in the late 1980s. According to Morse and Carter [28], suffering in as part of the concept of endurance and mentioned that “suffering is the emotional response to the phenomena that has been endured or the response to an anticipated future that is lost or destroyed or to an irrevocably altered present or future because of the past event”. Because of this, Marilyn Rawnsley [29], a nursing professor and clinician, offered an alternative: “I would argue for the concept of suffering as a multidimensional phenomenon that incorporates endurance as well as expressive symptoms of distress. Expressions of suffering shaded through developmental, cultural, and demographic variations may well manifest as endurance for some and anguish or despair or sorrow for others”. Morse [30] improved her theories and then established that “suffering is perceived as comprising two major behavioural states: enduring (in which emotions are suppressed; it is manifested as an emotionless state) and emotional suffering (an overt state of distress in which emotions are released)”. Again, the related concept of “distress” is connected to suffering as a concept. As distinguished in the previous examples, the concept of distress or symptom distress is regularly interrelated and difficult to separate from the concept of suffering.

Hinds and a group of researchers defined the concept of symptom distress in patients with cancer as “an individual’s report of his or her awareness of one or more changes in normal function, sensation, or appearance that cause him or her some degree of physical discomfort, mental anguish or suffering” [31]. Based on Hinds’s job as a foundation, the author would define suffering in patients with cancer as an individual’s description of his or her consciousness of one or more changes in usual function, feeling, or appearance that lead to some degree of physical discomfort, mental agony, or distress due to exposure to a situation or a perceived threat. Therefore, one or more changes in normal psychological, social, physiological and spiritual functioning can cause suffering. Overall, suffering historically helps contextualize it with health problems, making its relevance in oncology nursing knowledge recognizable.

From 1987-1994 approximately 242 articles in oncology nursing were disease specific in nature [32]. For instance, most of the articles addressed suffering among patients with cancers from a wide variety of conditions, such as anaemia, acne, fatigue and infection which are common symptoms of disease process and complications of the intensive treatment modalities that cause suffering. Patients with cancer experience many symptoms related to the disease process and

management. These symptoms can be physical, psychological, social, and spiritual, and the symptoms appear to be not isolated but in clusters that cause suffering [33].

5. Measurement of Suffering Among Patients with Cancer

The author believes that from the perception of patients with cancer, suffering is often not measured. Coyle [34] mentioned “Suffering is something that happens within a person. It may be deduced, inferred, and theorized by others, but only direct testimony communicates the suffering felt by an individual”. Also, Harrison [35] states “Hearing patients speak has a profound effect on the way we understand their suffering... Listening for gaps in the patient’s story and allowing it to unfold at a pace determined by the patient is more likely to result in the opportunity to become a partner in care, and in that way, to learn the patient’s suffering”. To relieve suffering, oncology nurses must understand the multiple dimensions of the person who is suffering [36]. There have been few qualitative studies conducted on patients with cancer discuss self-report. This kind of research may give the oncology nurses an accurate, clear precise holistic picture of the nature and scope of suffering among patients with cancer and provide critical data or information about what nursing interventions can be planned to avoid or reduce this suffering. From the author’s experience in oncology nursing, to manage patient’s symptoms by using effective nursing interventions, oncology nurses need to know the symptoms. In addition to intensity and regularity, and their needs to recognize how much suffering they cause. In fact, many researchers measure each symptom as a separate part of the whole person, such as pain, nausea, vomiting, and fatigue [37-39].

Many studies have been conducted that consider the physical symptoms of patients with cancer as an essential part of measuring suffering. A group of researchers developed the Behavioural Affective and Somatic Experiences Scale, a nurse-report instrument, to assess behavioural, affective, and somatic outcomes in the acute phase of bone marrow transplant [40]. Five subscales were measured which are somatic distress, activity, interaction compliance and mood/behaviour. Collins and other researchers [41] used the Memorial Symptom Assessment Scale (MSAS) for adults to determine symptom prevalence, distress and characteristics. The MSAS subscale scores use to measure of physical, psychological, and most distress symptoms [41]. However, there may be some symptoms that patients are experiencing in some cases that are not mentioned with these instruments. For instance, the instrument asks about “irritability” but does not enclose frustration, and it assesses how “I don’t look like myself” but not the thought of “comfortably socializing” with friends. These tools used to measure symptom distress but they are lacking in the richness of expression that can be found in patients with cancer, particularly in social and family relationships and the sense of being ill. Similarly, with other quantitative instruments, there also some challenges to using

these tools for measurements of suffering, these include boundaries related to verbal communication and reading skills. These scales are developed to measure symptoms or symptom distress, but they do not measure suffering.

