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I am submitting herewith a dissertation written by Lois Starnes Doane entitled "Small Windows of Hope: Understanding the Meaning of Fatigue Experienced by Cancer Patients." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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Small Windows of Hope: Understanding the Meaning of Fatigue Experienced by Cancer Patients

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Lois Starnes Doane
December 2009

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Dedication

This dissertation is dedicated to my sons, William Landon Starnes Doane and Tyler Starnes Doane, who encouraged me to pursue my doctorate. To Landon, thanks for your love, support and for being so proud of me, and to Tyler, who is smiling down from Heaven and is saying, "Mom, I knew you would do it; please be happy."

Also, a special acknowledgment to my mother, Mabel Starnes Gilliam, who taught me the love of God and the importance of caring for other people. A special thanks to my sister, Linda Starnes Lumpkins, who supported me in this professional endeavor, and who has always walked with me throughout my life's journey. A special recognition to my late father, Elmer Lee Starnes, who always encouraged me to utilize my God-given gifts and talents.

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Abstract

The purpose of the study was to describe the experience of early stage breast cancer women who were living with cancer-related fatigue. Using a phenomenological approach based on the work of Merleau-Ponty, the researcher completed six interviews in which women described the experience of being tired each day.

Interviews were transcribed verbatim and analyzed using a hermeneutical approach developed by Pollio and applied to nursing research by Thomas. Each interview was examined within the context of all the interviews to identify themes noted in all transcriptions. Dealing with the prevailing and profound fatigue that entrenched these women's lives was overwhelming. There was an overarching sense of living in the "Shadow of Death," which served as the contextual ground. This sense of looming in the "Shadow of Death" reflected that these women survived cancer and cancer therapies; however, fatigue rendered their bodies, minds and lives changed…..an irreversible change.

Living with fatigue was described by the women as "part of weaving the fabric of my life," yet the tapestry was never complete and had many imperfections. These flawed threads in the tapestry emerged as four figural themes: "Being Alone in my Cave," "Coming Out of the Cocoon," "It's a Lost Fight" and "Who am I Now?"

They described living in two worlds: one being hard and demanding, regardless of how hard they worked to overcome their fatigue; the second world served as a safe

refuge, a cave, that allowed them to “peer through the window of hope” into the outside world. As fatigue improved they initiated “coming out of the cocoon,” but realized their bodies were entrapped with many losses.

Losses were described as “permanent visitors” which led to feelings of loneliness and despair with their life being relegated to a non-participative role with family, friends and work. Regardless of effort, their recalcitrant body was unable to overcome the fatigue. With fortitude, they confronted a search for the “old me” to realize every fabric of their life had changed, never to return to the “old self” which left them to peer into the outside world while searching for small “windows of hope.”

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CHAPTER I

INTRODUCTION

Early treatment of patients with cancer clearly has resulted in increased cure and survival rates; however, therapy frequently results in short- and long-term consequences that affect patients' physical and emotional well-being. Fatigue is one such side effect that is profound and pervasive. According to a Fatigue Coalition survey, patients with cancer rated fatigue ahead of pain, nausea, and depression as the cancer-related condition being the most common and troublesome, the longest lasting, and having the greatest impact on their day-to-day functioning and economic well-being (Vogelsang, Breitbart, & Cella, 1997). Fatigue is the most common and distressing symptom resulting from cancer therapies: 60-100% of patients receiving chemotherapy report experiencing fatigue, which has been termed the "common denominator" of symptom distress (Winningham et al., 1994). The impact of cancer-related fatigue on the patient's quality of life and ability to carry out activities of daily living has significant implications for patients who experience a notable decline in functional ability during and after cancer treatment (Nail & Winningham, 1995). The fatigue is associated with considerable psychological distress and can impose a significant financial burden by limiting a patient's ability to work. Approximately 28% of cancer patients experiencing fatigue terminate their work indefinitely and 23% accept disability. Approximately 11% of family members take family medical leave to care for their loved ones experiencing fatigue (Breithart, Cella, & Curt, 2000). Not only does fatigue impact the patient and families' quality of life but may also impact survival. Mormont, Watermont, and

Bluezen (2000) reported a five-fold lower survival, poorer quality of life and more fatigue when rest and activity are interrupted.

In fact, cancer survivors consider management of their cancer-related fatigue as their highest priority in cancer care as their fatigue remains a chronic health problem long after the treatments are completed (Bower & Ganz, 2007). A recent review of the literature reported by Stone (2008), and De Jong, Courtens, Abu-Saad, and Schouten (2002) concluded that post-treatment fatigue persists up to five years after completion of breast cancer treatments. Bower et al. (2006) reported that 34% of long-term breast carcinoma survivors reported significant fatigue at 5-10 years after diagnosis.

While this extreme exhaustion has been recognized as an almost universal side effect of cancer and cancer treatment, the phenomenon is multifaceted, is subjectively measured, and has only been studied minimally to understand the meaning of the fatigue from the patient's perspective. The complex nature and etiologies of the symptom have challenged researchers, and the knowledge regarding fatigue and its relationship with other factors are limited. Despite the widespread recognition of the tiredness as a symptom of disease or as a result of treatment, the concept is not clearly defined nor clearly understood from either the patient's or researcher's perspective. There is no understanding of how a cancer patient defines fatigue, how it impacts on his/her quality of life, and what long-term effects it has on the patient.

There are minimal qualitative or quantitative studies delineating how fatigue impacts the various domains of quality of life, including physical, social, emotional, psychosocial and spiritual dimensions. Neither is there information about the patient

experiencing difficulty in being employed while dealing with cancer-related fatigue. Therefore, the phenomenological approach to studying cancer-related fatigue provides an opportunity to gain an understanding of the essence of this unrelenting symptom. The outcome of the study may equip the healthcare professional to better understand what it is like for the patient to experience this extreme exhaustion. With this understanding, strategies can be implemented to improve the cancer patient's quality of life.

Purpose of Study

The purpose of the study is to describe the breast cancer patient's lived experience of fatigue. By using an existential phenomenological approach, a rich description of the patient's perception of living with being tired will be obtained.

Philosophical Lens: Phenomenology

The qualitative approach selected to develop an understanding of the phenomenon of cancer-related fatigue is existential phenomenology, which is derived from the perspective of Merleau-Ponty. He proposes that an experience consists of "the essence that is identified through a perception" or through "being in the world" or "being-with-others." A phenomenological report strives to "give direct description of our experience." His premise is further elucidated by realizing that to understand an individual's experience; one must view the meaning of that experience for the person holistically. The understanding of the meaning, or perception, evolves from the interaction of the individual with his/her environment. The term "figural" refers to awareness of certain aspects in the environment over others. "Intentionality" refers to the

direction of the human experience, including perception, and also includes events, objects and the "phenomena in the world" (Merleau-Ponty, 1962). The objects that capture us or that we seek after reveal what is significant to us, really telling us who we are. Furthermore, perception provides a direct experience of events, objects and the phenomena of the world. According to Merleau-Ponty (1962), our existence is always experienced as a way of "standing out" while the things experienced as further away and more indefinite are termed as "ground". In other words, when looking at a figure and the world, we can only focus on one at a time (Thomas & Pollio, 2002, pp. 14-15).

The existential phenomenological approach enables us to describe who we are and how we live in life as well as it enables the human being to appreciate both our freedom and responsibility in shaping the situation we are facing. It thus allows people with cancer-related fatigue to describe their experience of fatigue from their own and unique perspective, including those changes in freedoms and responsibilities that have evolved secondary to the development of fatigue. This approach is selected because there first must be an understanding of what the cancer patient experiences with their fatigue before a conceptual framework or practice guideline can be developed to treat and manage these patients. It is important to go into the world of the cancer patient and hear what is happening to those who are experiencing the symptom in order to really understand the experience of cancer-related fatigue.

In addition, the approach is selected because it deeply connects with cancer patients and helps to understand them more holistically as they deal with the cancer trajectory. The nurse's caring becomes important for cancer survivors as cancer-related

fatigue may persist for an extended time, despite completion of treatment and a good prognosis. This becomes even more important as more than half of cancer patients will be treated and never acquire a remission of their potentially terminal disease. Having the presence of a caring oncology nurse who is genuinely interested in the world of the patient becomes extremely important in helping the patient live each day to its fullest and ultimately improve their quality of life, regardless of the time remaining.

Summary of Research

In summary, the paucity of phenomenological studies about cancer-related fatigue provides a rationale to study the phenomena from the inception of the clinical symptom throughout the trajectory of the cancer experience. Without an understanding of the patient's experience, the healthcare provider has no basis knowing how to approach the patient about managing their fatigue. Therefore, an in-depth understanding of the experience of cancer-related fatigue is pivotal to identifying strategies to assist the patient in dealing with their fatigue. By understanding the experience of the patient's fatigue, the healthcare provider assists the patient to identify management strategies for their fatigue, thus ultimately improving the patient's quality of life.