In addition, another group of researchers wrote a handbook of measures to assess well-being of children with cancer [42]. This handbook provided some screening tools as an interdisciplinary guide for medical staff and researchers who work with children. It includes quantitative measures with some evidence of adequate psychometric characteristics. Even though some of the themes may be used to measure symptoms in children with cancer, none are particular for measuring suffering in adult patients with cancer. These symptoms can be physically, psychologically, socially, and spiritually, and the symptoms lean to be not isolated but in clusters that cause suffering [33]. However, qualitative studies about perceptions of patients with cancer include feelings and the meanings are connected to lived experiences related to cancer and its treatment may define suffering. These feelings are related to changes in normal body function, sensation, or appearance that cause physical pain, mental agony, or distress [4].

A long time ago, defining suffering has been usually anecdotal or experience related opinions, observations, and reports from formal and informal caregivers [19, 43-45]. All the researchers studied and measured only the physical symptoms not suffering. A few studies have been conducted to expand the perceptions of patients with cancer toward suffering related to the cancer and its treatment. In part of a larger study, Woodgate [46] described the effect of cancer and its symptoms on the adults' sense of self. Moreover, most of the research has tried to define the suffering from the patient's point of view, have mostly measured the patient's perceptions in predominately middle-class and white populations [4]. Although Martinson [47-51] has studied Chinese children with cancer, her studies have also focused only on family caregivers of patients with cancer. Only one article published [50] which focused on the reactions of Chinese children who have cancer.

Suffering frequently has been described as difficult to assess or measure, even though there might be some limited, observable physical signs such as crying or unpleasant facial expression due to pain. The existential quality of suffering addressed by some authors, alongside with stress on meaning, also support the nature of suffering as a subjective experience and the reality is that the experience of suffering in another person should be inferred.

6. Defining Attributes

Defining attributes are criteria of a concept that show frequently and differentiate it from other concepts [6]. After reviewing the varying definitions of suffering and contextualizing it with health problems among patients with cancer, the attributes are defined as follow: individualized, subjective, complex, and provides meaning of loss. First, attribute of "individualized" was obtained from authors' recurrent reference to suffering as an experience that differs

from individual to another, and is account upon individual understanding or interpretation. Rodgers and Cowles [32] state "In spite of the "universal" existence of suffering, the experience of suffering, itself, is highly individualized in nature". Second, the subjective nature of sufferings depends on this concept of "individualized" and was mainly major aspect of this concept as noted in the literature. Third, complex nature of suffering, the individual and subjective nature of suffering lead to complex nature of concept of suffering. While suffering cannot be actively observed or measured, it has an inimitable ambiguity and abstractness, which composes it appear predominantly complex. This complexity is mixed by the observation that suffering has physical, social, psychological, cognitive, and spiritual elements. Suffering may be associated by physical and psychological manifestations such as weeping and unpleasant facial expression, physical pain, feeling of panic or blame, and expression of mental agony. Fourth, meaning to a situation, depend on this agreement, is that suffering to have the task of meaning to a situation, and not astonishingly, this meaning is extremely negative in nature. From the examined literature, the meaning that characterizes suffering is quite philosophical, concerning an incredible sense of the loss of the individual's integrity, independence, or control over condition or being.

However, a distinct definition for suffering among patients with cancer does not exist in the literature and therefore based upon the defining attributes listed above it is possible to provide a theoretical definition of suffering in patients with cancer: an individual's description of his or her consciousness of one or more changes in usual function, feeling, or appearance that lead to some degree of physical discomfort, mental agony, or distress due to exposure to a situation or a perceived threat. Therefore, one or more changes in normal psychological, social, physiological and spiritual functioning can cause suffering.

7. Related Concepts

An imperative part of concept analysis is identifying the concepts related to the concept of interest [6]. One of the more important observations about the concept of suffering is how the term of "pain" is used to articulate thought about suffering. As noted earlier, an individual looking for literature on suffering will be referred to the major heading of "pain" in several directories. Articles on suffering in general are hidden beneath this heading a long with a crowd of articles addressing physical pain particularly. On the other hand, it is obvious from the definition of suffering that emerged through this paper that pain and sufferings are not alike, even though there is a probable relationship between the two. Similarly revealing was the use of the term "distress", to express the concept of suffering. These terms weaken the usefulness of the concept of suffering mainly in that they fail to express the incredible strength associated with suffering. In addition, they give additional facts of the tendency to "talk around" the theme of suffering, so to talk, instead to confront it directly. The author suggests that it would be valuable to practice analyses of these

and other related concepts such as “agony” to provide a collection useful in characterizing a diversity of complex cancer patient's experiences and other individuals' experiences.

7.1. Distress

Distress draws its origins as a noun to the early 13th century and finds its etymology from a variety of sources: (a) Middle English, *destresse*, (b) Old French, *districtia*, and (c) Latin, *distringo* [52, 53]. In the 20th century, distress was utilized as an adjective and intended offered at sale for a loss [54]. In sea communication, distress indicate a situation of threat; for example, ships in distress or sinking, make distress calls [52, 54]. In addition, distress reflects damage of objects to construct them look older, to cause to be worried, be troubled or exhaust, issue to great difficulty, and cause pain or suffering [54, 55]. In relation to human emotion, distress relates to physical or mental agony or suffering [56]. Distress is utilized by healthcare professionals in the context of physical, spiritual, and emotional conditions. For example, fetal distress describes abnormal fetal heart rate. Symptom distress is an expression often used by oncology nurses. McCorkle and Young [57] defined symptom distress as “the degree of discomfort reported by patients in relation to their perceptions of the symptoms being experienced”. Although initialling their Symptom Distress Scale (SDS) McCorkle and Young [57] had patients rate, on a scale of 1–5, how distressed they were by symptoms related to cancer disease or cancer management. This scale was established to be a valid and reliable indicator of patient distress and established a scientific measurement of distress for utilize by nurses.

Rhodes and Watson [58] provided a further definition of symptom distress “the need to alter (restrain or reproduce) actions in response to a subjective indication of disease or illness”. Also, they state “Symptom distress is also the physical or mental agony or suffering resulting from the experience symptom occurrence and/or feeling states” [58]. Symptom distress is the degree of physical or mental hurt due to certain manifestations, such as fatigue [58]. According to Selye [59], symptom distress obviously refers to cause - a symptom - and effect - distress. Consequently, when symptom is used in this context it becomes a stressor. Distress is also used to represent spiritual pain. Heliker [60] maintained that the concepts of spirituality and spiritual distress are hard to grab as “definition is dependent upon the perspective of the conceiver”. Based upon the defining of symptom distress from reviewing the literature, it is possible for oncology nurses to differentiate between the concept of suffering and symptom distress.

7.2. Pain

Individuals experience physical pain by different daily “hurts and aches”, and rarely through more harsh injuries or illnesses. Pain is defined by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” [61]. Pain is

highly subjective to the individual experiencing it. A definition that is widely used in nursing was first given as early as 1968 by Margo McCaffery [62]. Pain is whatever the experiencing individual says it is, happening whenever he says it does. In one study conducted by Carr et al. [63], researchers found that pain occurs due to one of three causes: physical pain, the pain of loss or separation, and the pain of shame or humiliation. Pain is a physical sensation, like when you have a wound due to an accident, or have a toothache, or when you go into labor to have a baby, even your stomach, when you get hunger pain. This is all connected to your nerves, which act as sensors and send messages to your brain, and you have a physical reaction [62]. Suffering is alike, but not the same thing. If you have a toothache, that's the pain part of it, but the suffering would happen when you can't go to the doctor to find a solution to your problem, and you have to suffer with the pain, and perhaps the infection. There are other degrees of suffering as well, like when you lose someone you loved very much. The pain of that loss causes your heart to suffer, and it can take a long time to recover, or never recover at all! Pain is not something we choose. The death of a loved one; it is unexpected cruelty at the hands of another. Pain is what starving people experience. Finally, a Buddhist saying proclaims: “Pain is inevitable; suffering is optional” [64].