Significance of the Problem

While fatigue has been recognized as an almost universal side effect of cancer and cancer treatment and has been included in many studies for the past 25 years, effective treatments for fatigue have not yet been developed. In addition, researchers agree that fatigue related to cancer therapy is a multifaceted, subjectively measured phenomenon,

but no physiologic measurement that quantifies fatigue has been accepted (Winningham et al., 1994). Minimal research has been conducted to understand its mechanisms. Although the exhausting symptom impacts greatly on the patient's quality of life, very little is known about the clinical epidemiology of the fatigue and what interventions are most likely to be effective. Most studies of fatigue related to cancer treatment have focused on patients' subjective self-reported experiences, with a few studies measuring changes in fatigue over a course of repeated treatments (Jacobsen, et al., 1999). The complex nature and etiologies of fatigue have challenged researchers, and knowledge regarding fatigue and its relationship with other factors is limited. In addition, despite the prevalence of fatigue, surprisingly little is known about cancer-related fatigue that can guide nursing assessments and interventions.

Selecting cancer-related fatigue as a concept for study is of paramount importance to nursing as the knowledge of fatigue reported in the nursing literature is derived from other disciplines that have investigated fatigue. The nursing perspective is unique among health disciplines. It is concerned not only with the health status of the whole person and the family subsystem, but it also is concerned with people's subjective perceptions and objective responses to their health status. This is a broader view of the person's response to fatigue than the focus found in other disciplines. Therefore, the concept of cancer-related fatigue needs to be further elucidated so that from a nursing perspective, cancer-related fatigue can be described, explained, and predicted with a plan to prescribe appropriate nursing care. In addition, there is a paucity of studies that reflect how a

cancer patient would define his/her fatigue, how it impacts on his/her quality of life, and how to manage the symptom.

The terms associated with the phenomenon of cancer-related fatigue have not been well defined. However, Ream, & Richardson, (1996) have observed that "the saliency of the definition derived from a concept analysis for clinical populations has been determined through minimal phenomenological inquiry" (p. 45). Further phenomenological, empirical and theoretical work is therefore needed to clarify and test the definitions and models of fatigue.

Efforts to develop research-based treatment guidelines for cancer-related fatigue have been challenged by the lack of phenomenological studies, disagreement about an acceptable definition, and the absence of formal diagnostic criteria. Any proposed definition of cancer-related fatigue must recognize that it can occur as a warning sign of an impending health crisis, such as the diagnosis or recurrence of cancer; a potential side effect of cancer treatment, such as surgery, chemotherapy, radiotherapy, bone marrow transplant or biotherapy; or a possible complication of post-treatment recovery. Multiple definitions and discipline-specific perspectives on cancer-related fatigue exist that make it difficult to synthesize the literature and determine cumulative findings that are useful to nursing practice. In addition, an urgent need exists for a consistent, research-based definition of fatigue. This definition should include consideration of etiologies and mechanisms of fatigue that may distinguish true fatigue from expressions such as tiredness, lack of energy, and other common terms (Winningham, et al., 1994).

Aside from the aforementioned reasons that research is warranted, it is of paramount importance to understand the patient's experience of their fatigue. Cancer-related fatigue cannot be explained by physiologic mechanisms alone. It must be understood from the patient's perspective as he/she describes the meaning of fatigue which may include physical, psychological, social and spiritual aspects which potentially may impact the patient "quality of life." Additionally, an understanding of these most common symptoms experienced by cancer patients is needed before treatment strategies can be pursued. Despite the current knowledge about cancer-related fatigue, healthcare professionals have little understanding about the meaning of fatigue from the patient's perspective. Therefore, appreciating the patient's perception of their fatigue will enable the healthcare professional not only define fatigue but identify various strategies to help deal with cancer patients' experience.

Historical Perspective

In order to gain a perspective on the cancer-related fatigue syndrome, it is necessary to retrace the paths of discovery and to examine fatigue as part of historical and universal phenomenon. Fatigue is best understood from the point of view of energetics. Energetics is the study of energy in its many forms and how it is used in organisms, specifically the cells of the human body. As such, it is the underlying principle of how organisms live and function, specifically: metabolism, anabolism and catabolism. There is also a phenomenon, entropy, which works against all life, from conception to death. From an energetic perspective, this phenomenon of entropy serves as the foundation of fatigue (Winningham & Burke, 2000).

Investigating the nature of fatigue-related issues goes back at least two millennia to Hippocrates. Vitalism, which considered life to be activated and maintained by some intrinsic, inestimable, and immeasurable factor, was an outgrowth of Aristotle's philosophy. The most powerful challenge to vitalism, as a scientific theory, came in the early 1600s when Descartes presented his philosophy of mechanics. Descartes made many and varied contributions to science that are still having an influence today, including the influence of the mind on the body and psychoneuroimmunology (Winningham & Burke, 2000).

Although vitalism generally fell into disrepute among scientists, vestiges remained. As late as the nineteenth century, invalids or sick individuals, including cancer patients showing fatigability, weakness or cachexia, were identified as lacking in "vital powers" or "vital force" (Winningham & Burke, 2000, p. 15).

On a more basic level, the idea of another source of energy was central to the development of Han Selye's general adaptation syndrome (stress) theory, which was called adaptive energy. Although this energy was not derived from nutrient utilization in metabolism, he acknowledged he had no idea what it was, just that it existed. Selye proposed that adaptive energy held the key to understanding fatigue and aging (Winningham & Burke, 2000).

The use of the word "fatigue" has come mainly from science, physiology, and engineering. During wartime, in particular, a large amount of funding went into fatigue research focused on alertness and performance in pilots flying bombers, in workers manufacturing, and in technicians monitoring instruments. During peacetimes,

industrialists focused on similar issues, but for a different reason, as they sought ways to analyze and optimize efficiency of workers' performance. Subsequent foci on fatigue centered on neuromuscular and endocrine aspects as well as cognitive factors. Since World War II, NASA has picked up the trail of fatigue-related research because of its relationship to performance and well being in astronauts, with a focus on harmful effects of bed rest. More recent work has focused on elucidating the influence of neurohumoral immunologic factors, such as cytokines. All this work has significance for understanding and defining fatigue in cancer (Winningham & Burke, 2000).

There is no consensus on what the word "fatigue" means, especially for cancer patients. To conceptualize a sense of the term "cancer-related fatigue," there must be an understanding that there are approximately 22 words associated with the etymology of fatigue including asthenia, cachexia, exhaustion, fatigue, sleepiness, tired to weariness (Winningham & Burke, 2000). It is doubtful whether most patients tested by current cancer fatigue scales could give an adequate or accurate description or definition of many of the words in the scale. A concise definition of fatigue has escaped elucidation because the mechanisms appear to be so complex and multidimensional. It is noteworthy; however, that many of the words used in fatigue scales measure quality of life issues, which will be taken into consideration when asking the cancer patient to describe their fatigue experience.

Nursing Historical Perspective

The inception of the concept of fatigue as it applies to nursing is relegated to Florence Nightingale who wrote about a deficit of vital force or vital powers. She observed what we today term fatigue in a variety of patients (Winningham & Burke, 2000). Nursing-oriented theories explaining the onset and experience of fatigue have evolved in the absence of pathophysiologic theories of fatigue. Preliminary pathophysiologic hypotheses linking fatigue with changes in muscles and nerves and alternations in neural activity remain unsubstantiated. Nursing-oriented fatigue theories depict factors that can act independently or concurrently to influence the manifestation of fatigue. These practice-oriented theories are relatively unsophisticated and, therefore, limited in their predictive capacity, but they offer tentative guidelines for clinical practice and indicate directions for research. These theories focus predominantly on energy utilization and conservation. The five most frequently cited and relevant theories for the development of fatigue initiatives are Ryden's Conceptual Framework of Energy Expenditure (Ryden, 1977); Aistairs Organizing Framework (Aistairs, 1987); Irvine, Vincent, Graydon, Bubela, & Thompson's Energy Analysis Model (1994); Piper, Lindsey, & Dodd's Integrated Fatigue Model (1987) and Winningham's Psychobiological-Entropy Model (1994).

Ryden's Conceptual Framework of Energy Expenditure (1977) is the least sophisticated of these fatigue theories. It provides some understanding of fatigue and the factors that can lead to it as well as a limited explanation of how the process evolves. With this theory, the human body is depicted as an open system that obtains energy from

the environment to sustain life. When the energy obtained exceeds essential life-supporting demands, Ryden proposes that an excess becomes available for nonessential activities, including work, socializing, and hobbies. During periods of illness, energy demands escalate to allow healing and rehabilitation, leaving little in reserve for other often rewarding activities. Patients with cancer commonly need energy to cope with the demands of the disease and its treatment. Ryden perceives the stress associated with adapting to cancer as a wasteful demand on limited energy resources that, if unremitting, can deplete reserves and cause fatigue. The simplicity of Ryden's model is attractive because it provides a basic and concise explanation of fatigue that can be applied widely. The framework explains little about the fatigue process beyond asserting that it arises from the interplay of energy supply and demand and proposing strategies, including energy conservation and the management of stress, for combating energy deficits (Ryden, 1977).