8. Consequences

The consequences of suffering among patients with cancer are commonly interesting, as they include a change in value and an affect sense of reality. Mainly, the consequences are negative in nature. Coping mechanism and recourses are influence their effectiveness [32]. There may are isolation, dysfunction, fatigue, burnout and drastically deceased quality of life for people who suffer [65]. Another study revealed that patients with cancer became depressed because of suffering [9]. Negative consequences also may occur for other people related to the suffering patients such as family members and friends. These negative consequences include feeling of helplessness and confrontation [66], especially when there is a need to act to improve or reduce suffering, even so the appropriate option of action is unclear. In addition, family caregivers of patients with cancer suffer from many physical (back pain), emotional (depression) and social problems (lack of social interaction and inability to make friends) related to many commitments to provide safe care for their loved cancer relatives [67]. These problems are consequences of suffering among patients with cancer and their family caregivers. However, the negative explanation attached to the threat and the consequences of suffering may create positive outcomes as well, such as personal growth, strength, increase religious conviction, change value and vision [9].

9. Model Case

An exemplar to demonstrate the concept of suffering among patients with cancer:

Ali is a 22-year-old Saudi boy with Hodgkin Lymphoma (HL) relapse. He is in the middle of his second-year

chemotherapy course. His chemotherapy course is regular, intensive, and can be in inpatient and outpatient units. Part of the assessment in the clinic in each time, is asking him "Do you have any kind of pain?" every time he has stayed silence and think before he answers. His answers is: "no", "but, I was nauseated and I vomited twice yesterday, so I couldn't go out with my colleagues to do shopping"; "sometimes I lost much hair"; "Why I have "mucositis" for long time?"; "Well, I had "diarrhea", but no more"; "I couldn't go to the university Monday because I felt weakness in my whole body"; "I actually didn't like to eat the food that I like yesterday".

The question in this case was related to his pain. Patient's answers included a variety group of symptoms and their meaning. The lymphoma and its treatment have created physical, social, psychological, and may be spiritual symptoms that are the antecedents of suffering. Regarding to

the author's definition of suffering, one or more changes in normal function, feeling, or appearance are leading physical pain, mental agony, or distress. An oncology nurse is not "getting at" or measuring his suffering.

10. Contrary Case

Mrs. Fatimah, 63-year-old, was informed by her family doctor that she had uterine cancer and that several treatment options existed. She was optimistic to undergo treatment. Mrs. Fatimah told her doctor not to worry about her: she was satisfied in her life, would be just fine, and did not want treatment. She did not show perceived inability to cope, change in emotional status, physical pain, financial problems, communication of discomfort, or harm. She was not suffering.

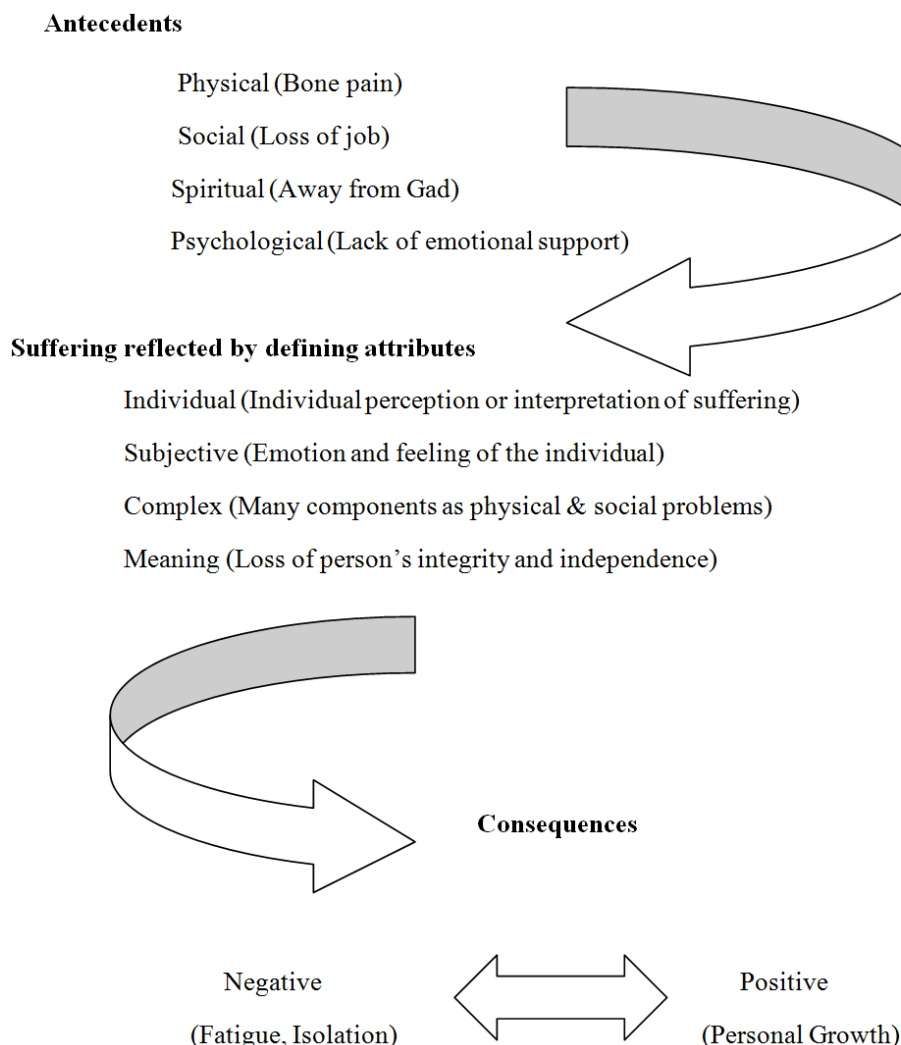


Figure 1. Antecedents, attributes and consequences of suffering among patients with cancer.

11. Conclusion and Nursing Implications

Suffering as a concept has great implications in oncology nursing. Cancer is on the rise and suffering (physical, psychological, social, and spiritual) is a serious problem that

faces patients with cancer. Suffering is practically and empirically seen only among nurses who work closely to patients and families. Suffering is an imperative concept in helping oncology nurses to provide optimum care for patients with cancer and their relatives. From presentation of attributes related to the concept of suffering and consequences in this

study, nurses should be enabled to identify suffering when present among patients with cancer. Also, this concept analysis identified areas for further knowledge development that may help the oncology nurses design interventions to prevent or reduce this suffering.

Oncology nurses can utilize the research on suffering to improve evidence base practice. Evidence base practice has a great relevance in our healthcare system today, and the research on suffering and its effects may act towards influencing nursing interventions on caring of patients with cancer. The author believes a qualitative study of the lived experiences of patients with different cancer diagnoses, at various ages, and at various points on the cancer illness curve by conducting grounded theory or phenomenology studies would contribute oncology nurses understanding of these patients. Knowledge of how patients with cancer experience this distress and the degree of suffering they truly experience would facilitate oncology nurses to design interventions to prevent or improve this suffering. To define the concept of suffering, studies need to be prepared with the several participants working with cancer patients, such as doctors, nurses and social workers, applying methods focussed at discovering the unique patients' experiences. Furthermore, many authors noted that not only is there a lack of research to help oncology nurses in identifying and dealing with suffering among patients with cancer, but also there is a lack of sufficient conceptual foundation for examination of suffering as a human experience. Therefore, more research on conceptual clarity of suffering in oncology nursing literature is needed. Finally, cultural differences need to be examined in a large more diverse sample size to ensure its applicability and validity cross culturally. If more support is generated for cross cultural research, the author believes that this concept has great relevance in the globalization of oncology nursing knowledge.