In another one of the earliest theoretical articles on fatigue in cancer, Aistairs (1987) built upon Selye's stress and general adaptation syndrome concepts. Aistairs also perceives fatigue as an energy deficit. However, the Organizing Framework is more detailed than Ryden's (1977) framework and explains how periods of under stimulation in addition to periods of stress and stimulation act through feedback systems to lead to fatigue (Aistairs, 1987). These details make this theory more useful, as they provide an explanation for the association patients frequently make between inactivity, boredom, and fatigue. This theory identifies stress as the principal cause of fatigue in patients with cancer and incorporates physical stressors in the framework, including pain, infection,

and anemia, as well as emotional stressors. Assessment of the impact of stress-relieving strategies on perceptions of fatigue can empirically test the link between stress and fatigue. Aistairs' framework advocates meditation, exercise, progressive muscle relaxation, time management, and patient education as strategies for relieving stress. Although the framework is relatively unsophisticated, it provides a clear and concise explanation of fatigue and the processes that lead to it (Aistairs, 1987).

Irvine, Vincent, Grayden, Babela, and Thompson's Energy Analysis Model (1994) is similar to Ryden's Theory. The theoretical framework also conceptualizes the human body as an open system dependent on energy sources from external and internal environments for the production of energy. It proposes that fatigue arises when external supplies are reduced, internal supplies are interrupted, and energy demands are high. However, the major difference between the Energy Analysis Model, which was devised specifically for patients with cancer, and those described previously lies in the inclusion of another variable. This variable incorporates a variety of factors unique to cancer that affects energy metabolism and expenditure. These include factors related to the disease, treatment responses, and symptoms associated with cancer and its treatment. Unfortunately, the model does not explain the action of these energy-response modifiers on fatigue (Irvine, Vincent, Graydon, Bubela, & Thompson, 1994).

A fourth model, Piper Integrated Fatigue Model, was derived deductively from a review of the fatigue literature (Piper et al., 1987). It is a comprehensive framework that describes thirteen biological and psychosocial factors that influence the signs and symptoms of fatigue in clinical populations. This widely applicable model delineates the

multiple factors that can interrelate and lead to the chronic fatigue that patients with cancer frequently report. Furthermore, it alludes to the multiple ways in which fatigue can be manifested and provides a useful basis for nursing assessment. It fails, however, to indicate the relationships among the variables and their weighting or hierarchy. It provides insight into the phenomenon and supports the notion seen in clinical practice that fatigue becomes more complex to manage as it becomes a chronic symptom, at which point a combination of strategies may be required for relief of the fatigue (Piper, Lindsey, & Dodd, 1987). The Winningham et al. (1994) Psychobiological-Entropy Model currently provides the most sophisticated explanation of fatigue and its implications for patients' functional status. The model defines fatigue as an energy deficit that arises from preexisting conditions and disease, related symptoms, treatment, environmental influences, and inactivity. According to this model, fatigue fulfills a unique and substantial role in the origin of disability that sets it apart from other symptoms. Although fatigue can be one of a myriad of primary symptoms that can lead to decreased activity, the secondary fatigue that arises from reduced physical activity is critical. This leads to a cycle of decreased activity, fatigue, and reduced functional status that result in a vicious cycle of decreased mobility and subsequent disability. It is suggested that interventions for fatigue should occur at two levels. First, interventions should aim to manage the symptoms and factors that contribute to primary fatigue. Second, they should aim to prevent secondary fatigue by achieving an optimal balance between restorative rest and restorative activity (Winningham et al., 1994). Therefore, it

seems appropriate that it is important to understand the patient's experience of fatigue to better understand how it impacts on their daily activities.

Several attributes related to cancer-related fatigue have been identified. Although the literature is relatively unsophisticated and the discussion varies in scope, there are a number of common features identified, in particular, a change in energy, which is connoted by terms such as energy input, energy consumption, and energy output or expenditure. All of these terms focus on energetics, which has both physiologic and psychosocial components that are attributable to fatigue. The physiologic attributes include weakness, exhaustion, malaise, tiredness, decreased functioning, immobility, sleep disturbances, adaptation and lack of learning, remembering and performing tasks every day. The psychosocial attributes include stress, anxiety, depression and a diminished will to live.

The phenomenon of cancer-related fatigue reflects approximately six patterns that warrant identification and discussion. First, in the cancer patient, whether they are receiving treatment or not, there is the potential of changes in their energy and energy substrate patterns. There also is an accumulation of metabolites. Both of these result in a decrease in the synthesis of protein and muscle contraction with a resultant muscle loss and extreme weakness. Second, there is a potential change in disease state, symptom patterns, sleep/wake patterns and activity/rest patterns which may result in muscles wasting and further disability. Third, each treatment modality can impact greatly on the degree of cancer-related fatigue. From a surgical standpoint, there appears to be a central mechanism that is triggered from various insults to the body, including the surgical

procedure, anesthesia, pain, narcotic analgesics and psychoactive drugs. Fatigue is the end result of these interventions. In addition, both radiotherapy and chemotherapy affect the patient in several ways. From a psychological perspective, the patient may experience stress, mood variation, and sleep pattern disruptions. These treatments also may affect the patient physiologically in several ways including nausea, vomiting, pain, cachexia, and anemia and drug interactions. Biotherapy impacts the patient's energy level greatly because of the exposure to both exogenous and endogenous cytokines with a resultant fatigue, including mental effects, malaise, cognitive deficits, mental and motor slowing, and somnolence, lack of initiative, slurred speech, sensory deficits and changes in expression such as changes in handwriting. The fourth area focuses on changes in regulation and transmission patterns as well as social and psychological factors. It appears that there are underlying changes in neural mechanisms which block competing and distracting stimuli. Consequently, there is impairment in cognitive functioning which results in decreased concentration, difficulty in thinking and diminished attention and impaired perceptions and forgetfulness. The fifth pattern reflects changes in life events with counterproductive health belief practices, such as prior trauma and anxiety. The sixth factor is innate host factors such as blood count, nadir count and the immune system (Piper et al., 1987). As the result of the physiological, behavioral and biochemical changes in these symptom patterns, there is a possible manifestation of fatigue. It can impact quality of life greatly, including physical well-being, psychological well-being, social well-being and spiritual well-being (Ferrell, 2008).

Cancer-related fatigue is a multifaceted problem. The common threads identified are subjective feelings of weariness, weakness, exhaustion and lack of energy and causation from exertion and/or stress. It leads to increased discomfort and decreased efficiency, and deterioration of both mental and physical activities (Ferrell, Grant, Dean, Funk, & Ly, 1996). This, however, needs to be substantiated from a phenomenological perspective.

Most researchers are concerned about causes of fatigue, such as physiologic, psychological and situational factors, rather than the quality of the resulting experience of fatigue per se. Furthermore, they have not interviewed patients who are experiencing the fatigue in order to elucidate the meaning of the fatigue. Therefore, their definition of cancer-related fatigue often does not reflect the quality of life issues surrounding this most prevalent patient complaint. The immediate effects of fatigue, such as the inability to function or maintain normal activities lead to issues surrounding the patient's quality of life. Including an understanding of the patient's experience and quality of life issues are essential components in a study of cancer-related fatigue. This extends the current view of fatigue beyond the physical symptoms. Not only is the physical well-being important, but also psychological, social and spiritual concern.

Analysis of data from Ferrell's Quality of Life Model (Ferrell, 2008) reveals that fatigue is a symptom that affects all dimensions of quality of life. From the physical well-being domain, attributes such as energy, functional ability, pain, sleep, rest and strength are considered. Included in the psychological well-being domain are anxiety, frustration, feeling useless, and fear of the meaning of fatigue, coping, and loss of

independence, cognition and depression. The third domain, social well-being, includes: impact on work/financial impact, leisure activities, family roles/relationships and affection and sexual function. The fourth domain, spiritual well-being, includes changes in spirituality, hopelessness, meaning of fatigue and changes in priorities in order to deal with the energy deficit (Ferrell et al., 1996). Therefore, to be more encompassing and to better understand the term, cancer-related fatigue and its consequences, quality of life issues should be explored in the study of cancer-related fatigue. A phenomenological study would illuminate how the patient's quality of life is impacted secondary to the experienced fatigue.

Cancer-related fatigue continues to be a major debilitating symptom for individuals with cancer, affecting activities of daily living, impacting treatment choices, and decreasing quality of life. As patients with cancer become too tired to participate fully in the roles and activities that make life meaningful, the most important impact of fatigue may be in the realm of quality of life. A qualitative research perspective using a phenomenological approach to determine the experience of the patient dealing with cancer-related fatigue is noticeably absent. Because of that, there is a lack of practice theories to guide clinical interventions based on understanding the experience of the patient confronting and dealing with fatigue. Therefore, interviewing patients to understand their experience of dealing with their fatigue seems appropriate as the challenge is to acquire knowledge about the experience of cancer-related fatigue so management strategies can be identified to assist the patients in dealing with this most

unrelenting symptomology. Moreover, by identifying resources it will better equip the patient to deal with their fatigue.