References

- [1] Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal, A. (2015). Global Cancer Statistics, 2012. *A Cancer Journal for Clinicians*, 65 (2), 87–108.
- [2] Saudi Cancer Registry. (2016). Cancer incidence report Saudi Arabia 2013. <http://www.chs.gov.sa/Ar/HealthCenters/NCC/CancerRegistry/CancerRegistryRports/2013.pdf>. Accessed at 21st July 2017.
- [3] National Cancer Registry. (2001). *Cancer incidence report, Saudi Arabia: 1997–1998*. Ministry of Health, Kingdom of Saudi Arabia.
- [4] Fochman, D. (2006). The concept of suffering in children and adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23 (2), 92-102.
- [5] Clark, M., Rummans, T., Sloan, J., Jensen, A., Atherton, P., Frost, M., et. al. (2006). Quality of life of caregivers of patients with advanced-stage cancer. *American Journal of Hospice and Palliative Medicine*, 23(3), 185-191.
- [6] Chin, P. L., & Kramer, M. K. (2008). *Integrated theory and knowledge development in nursing* (7th ed.). United State of America: Mosby. pp. 179-218.
- [7] Meleis, A. (1991). *Theoretical nursing development and progress* (2ed ed.). Philadelphia: J. B. Lippincott Co.
- [8] Barber, K., Fitzgerald, H., Howell, T., & Pontisso, R. (2005). *Oxford Canadian dictionary of current English*. Canada: Oxford University Press.
- [9] Seyama, R., & Kanda, K. (2008). Suffering among the families of cancer patients: Conceptual analysis. *Kitakanto Medicine Journal*, 58, 71-76.
- [10] Viktor, F. E. (2006). *Man's search for meaning* (pp. 132). Boston: Beacon Press.
- [11] Ronald, B. M. (2005). Suffering in psychology: The demoralization of psychotherapeutic practice. *Journal of Psychotherapy Integrations*, 15(3), 299-336.
- [12] Kleinman, A. (1998). *The illness narratives: Suffering, healing, and the human condition*. Doubleday: Dell Publishing Group.
- [13] Black, H., & Rubinstein, R. (2004). Themes of suffering in the late life. *The Journal of Gerontology*, 59, 17-24.
- [14] Haq, I. (2002). Faith and suffering in Islam. *The Stauros Notebook*, 12(3), 8.
- [15] Adams, A. (2017). Suffering Under a Great Injustice. <https://www.loc.gov/loc/lcib/02034/internment.html>. Accessed at 1st August 2017.
- [16] Cassell, E. J. (1991). *The nature of suffering and the goals of medicine*. New York: Oxford University Press. pp. 33 & 531.
- [17] Ferrell, B. R., & Coyle, N. (2008). The nature of suffering and the goals of nursing. *Oncology Nursing Forum*, 35(2), 241-247.
- [18] Kaneeko, M., Majima, T., et al. (2006). Development of suffering questionnaire. *Journal of Japan Academic Nursing*, 26 (3), 3-12.
- [19] Cassell, E. J. (1999). Diagnosing suffering: A perspective. *Annals of Internal Medicine*, 131, 531-534.
- [20] Rowe, J. (2003). The suffering of the healer. *Nursing Forum*, 38(4), 16-20.
- [21] Fineberg, I. C., Wenger, N., & Saltzman, K. B. (2006). Unrestricted opiate administration for pain and suffering at the end of life: Knowledge and attitudes as barriers to care. *Journal of Palliative medicine*, 9 (4), 873-883.
- [22] Holm, A. L., & Severinsson, E. (2006). The emotional pain and distress of borderline personality disorder: A review of the literature. *Journal of Mental Health Nursing*, 17, 27-35.
- [23] Arman, M., Rehnsfeldt, A., Lindholm, L., & Hamrin, E. (2002). The face of suffering among women with breast cancer—Being in a field of forces. *Cancer Nursing*, 25(2), 96-103.
- [24] Kahn, D. L., & Steeves, R. H. (1996). *An understanding of suffering grounded in Clinical practice and research*. In B. R. Ferrell (Ed.), *Suffering*. Sudbury, MA: Jones & Bartlett. pp. 3-47.
- [25] Ferrell, B. R. (1996). *Suffering*. United State of America: Jones & Bartlett Publishers International. pp. 105.
- [26] Travelbee J. (1971). *Interpersonal aspects of nursing* (2nd ed.). Philadelphia: FA Davis Company.

- [27] Spross, J. A. (1993). Pain, suffering, and spiritual well-being: Assessment and interventions. *Quality of Life. A Nursing Challenge*, 2, 71-79.
- [28] Morse, J. M., & Carter, B. (1996). The essence of enduring and suffering: The reformulation of self. *Scholarly Inquiry for Nursing Practice*, 10(1), 43-50.
- [29] Rawnsley, M. M. (1996). Response to "The essence of enduring and expressions of suffering: The reformulation of self." *Scholarly Inquiry for Nursing Practice*, 10(1), 61-6.
- [30] Morse, J. M. (2001). Toward a praxis theory of suffering. *Advances in Nursing Science*, 24(1), 47-59.
- [31] Hinds, P. S., Quargnenti, A. G., & Wentz, T. J. (1992). Measuring symptom distress in adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 9(1), 84-86.
- [32] Rodgers, B., & Cowles, K. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing*, 25(5), 1048-1053.
- [33] Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33(5), 668-676.
- [34] Coyle, N. (2003). Phenomenology: Learning from our patients and ourselves. *International Journal of Palliative Nursing*, 9(11), 464-466.
- [35] Harrison, E. (2001). Advancing nursing scholarship through the interpretation of imaginative literature: Ancestral connectedness and the survival of the sufferer. *Advances in Nursing Science*, 24(2), 65-80.
- [36] Kane, J. R., Hellsten, M. B., & Coldsmith, A. (2004). Human suffering: The need for relationship-based research in pediatric end-of-life care. *Journal of Pediatric Oncology Nursing*, 21(3), 180-185.
- [37] Mystakidou, K., Parpa, E., Katsouda, E., & Galanos, A. (2005). Pain and desire for hastened death in terminally ill cancer patients. *Cancer Nursing*, 28(4), 318-324.
- [38] Schwartzberg, L. S. (2007). Chemotherapy-induced nausea and vomiting: Clinician and patient perspectives. *The Journal of Supportive Oncology*, 5(2), 5-12.
- [39] Ross, D., & Alexander, C. (2001). Management of common symptoms in terminally ill patient: part I: Fatigue, anorexia, cachexia, nausea and vomiting. *American Family Physician*, 64(5), 807-814.
- [40] Phipps, S., Hinds, P. S., Channell, S., & Bell, G. L. (1994). Measurement of behavioral, affective, and somatic responses to pediatric bone marrow transplantation: Development of the BASES scale. *Journal of Pediatric Oncology Nursing*, 1(3), 109-117.
- [41] Collins, J. J., Byrnes, M. E., Dunkel, I. J., Lapin, J., Nadel, T., Thaler, H. T., et al. (2000). The measurement of symptoms in children with cancer. *Journal of Pain and Symptom Management*, 19(5), 363-377.
- [42] Naar-King, S., Ellis, D. A., & Frey, M. A. (2004). *Assessing children's well-being: A handbook of measures*. Hillsdale, NJ: Lawrence Erlbaum.
- [43] Berde, C., & Wolfe, J. (2003). Pain, anxiety, distress and suffering: Interrelated, but not interchangeable. *Journal of Pediatrics*, 142, 361-363.
- [44] Lobchuk, M. M. (2003). The Memorial Symptom Assessment Scale: Modified for use in understanding family caregivers' perceptions of cancer patients' symptom experience. *Journal of Pain and Symptom Management*, 26(1), 644-654.
- [45] Wolfe, J., Klar, N., Grier, H., Duncan, J., Salem-Schatz, S., Emmanuel, E. J., et al. (2000). Understanding of prognosis among parents of children who died of cancer. *Journal of the American Medical Association*, 284(19), 2469-2475.