As alluded to, defining cancer-related fatigue is rather difficult as it is a complex syndrome. For the past twenty-five years, oncology healthcare professionals have attempted to define the term. At present, all would agree on one aspect: there is no precise definition as it continues to be an explorative endeavor. Therefore, it is incumbent on nurses to study the number one complaint that cancer patients experience from a phenomenological perspective so that we can better understand their experience. Now is the time to define the term from a patient's perspective.

Research Question

Despite the prevalence of fatigue, surprisingly little is known about the main complaint that cancer patients experience that can guide nursing assessments and interventions. The etiology of cancer-related fatigue is unknown. Clearly, there is further need to develop nursing theories about cancer-related fatigue. Theories, however, cannot be developed until the human experience of cancer-related fatigue is described because the people who live the experience of the fatigue are the experts. It is incumbent to understand the phenomenon of cancer-related fatigue before there can be an understanding of the functional descriptions of fatigue that are often described in the literature, such as malaise, weakness, exhaustion, asthenia, and cognitive dysfunction. Therefore, the issue in question is: What is the meaning of the fatigue that cancer patients experience? What is it is like to experience cancer-related fatigue? What does the cancer-related fatigue feel like? To answer these questions, the participants will be asked what it

has been like to live with being tired each day. The answers to this question become important because despite the widespread recognition of fatigue as a symptom of disease or as a result of treatment, the phenomenon is neither clearly defined nor clearly understood.

Theoretical Definitions

Cancer-Related Fatigue:

Cancer-related fatigue is a self-recognized, multidimensional syndrome, resulting in physical, mental, social and psychological deficits that profoundly affect quality of life and may occur at any time during the cancer diagnosis/treatment continuum.

Quality of Life:

Quality of life is a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her and includes physical, psychological, social and spiritual domains.

Activities of Daily Living:

Activities of daily living are self-care activities that the patient must accomplish each day to meet personal needs, such personal hygiene/bathing, dressing/ grooming, feeding, and toileting.

Assumptions

1. Oncology patients who receive cancer treatment(s) experience some degree of fatigue.
2. Oncology patients will be forthright in sharing their experience about their fatigue.
3. Cancer-related fatigue impacts the patient's quality of life and affects the physical, emotional, psychosocial and spiritual domains.
4. Cancer-related fatigue affects the patient's ability to remain employed and impacts their financial status.
5. Cancer-related fatigue may affect the patient's will to live more so than having received the diagnosis of cancer.
6. Oncology patients will feel comfortable in sharing their experience with an oncology nurse.
7. Cancer-related fatigue may vary depending on the treatment modality.
8. The level of cancer-related fatigue may vary throughout the course of the therapy.
9. Cancer-related fatigue may persist indefinitely after the treatment is completed.

Delimitations

The study will be confined to patients with early stage breast cancer who have received radiotherapy and chemotherapy; age 65 years or younger; able to read and write;

and not suffering from diseases previously shown to be associated with fatigue, such as rheumatoid arthritis, lupus erythematosis, diabetes and heart disease.

Limitations

The study will not be generalized to all types of cancer patients receiving all treatment modalities. However, findings of qualitative studies may be transferable to clients in other settings, if clinicians judge that the themes are relevant to these clients. Ray (1994) purports that clinicians use findings of a study in the context of their practice when validity and relevance are present. The richness of the story determines how well the results can be utilized in the clinical setting.

While fatigue has been recognized as an almost universal side effect of cancer and cancer treatment and has been included in many studies for the past twenty-five years, understanding the patient's experience with cancer-related fatigue has not yet been illuminated. A phenomenological study will provide insight and understanding about cancer-related fatigue. The narrative approach to qualitative research enables the patient to share their story which in itself may be therapeutic and thus may help the patient to cope with the diagnosis of cancer. In addition, by sharing their story, patients may be enabled to "make sense" about their catastrophic illness. There is a paucity of studies focusing on the patients' subjective self-reported experiences of fatigue, with a few studies measuring changes in fatigue over a course of repeated treatments (Jacobsen et al, 1999). The complex nature and etiologies of fatigue have challenged researchers, and knowledge regarding fatigue and its relationship with other factors is limited. Therefore, conducting a phenomenological study will serve as the basis to better understand the

phenomena of fatigue and thus enable the healthcare provider to strategize in providing management strategies to reduce or ameliorate the devastating symptom.

Summary

Fatigue has been described as a universal symptom among cancer patients by the National Comprehensive Cancer Network Cancer-Related Fatigue Panel (NCCN, 2007). Despite an increasing number of surveys that have focused on cancer-related fatigue, little is known about the experience of cancer-related fatigue for the patient. In addition, the current management strategies are largely based on anecdotal reports. Nonetheless, the growing recognition that fatigue is a major quality of life concern among cancer patients is motivating an effort to recognize strategies to help reduce and ameliorate the unrelenting symptomology. To address this concern, studying the experience of the patient serves as the basis for understanding. Although cancer-related fatigue is a complex symptom that is variably described and related to a large number of diverse processes, understanding fatigue and identifying appropriate management strategies cannot evolve until the patient's experience is understood.

CHAPTER II

REVIEW OF LITERATURE

Cancer-related fatigue is a difficult subject to discuss as minimal research has been conducted to investigate the mechanisms of this devastating cancer symptom. Fatigue has a dramatic effect on the lives of cancer patients and can be induced by the disease, the treatments, and the physiologic and psychologic stresses associated with cancer. Most of the work on fatigue has been incidental to studies performed to evaluate other symptoms or disease mechanisms, rather than the primary focus of the symptom. Many of the substances proposed to mediate fatigue also have multiple physiologic effects, making it difficult to determine the direct contribution to fatigue.

The "state of cancer-related fatigue" will be discussed in the following ways: First, a framework for addressing the problem will be developed, focusing on what is currently known from the patient experiencing the fatigue as well as the mechanisms of cancer-related fatigue including both physiologic and psychologic factors. Correlates associated with cancer-related fatigue also will be discussed. Subsequently, the effect of these factors on quality of life will be reviewed. Assessment of cancer-related fatigue also will be considered. General treatment recommendations based on current scientific knowledge of the field will then be put forth. The summary of the framework is based on a Medline and CINAHL database search primarily from 1996-2009. A few studies are cited prior to this period as they serve as pivotal studies for the topic of cancer-related fatigue.

The diagram in Figure 1. provides an overview of the literature search on cancer-related fatigue. The search includes four major components related to cancer-related fatigue: mechanism, quality of life, assessments and interventions. Within each category are listed components and associated correlates. Derived from the literature review, three themes emerged as areas of further research, including mechanisms underlying fatigue needed to prevent and treat the fatigue, issues surrounding quality of life, and the need for qualitative studies from the patient's perception. The following pages will provide the studies that have been conducted in each aforementioned category.

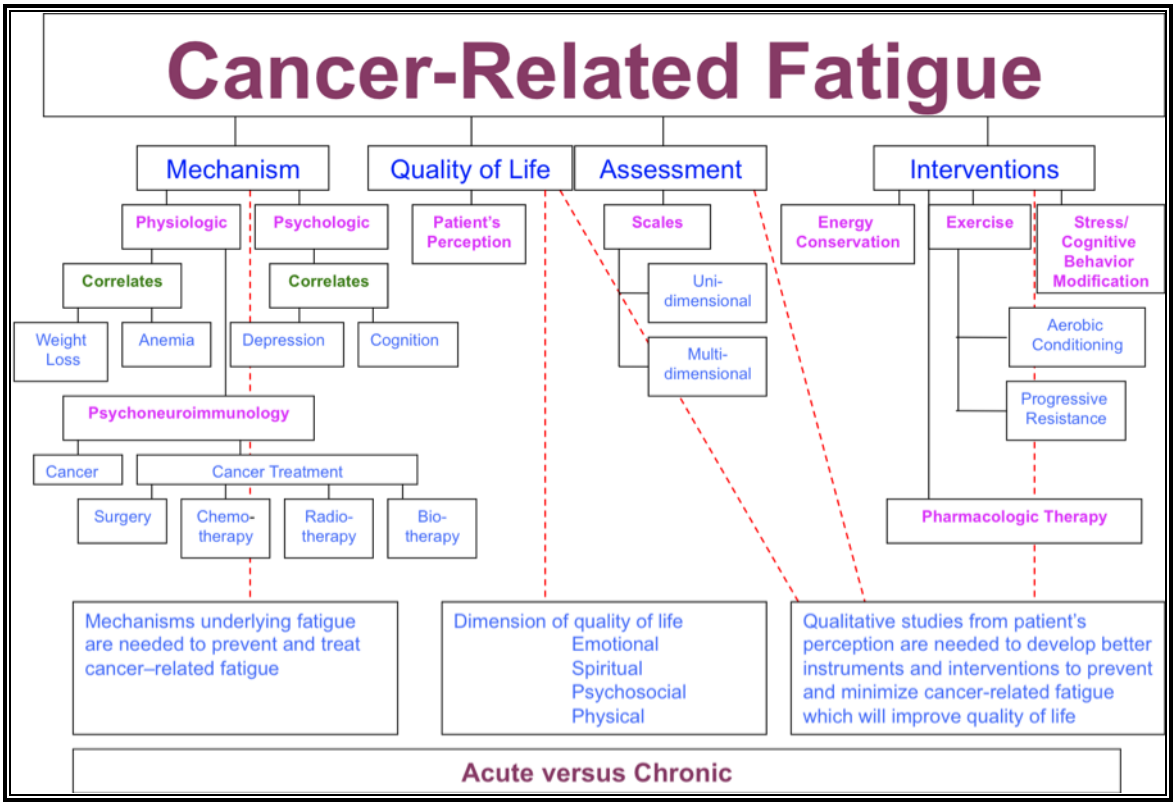


Figure 1: Diagram of Literature Review

Introduction

Early treatment of patients with cancer clearly has demonstrated increased cure and survival rates; however, therapy frequently results in short- and long-term consequences that affect patients' physical and emotional well-being. Fatigue is one such side effect. Cancer-related fatigue is a pervasive and distressing phenomenon that presents a unique challenge to cancer survivors and those who care for them. According to a Fatigue Coalition survey, patients with cancer rated fatigue ahead of pain, nausea, and depression as the cancer-related condition being the most common and troublesome, the longest lasting, and having the greatest impact on their day-to-day functioning and economic well-being (Vogelzang, Breibart, & Cella, 1997). Fatigue is the most common and distressing symptom resulting from cancer therapies; 60-100% of patients receiving chemotherapy report experiencing fatigue, which has been termed the "common denominator" of symptom distress (Winningham et al., 1994).

The impact of cancer-related fatigue on quality of life and ability to carry out activities of daily living has significant implications for patients who experience a notable decline in functional ability during and after cancer treatment (Nail & Winningham, 1995). Fatigue may be present even before treatment begins; it can increase during the course of cancer treatment; and it can persist at a higher-than-baseline rate. Unfortunately, fatigue is not limited to the period of active disease and treatment; it may last for years after treatment is completed when the individual is considered to be in remission (Blesch, Paice, & Wickham, 1991).

Since fatigue may have a detrimental effect on the ability to direct one's attention or to concentrate, it may adversely affect patients' ability to comprehend and retain important information related to the disease and its treatment options (Cimprich, 1995). Fatigue may also affect patients' compliance with the treatment regimen, or lead to interruptions in, or premature withdrawal from, treatment. Failure to complete recommended treatment on the optimal schedule reduces the chance of remission or cure (Nail, Jones, Greene, Schipper, & Jensen, 1991). The prevalence, onset and persistence of the symptom are insurmountable challenges, both for the patient and the healthcare professional, because there are minimal interventions to help the underlying symptom mechanisms which are not understood.

Fatigue is more common in cancer patients than in any other medical populations. At least nine epidemiological studies of fatigue in the general population and patients presenting to primary care practitioners indicate that fatigue is up to seven times more prevalent in cancer patients as in the general population (Morrow, Andrews, Hickok, Roscoe, & Matteson, 2002). Though cancer-related fatigue is highly prevalent, it seems the symptom is an inappropriate response to cancer therapy, especially since it occurs in the absence of physical activity.

Experiencing Cancer-Related Fatigue

While there is minimal evidence in the literature about cancer-related fatigue being studied from a phenomenological perspective, a few studies have been conducted on the phenomenon. An overview of the conducted research follows. A study conducted by Pearse and Richardson (1996) describes cancer-related fatigue from a

phenomenological perspective. Six patients were interviewed and the emerged themes from the interviews reflected both a shared and individual experience of fatigue. These themes included the causes and consequences of the fatigue as well as the nature of the fatigue. Unfortunately, the experiences of the patients are not discussed well; neither is there a discussion of how the fatigue impacts the patient's quality of life. It appears the authors ask more specific questions than one would typically expect in a phenomenological study. The authors state there was an attempt to evaluate reliability and validity; however, there is no delineation of how that was achieved.

A second study conducted by Lindqvist, Widmark, and Rasmussen (2004) reflected the researchers' intent to illuminate the meaning of cancer-related fatigue as experienced by four cancer patients in a palliative care program. The interviews were interpreted using a phenomenological-hermeneutic approach inspired by the philosophy of Ricoeur. The findings reflect that the world of fatigue for the cancer patient is connected with incurable cancer. Paradoxes that represent struggles between body, mind and intellectual understanding are identified. These representations have important implications for healthcare professionals who are communicating with patients about fatigue. Unfortunately, the suggestions for care providers are not delineated in the paper.

A phenomenological inquiry about fatigue in patients with cancer and chronic obstructive airways disease was reported by Ream and Richardson (2004). Nine patients with cancer receiving chemotherapy and six participants with chronic obstructive airway disease were interviewed. The experience of fatigue was similar in both groups. Fatigue was described as distressing because it precludes the patient's normal work and

recreational roles causing frustration, depression, and grief. Reliability and validity of the findings were established. However, further studies are needed in order to study the phenomenon across additional types of patients.

In summary, very few phenomenological studies have been conducted. From the aforementioned studies, it is obvious that few authors have contributed to the literature in understanding what fatigue means to the patient. Despite advances in symptom management in oncology, this persistent and late side effect remains a major source of distress for the cancer survivor. Therefore, it is a professional responsibility for us to go to the patient and hear their words so we can begin to articulate the meaning of fatigue, how it impacts the patient and family, and how can we better serve the patient in helping them deal with their pervasive fatigue.

Antecedents to Fatigue: Physiologic and Psychologic Mechanism

The etiology of cancer-related fatigue is multifactorial and is proposed to involve dysregulation of several interrelated biochemical, physiological and psychological systems. Additionally, the fatigue generally differs with each individual and the phase of their illness as well as the treatment modality they're receiving. Subsequent discussion will include physiologic mechanisms: psychoneuroimmunology, various cancer treatment modalities, muscle function, anemia and weight correlates. Psychologic mechanisms will include depression, distress and cognition. Quality of life issues and assessment of fatigue also will be addressed.

Antecedents to Fatigue: Physiologic

Psychoneuroimmunology

The bi-directional pathways between the immune system and the brain may be at the heart of some of the side effects of cancer and its treatment. The immune-to-brain communication and the pro-inflammatory cytokines in the periphery and brain could be important mediators of these symptoms the patient experiences, including fatigue. Inn as study by Ahles and Saykin (2002), they found that many of the cognitive disturbances observed in cancer patients seem more readily associated with the frontal cortex more so than hippocampal dysfunction, but it may be that activation of the immune-to-brain circuitry that leads to cytokine-induced disturbances in the frontal cortex as well as the hippocampus. Ahles proposes that a number of the "quality of life" issues, including cancer-related fatigue, may be due to the aforementioned immune-to-central nervous system communication. Ahles & Saykin (2002) contends that in related fashion, fatigue is a "debilitating concomitant of chemotherapy, and fatigue is not unlike the behavioral changes that are a part of the sickness pattern" (Ahles & Saykin, 2002, p. 486). While the study is considered a landmark study in psychoneuroimmunology, the study is small and employs a correlational design.

There is a suggestion that the immune to brain communication with the consequent induction of cytokines within the brain might produce cognitive disturbances, especially memory disturbance. This becomes extremely relevant in reference to cancer-related fatigue as memory and cognition are affected greatly in cancer-related fatigue. A study by Dean and Ferrell (1995) includes patients receiving interferon alpha for

malignant melanoma. Fatigue persists throughout the therapy with the affect domain being the most affected; as a result, the patient's memory and cognition are greatly impaired. In consideration of the areas that are known about the immune to brain communication, it seems reasonable that cancer-related fatigue may be precipitated by the sickness syndrome that evolves as a result of these communications (Dantzer & Bluthe, 1993). The study includes a small number of patients and is descriptive in nature.

As alluded to, regardless of the underlying cause, cytokines are crucial contributors to the sickness behavior, including the fatigue that patients experience. These cytokines have a wide spectrum of central and peripheral effects that contribute to the host defense, including effects on energy. When laboratory animals are injected with IL-1 Beta and TNF-alpha, they show fatigue as well as decreased activity, anorexia, increased somnolence, and social withdrawal (Dantzer, 2001).

In addition, tumor development is a very complex process. Cancer is not one disease; rather it consists of more than a 100 different types of disease entities that often behave differently. Some of the tumors are more likely to be associated with stress-related alterations. Van der Pompe and Antoni (1996) studied metastatic breast cancer patients who have elevated cortisol levels but attenuated ACTH and cortisol regression to a behavior challenge. They propose that the elevated cortisol is due to the increased metabolic clearance of cortisol secondary to increased utilization of metabolic substrates in the presence of tumor. While the results are noteworthy, the patients were not stratified. Some of the patients were not receiving therapy and another cohort was pre-terminal.