- [46] Woodgate, R. L. (2005). A different way of being: Adolescents' experiences with cancer. *Cancer Nursing*, 28(1), 8-15.
- [47] Martinson, I. M. (1989). Impact of childhood cancer on family care in Taiwan. *Pediatric Nursing*, 15(6), 636-637.
- [48] Martinson, I. M., Chiang, C. Y. L., & Liang, Y. H. (1997). Distress symptoms and support symptoms of Chinese parents of children with cancer. *Cancer Nursing*, 20(2), 1-6.
- [49] Martinson, I. M., Leavitt, M., Liu, C., Armstrong, V., Hornberger, L., Ziang, J. Q., et al. (1999). Common themes and ethnic differences in family caregiving the first year after diagnosis of childhood cancer: Part I. *Journal of Pediatric Nursing*, 14(2), 99-109.
- [50] Martinson, I. M., & Liang, Y. H. (1992). The reactions of Chinese children who have cancer. *Pediatric Nursing*, 18(4), 345-349.
- [51] Martinson, I. M., & Yee, K. H. (2003). Parental involvement in restoring health of a child with cancer in Hong Kong. *Journal of Pediatric Oncology Nursing*, 20(5), 233-244.
- [52] Simpson J. A. & Weiner E. S. C. (1989). *The Oxford English Dictionary* (2nd ed.). Oxford, UK: Clarendon Press.
- [53] Spraycar, M. (1995). *Stedman's Medical Dictionary* (26th ed.). Baltimore, MD: Williams & Wilkins Inc.
- [54] *Merriam-Webster's Collegiate Dictionary* (11th ed.). (2014). United State of America: Merriam-Webster Incorporated.
- [55] Gove P. B. (2000). *Webster's third new international dictionary of the English language unabridged*. Springfield, MA: G & C Merriam Co.
- [56] Newman W. A. (2003). *Dorland's Illustrated Medical Dictionary* (30th ed.). Philadelphia, PA: W. B. Saunders Co.
- [57] McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing*, 5, 373-378.
- [58] Rhodes, V. A., & Watson, P. M. (1987). Symptom distress—the concept: Past and present. *Seminars in Oncology Nursing*, 3, 242-247.
- [59] Selye, H. (1976). Further thoughts on "stress without distress". *Medical Times*, 104, 124-132.
- [60] Heliker, D. (1992). Re-evaluation of nursing diagnosis: Spiritual distress. *Nursing Forum*, 27, 15-20.
- [61] Merskey, H. (1964). An Investigation of pain in psychological illness. *Pain Journal*, 5 (6), 250.
- [62] Mc Caffery, M. (1999). *Pain clinical manual*. St Louis: Mosby.
- [63] Carr, D. B., Loeser, D. J., & Morris, D. B. (2005). Narrative, pain, and suffering. *The new English Journal of Medicine*, 15, 353-1637.

- [64] Blog, S. (2007). The meeting of the minds: pain verses suffering.
<http://hanssinenglish.blogspot.com/2007/10/pain-versus-suffering.html>. Accessed at 1st August 2017.
- [65] Saboo, B. (2008). Adverse psychological consequences: Compassions fatigue, burnout and vicarious traumatisatation: Are nurses who provide palliative and haematological cancer care vulnerable? *Indian Journal of Palliative Care*, 14(1), 23-29.
- [66] Latalski, M., Kulik, T. B., Skorzynska, H., & Zolnierczuk, K. (2001). Social consequences of breast cancer for women suffering from the disease. *Wiadomosci Lekarskie*, 54(7-8), 391-398.
- [67] Murray, S., Grand, E., & Kendall, M. (2008). Dying from cancer in developed and developing countries: Lessons from two qualitative interview studies of patients and their carers. *Journal of Palliative Medicine*, 326, 1-5.