To further elucidate the picture, some malignancies actually have high levels of cytokines, which may further precipitate fatigue in cancer patients. Lymphoma patients have high levels of IL-6 and IL-10. There is a correlation between the level of IL-6 and IL-10 and the presence of B-symptoms; both cytokines have been found to be a prognostic factor in chronic lymphocytic leukemia (Wetzler et al., 1994). Hodgkin's disease patients also have a high level of Il-6 and IL-10 (Seymour, Talpz, Hagemeister, Cabanillas & Kurzrock, 1997). Interleukin-6 is the most important independent prognostic factor for predicting the complete remission rate and disease-free survival of patients with diffuse large cell lymphoma (Preti, et al., 1997). IL-6 levels are also elevated in renal cell carcinoma and serve as a prognostic factor for this malignancy The IL-6 serves as an autocrine growth factor for renal malignant cell lines. To further complicate the picture, in some malignancies, such as chronic myelogenous leukemia, not only is IL-1 elevated as the disease progresses, but also there is increased level of the endogenous antagonist to IL-1 receptor antagonist (Dean, 1999).

A more recent study by Collado-Hidalgo et al. (2006) studied the inflammatory biomarkers for persistent fatigue in breast cancer survivors. The experimental design included 50 fatigued and non-fatigued breast cancer survivors with immunologic biomarkers completed on both groups. The researchers concluded that there was a link between fatigue and inflammatory markers showing a functional alteration in proinflammatory cytokine response to liposaccharide, which may define a prognostic biomarker of behavioral fatigue. The researchers proposed that cancer-related fatigue

might stem from an aberrant process that precipitates an aging process that is precipitated by cancer therapy (p. 2765).

A longitudinal pilot study examining fatigue, the related correlates of sleep and depression and select biomarkers were studied over time in females with early stage breast cancer receiving chemotherapy. A prospective repeated measures pilot study was conducted over 12 months. Findings suggested that fatigue, sleep and depression were more prevalent in the breast cancer group compared to the cancer-free group. The researchers suggested that the biomarkers, serum cortisol, melatonin, serotonin, cytokines and other endocrine-based chemicals, may help explain the fatigue in cancer patients (Payne, Piper, Rabinowitz, & Zimmerman, 2006).

Orre, Murison, and Dahl (2009) investigated circulating levels of various inflammatory markers in relation to cancer-related fatigue in long-term survivors of testicular cancer. Various cytokines and CRP levels were measured. Results indicate that chronic cancer-related fatigue is associated with higher levels of circulating IL-1ra and CRP, possibly mitigated by physiological morbidity. It is speculative that low-grade inflammatory processes are involved in the pathogenesis of chronic cancer-related fatigue in cancer survivors

In summary, the paucity of studies reveal conflicting results. A small number of studies have been conducted on the relationship of fatigue and the psychoneuro-immunology system. The majority of the studies do not reveal that there is a correlation identified.

Cancer Therapies

Chemotherapy

In addition to the cancer itself precipitating fatigue, the four cancer treatment modalities also increase the risk of developing fatigue. In breast cancer patients receiving chemotherapy, fatigue increased significantly following the initiation of chemotherapy, but the reported fatigue did not differ significantly between the first and last treatment (De Jong, Candel, & Schouten, 2004). Many chemotherapeutic agents lead to high levels of circulating cytokines. Osterlund (2001) conducted a study to assess the inflammatory reaction in colorectal patients who were treated with raltitrexed and oral carmofur versus 5-fluorouracil (5 FU). Compared to the 5 FU patients, the patients treated with the two-drug combination had elevated S-IL-6 and S-TNF alpha. These findings suggest that these patients possibly developed a drug-related system inflammation, which ultimately could increase the patient's risk for developing fatigue as well as other sick behaviors. The experimental study was designed well, but small numbers of patients were entered in the study. The degree of freedom indicates that approximately twenty-five percent of the patients did not remain in the study.

In addition, there are long- term effects on immune function with chemo-therapeutic agents (Osterlund, 2001; Ahles et al., 1998). Bower, Ganz, Aziz and Fahey (2002) found laboratory value changes in two cell populations among fatigued breast cancer survivors. There were lower percentage of naive CD_4 T cells and NK cells in these breast cancer survivors. They propose that the changes perhaps are reflective of the lack of cell recovery from chemotherapy. However, other studies conducted on breast

cancer patients have shown deficits in naïve CD_4 T cells for approximately five years after therapy has been completed (Hakim, Copeda, & Kaimei, 1997). According to Bower, Ganz, and Desmond (2000), the prolonged depression of these cells may result from the immune system remaining activated in order to maintain homeostasis that turn on the production of cells as they are depleted. The authors also propose, conversely, that there may be changes in the lymphocyte trafficking that occurs as a result of immune activation in other parts of the body, thus resulting in decreased circulating levels of immune cells (Bower et al., 2000). These explanations may provide the answer for the reason long-term survivors continue to experience debilitating fatigue. Although the majority of the studies are pilot studies, the results are noteworthy and have led to current research studies being conducted.

A pilot study assessing the level of fatigue in women receiving dose-dense versus standard chemotherapy for breast cancer was conducted by Sura, Murphy, and Gonzales (2006). Fatigue scores were significantly higher in women with the following characteristics: undergone a mastectomy, working, HER 2 positive, and a tumor size larger than 2 cm. Women who received dose-dense chemotherapy also had high levels of fatigue. This is understandable as the women who had larger tumors and were HER-2 positive would have been the patients who received dose-dense therapy.

Hartvig, Aulin, Hugerth, Wallenbery, and Wagenius (2006) conducted a prospective study evaluating fatigue in cancer patients treated with cytotoxic drugs. Ninety-two per cent of patients experienced significant fatigue. The lung and breast cancer patients experienced more fatigue than patients with other cancers. The patients'

quality of life was affected. The same level of fatigue was seen both in both out- and in-patient settings.

Radiotherapy

The second modality, radiotherapy, also is linked to causing an increased level of cytokines. According to Doukas and Gallicchio (1995), irradiation of cell types that are known constituents of the bone marrow microenvironment stimulates an increased level of GM-CSF, M-CSF, IL-6 and IL-1. Cytokine release of growth factors from irradiated endothelial cells in vitro produce platelet-derived growth factor and fibroblast growth factor. Irradiated alveolar macrophages exhibit enhanced production and release of TGF-alpha and THF-beta. Both normal tissues and tumors may elaborate cytokines as part of the response to irradiation. These cytokines may influence local cellular growth and cause endocrine effects on other tissues. It appears that IL-1 has a protective role so normal tissue can repair (Doukas & Gallicchio, 1995).

A study by Greenberg, Gray, and Mannix (1993) assessed sleep and fatigue associated with radiotherapy. They determined their relationship of the level of fatigue to interleukin 1 levels. Ranked serum IL-1 rises between weeks one and four of radiotherapy, as fatigue scores rise. The results suggest that localized radiotherapy is associated with increased fatigue and sleep requirements independent of depressive symptoms. It also suggests that the relative serum IL-1 changes may be one signal for the systemic reaction and the subjective fatigue associated with the acute effects of radiotherapy.

Another study conducted on breast cancer patients involves studying women while they are undergoing adjuvant radiotherapy. The results reveal there is no evidence that anxiety, depression, serum levels of IL-1 Beta, IL-6 and tumor necrosis factor-alpha, or declining hemoglobin levels are responsible for the treatment-induced fatigue (Greenberg, Sawicka, Eisenthal, & Ross, 1992). Both experimental designs consist of an adequate number of participants. However, the results of the studies are contradictory.

A descriptive study by Hickok, Morrow, Roscoe, Mustian, and Okunieff, (2005) included 1129 patients who were assessed for various symptoms associated with radiotherapy. Results showed that the most common symptoms, fatigue, drowsiness and sleep problems, were the most severe symptoms, with fatigue being the most common of the 12 symptoms assessed, both at initiation of radiotherapy and during the course of the therapy. Female patients reported significantly more symptoms than male patients. The researchers also noted that fatigue worsened in frequency and intensity over the course of radiotherapy, as has been reported in other studies (Smets, Visser, & Garssen, 1996). There also was a close association between fatigue, difficulty in sleeping and drowsiness. Limitations of the study included the symptoms being assessed as rather general constructs. For example, fatigue could be related to sleepiness or as being associated with muscle fatigue. Because of the manner in which the questionnaire was constructed, the fatigue was associated more with tiredness than muscle weakness. Therefore, construction of the questions should have been clear so the patient responded accurately.

Brown et al. (2006) conducted a study of 115 newly diagnosed cancer patients randomized to standard arm of care versus standard care plus eight sessions of ninety

minutes each of structured multidisciplinary interventions. Results showed that the interventions had no impact on fatigue, and it was suggested that the interventions may have worsened the fatigue in the intervention group. They did, however, find that a home exercise program was beneficial in improving fatigue.

The impact of fatigue on overall quality of life in breast and lung cancer patients receiving high-dose radiotherapy was studied by Dagnelie, Pijls-Johannesma, & Lambin (2007). Sixty-four patients completed the Treatment of Cancer Quality of Life Questionnaire. Results reflected that fatigue is by far the predominant contributor to patients' perceived overall quality of life. Findings further substantiate that fatigue in breast cancer patients is a major problem and warrants proper screening, assessment and treatment strategies to help reduce fatigue. The researchers recommend replicating the study in patients with a different tumor type and different stage of disease as well as a different treatment modality.

Biotherapy

The third modality, biotherapy, is recognized for producing severe fatigue and often is recognized as the treatment limiting and/or dose limiting side effect that is overwhelming to patients. In fact, the associated fatigue is the primary reason patients request to terminate the treatment. Numerous studies convey that biotherapy causes cancer-related fatigue. Studies from the mid-1980s to the present continue to identify fatigue as the major complaint that patients experience. Quesada and Talpaz (1986) cite fatigue as the most prevalent nonacute symptom. Even in low dose regimens of gamma interferon, 75% of patients experience fatigue. Because of severe fatigue, 75% of the

patients in a study conducted by Quesada and Talpz (1986) required dose reduction of gamma interferon with a minimal response to the treatment.

Almost 25 years later, fatigue continues to remain a major concern as cited in a study by Fu and Anderson (2002) in which fatigue is reported as moderate to severe in patients undergoing biotherapy for metastatic melanoma. While the studies are significantly important because of the overwhelming fatigue these patients experienced, the results are questionable because the researchers did not group the patients according to type of biotherapy being administered.

Surgery

The fourth modality, surgery, also plays a role in producing cytokines that may precipitate fatigue. The potential of surgery having a deleterious effect on the immune function is well established. Ben-Eliyahu (2003) suggests that stress and surgical excision of the primary tumor may promote tumor metastasis that would result in the release of cytokines. The surgery itself suppresses the cell-mediated immunity. As a result, it is possible that inflammation and infection may ensue. Subsequently, pro-inflammatory cytokines are released which increase the risk of fatigue during the recuperative period. As a result of the pathways being activated in the patient with the malignancy as well as the patient undergoing treatment(s) for their malignancy, it is possible that the release of the cytokines can precipitate an overwhelming fatigue. This pilot study reveals noteworthy findings; however, further studies need to be conducted.

Muscle Function

In addition, the examination of muscle function is one way to understand physiologic mechanisms of fatigue. Potential mechanisms for decreased muscle contractility include accumulation of metabolic products and loss of muscle protein. The results of studies in patients and animals with cancer indicate that tumor presence is associated with decreased synthesis of protein (Pain, Randal, & Garlick, 1984; Svaninger, Lundberg, & Lundholm, 1983). However, studies of protein loss in tumor-bearing animals and patients with cancer yield contradictory findings (Svaninger et al., 1983). The lack of consistent findings between the studies of muscle protein loss and those of muscle structure may reflect lack of control of confounding variable or methodological factors.

Yavuzsen et al. (2009) evaluated cancer-related fatigue using an objective measurement to ascertain whether the fatigue is more a centrally or peripherally mediated disorder. Both cancer patients and control group (non-cancer patients) underwent neuromuscular testing as well as measurement of fatigue and hemoglobin levels. Extensive testing of various muscles for their level of fatigue was completed. Results showed that cancer patients exhibited greater central fatigue, indicated by shorter endurance time and less voluntary muscle recruitment during a sustained muscle contraction.

Anemia and Weight Loss Correlates

Physiologic correlates such as anemia and weight loss are found in some cancer patients at diagnosis and can be exacerbated by cancer treatments. Cytokines have been

implicated in the suppression of erythrogenesis (Groopman & Itri, 1999). Studies have reported an increase in "energy" or quality of life in patients with anemia being treated with recombinant human erythropoietin alpha (Demetri, Kris, Wade, Degos, & Cella, 1998; Groopman & Itri, 1999), but the precise relationship between fatigue and measures of energy and quality of life remains to be identified from the study. In addition, patients who required blood transfusions and/or who did not respond to the epo alfa treatment were dropped from the study. As a result, the data were skewed.

A relationship between fatigue and anemia in patients undergoing cancer treatments has been postulated (Blesch et al., 1991; Maxwell, 1984); however, research has failed to show a consistent relationship between these variables (Irvine et al., 1994). Research studies specifically examining fatigue have found no correlation between fatigue and anemia (Brunier & Graydon, 1993; Cardenas & Kutner, 1982). It is known, however, that reduced erythropoietin production is common in patients with cancer who are receiving cancer treatment (Robbins et al., 1997) and further assessment of the relationship of fatigue to anemia is necessary. It is suggested that more attention needs to be centered on the symptomatic effects of anemia rather than on the physiological data. Therefore, addressing quality of life issues in relation to fatigue is further warranted (McCann & Boore, 2000).

Littlewood, Kallich, and San Miguel (2006) conducted an exploratory analysis that showed treating anemia improved functional health and well-being. An improvement in hemoglobin was associated with improvement in fatigue. The researchers recommended confirmation of their results with further prospective trials.

Cytokines may also contribute to cachexia (Tisdale, 1999). Many different molecules have been implicated and the most critical ones may vary among various types of cancer (Inui, 1995). In addition, Inui (1995) suggests that catabolic factors, such as lipid immobilizing factors and protein mobilizing factor that act directly on skeletal muscle and adipose tissue, may also play a role in cancer-related fatigue. In one published study of the relationship between fatigue and nutritional status over time in patients with lung cancer receiving radiation therapy, fatigue scores and various indicators of nutritional status were not related (Beach, Siebeneck, Buderer, & Ferner, 2001). However, several variables were not controlled in the study; therefore, the results are questionable.

Antecedents to Fatigue: Psychologic

Depression and Distress

As mentioned, cancer-related fatigue may be one of the symptoms observed in the "sickness behavior." This concept helps to understand both the physiological and psychological impact of a cancer and the cancer therapy associated with the malignancy. It is increasingly clear that several of the symptoms, including depression and sleep disturbances the cancer patient experiences, have a biological component associated with them and probably exacerbates in an attempt for the host to fight the disease and to maintain a homeostatic balance. Dantzer (2001) proposes that there is a growing suspicion that proinflammatory cytokines are involved in the development of feelings of despair, depression and hopelessness that occur in many cancer patients. This is substantiated in a large number of patients who are receiving immunotherapy as they

develop significant depression. The current thinking is that proinflammatory cytokines are somehow involved in the development of a number of psychiatric disorders in addition to depression (Dantzer, 2001). It is noteworthy that Capuron et al. (2002) propose that it is becoming increasingly clear that the "sickness behavior" takes on more than one form including both a depressive syndrome (major depression) and a neurovegetative syndrome characterized by fatigue and anorexia.

One of the greatest challenges facing oncology healthcare professionals is distinguishing cancer-related fatigue from other psychosomatic and psychological ailments, such as depression. A study including 738 cancer patients revealed an extensive overlap with depression when utilizing multi-item measures of fatigue. However, the extent of the overlap between fatigue and depression is reduced when using a single-item measure for fatigue (Morrow, Hickok, & Raubertas, 2001). Similar results were observed in a study including 450 patients from an ongoing trial where fatigue and depression were assessed (Lai, Cella, & Dineen, 2005). Another study by Visser and Smets (1998) assessed the relationship between fatigue and depression in 308 patients who had been treated with radiotherapy. Results of the study indicated that depression and fatigue were independent conditions with different patterns over time. They concluded that fatigue increased over time but depression did not. It was determined that fatigue was not predictive of depression, and neither was depression predictive of fatigue.

Collectively, the evidence suggests that psychological distress is a potentially important variable to consider in studies of fatigue in cancer patients. Prolonged stress is proposed by Aistairs (1987) as the main cause of fatigue in the person with cancer. Such

responses may not only cause, but also result in, persistent fatigue. In cancer, depression and fatigue may co-exist, both resulting from identical biological factors. Aistairs (1987) proposes that both result from identical biological factors; however, the results reflect that patients with co-morbid diseases, which may cause depression and fatigue, were not excluded from the study (Hayes, 1991).

A more recent study by Reuter and Harter (2004) discussed the similarities and differences in the conception of fatigue and depressive disorders. In oncology, cancer-related fatigue is understood as a multidimensional construct with physical, cognitive and emotional factors. A comparison of these three factors with depression symptoms show that all the symptoms associated with fatigue have their corresponding symptoms in the concept of depression. Only the psychological symptoms of depression which go beyond the fatigue symptomatology, allow for a distinction between the syndromes. Reuter and Harter (2004) point out that it is important to consider the disadvantages of clearly outlining the diagnostic categories for these disorders. Doing so can "cover one's eyes" to the fact that when viewed from a phenomenological perspective, the boundaries between the disorders are always fluid. Clinically, these inflexible divisions can be restricting" (Reuter & Harter, 2004, p.133).

A study by Reuter et al. (2006) explored the relative contributions of coping, depression, pain and age, and the experience of cancer-related fatigue in a study of 353 women treated for primary breast cancer within one year of diagnosis. Fatigue was positively associated with depression and pain, but inversely related to age. The "fighting spirit" of the patient was not associated with less fatigue. Detectable only in the

multivariate analysis together with depression, the results suggested a weak association between coping and fatigue. Further longitudinal studies are warranted to explore the relationship between fatigue, age and coping styles.

A cross-sectional study that described the prevalence and associated variables with cancer-related fatigue in 79 patients treated with radiotherapy was conducted by Vistad, Fossa, Kristensen, and Dahl (2007). In a multivariate regression model, depression was the only variable significantly associated with chronic fatigue. A weakness of the study was the small sample size.

Von Ah, Kang, and Carpenter (2008) conducted a longitudinal study examining these potential predictors of cancer-related fatigue before, during, and after adjuvant therapy in women with breast cancer. Fatigue assessment utilizing Piper Integrated Fatigue Model and blood collections for cortisol levels, interleukin-1 beta, tumor necrosis factor alpha, and natural killer cell activity before adjuvant therapy were completed on 44 women. Mood disturbance was the most significant predictor of cancer-related fatigue. Findings suggest that interventions to reduce mood disturbances might be effective in decreasing cancer-related fatigue.

In summary, more systematic studies need to be performed to investigate the relationship between depression, anxiety and the fatigue experience of cancer patients. The characteristics of the individual including motivation, beliefs and attitudes, and the individual's perception of cancer should be considered.

Cognition

Though chemotherapy-related cognitive impairment was first described in the 1970s, it emerged as a significant concern both for the patient and healthcare provider in the late 1990s. "Chemobrain," a term used in the lay literature to describe the cognitive changes that occur after chemotherapy is seen in 17 - 75% of patients (Wefel, Lenzi, Theriault, Davis, & Myers, 2004). In most patients the changes are subtle with reports of changes in cognition which usually resolve after chemotherapy is completed. Unfortunately, 17 - 35% of patients experience more severe and long-lasting effects (Ahles & Saykin, 2002). Domains of cognition that generally are affected are memory, learning, executive function, speed of information acquisition and processing. Occasionally both motor functioning and spatial skills also are affected (Ahles & Saykin, 2007). Patients describe the phenomenon as "being in a fog" and "being slow at completing tasks"; they also voice a sense of "being unable to balance a checkbook" or "getting lost going to my office." Cognitive impairment is a great concern for the patient as it often interferes with their resumption of home responsibilities, work, school and social activities.

Advancements in neuroimaging assist in determining the functional and structural central nervous system (CNS) changes that may occur in cancer patients receiving chemotherapy. Brown, Simon, and Stemmer (1995) conducted a study on 13 breast cancer patients who had received high-dose chemotherapy regimen in preparation for bone marrow transplant. Eighty-seven percent of the patients developed white matter changes in the brain. The authors proposed that the changes occurred as early as 3

months post initiation of chemotherapy. A longitudinal, prospective follow-up study was conducted by Brown et al. (1995) to assess white matter changes post-chemotherapy in 8 breast cancer patients undergoing autologous stem cell transplant. Neuroimaging results demonstrated white matter changes as early as 3 months post-chemotherapy. The authors concluded in both studies that neuronal changes occurred early post-chemotherapy and were transient in nature. Limitations of both studies include a small sample as well as only evaluating patients who received high doses of chemotherapy in preparation for transplant.

To assess CNS pathophysiologic changes, in a longitudinal randomized study, Saykin, Ahles, and McDonald (2003) performed computerized tomography (CT) and positron-emission tomography (PET) scanning in 12 cancer survivors who had received chemotherapy 5 years ago. White matter changes were seen in the treatment group with no changes seen in the control group. The CNS changes occurred primarily in the domains of episodic and working memory as well as executive function of decision making and psychomotor problem solving.

Silverman, Dy, and Castellon (2007) studied eight breast cancer patients who had demonstrated significant neurocognitive changes following chemotherapy. Cognitive testing was conducted after PET scanning was completed. Results showed there were indications of mental slowness and diminished ability to maintain concentration, recall, and attention. Limitation of the study is a small sample size.

Researchers have also evaluated the effects of chemotherapy on the hippocampus. Yoshikawa et al. (2005) determined that hippocampal damage from chemotherapy may

be associated with memory deficits after studying 31 Japanese breast cancer patients who had received chemotherapy. They hypothesized that the damage may precipitate cognitive impairment. A follow-up randomized study was conducted to explore regional brain volume one and three years post-chemotherapy in breast cancer patients. Results showed that at one year post-chemotherapy, the right prefrontal volume was diminished; however, at the three year follow-up, normal volume was noted. The authors concluded that smaller volume was associated with changes in memory function, especially in areas of concentration, attention and visual memory. However, over time the volume changes did return to normal.

Further neurocognitive testing utilizing MRI was conducted by Ferguson, McDonald, Saykin, & Ahles, (2007). They evaluated CNS structural and functional changes in monozygotic twins, one of whom received chemotherapy for breast cancer. The twin who received chemotherapy demonstrated white matter hyper-intensities on structural MRI; she had experienced higher self-reports of cognitive dysfunction. There was no evidence of depression or anxiety in either twin. The twin who received chemotherapy had increased cortical activity, indicating that increased work was required to overcome the cognitive dysfunction. The authors concluded that the affected twin compensated for the deficits by working very hard to overcome the cognitive dysfunction such that she performed well on standardized neuropsychological tests.

Schagen, Das, and van Dam (2009) proposed that because there is ample evidence that psychological and physical complaints can increase with increased accessibility to relevant schemata, fatigued cancer patients may succumb to cognitive dysfunction.

Information about the symptom can be integrated into the memory through priming or pre-existing knowledge about the symptom. In other words, if the patient is aware of a possible side effect, such as fatigue and cognitive dysfunction, the patient is more likely to develop the symptom. The authors interviewed 261 breast cancer patients about their cognitive problems. Prior to the interview, half of the study participants were primed with a letter containing information about cognitive dysfunction and its association with chemotherapy. Results showed that patients who were primed about cognitive information were more likely to have cognitive problems post-chemotherapy. Results of the study have relevant implications both for clinical practice as well as future research.

In summary, cognitive disturbances have been observed especially in women during and after breast cancer adjuvant chemotherapy as well as after breast cancer surgery (Cimprich, 1992). These disturbances tend to be associated with the fatigue that as many as 99% of these women experience during and after cancer treatments. To address this significant problem, clinicians must routinely screen and perform further assessments to identify patients who are at risk for this debilitating condition and then implement treatment strategies including physical and psychosocial rehabilitation programs.

Quality of Life

The Fatigue Coalition Study II results show that fatigue is associated with significant physical, emotional, psychologic, and social consequences, with virtually every aspect of daily life being affected (Vogelzang, et al. 1997). Ahlberg, Ekman and Gaston-Johansson (2005) found highly statistically significant negative correlation

between fatigue and multiple domains of quality of life, including physical, emotional, cognitive and social as well as role functioning. They further demonstrated that over time these domains remained highly negatively correlated with fatigue. There is a paucity of studies that address these quality of life issues in the cancer patient. Ferrell et al. (1996) conducted an exploratory descriptive study that described the impact of fatigue on the quality of life of patients with cancer. The findings reflect that fatigue has an impact on all dimensions of quality of life including physical, psychological, social and spiritual well-being. The study is limited due to the methodology used which included analyzing data from mailed surveys, interview data, and focus groups (Ferrell et al., 1996).

A second study by Tanaka et al. (2002) compared the impact of dyspnea, pain and fatigue on daily life activities in ambulatory patients with advanced lung cancer. Results indicated that dyspnea and fatigue interfered with at least one daily life activity in more than half of the patients. One limitation of this study is the lack of variance in symptoms. Those patients who were physically or cognitively not well were excluded. A second limitation is the assessment form that was utilized; initially, it was validated for pain assessment. Also temporal sequences cannot be determined from the data because of it being a cross-sectional study. Difficulty in assessing the impact on daily life is noted as the severity of the symptoms is unclear.

Camarillo (1991) used case studies to describe perceptual meanings of fatigue experienced during chemotherapy. Fatigue was viewed as a negative experience that had impacted normal physical and social activities, challenged personal coping abilities and

was associated with a diverse symptomatology. Camarillo concluded that fatigue often disrupted the patient's ability and desire to accomplish valuable role functioning, ultimately diminishing quality of life. However, there was no link established among the dependent variable, fatigue, and the other independent variables. The study failed to reflect practice theory, thus eliminating the potential for interventions.

A preliminary study by Cimprich (1993) focused on changes in attention capacity and cognition in women who had a mastectomy. The experimental group who participated in the simple restorative activities showed enhanced recovery, including improved cognition. The study is limited because only thirty-two patients participated in the study. No identification was completed on the women who were diagnosed postoperatively with breast cancer. These findings, however, do provide a basis for further testing of the efficacy of attention-restoring activities.

A more recent study addressing quality of life issues followed a group of Hodgkin's disease patients for five years (Flechtner & Bottomley, 2003). Results reflect that there is a subgroup of patients whose fatigue persists at a medium to high level after five cancer-free years. Unfortunately, the researchers did not determine either statistical or clinical differences.

A cross-sectional study by Diaz et al. (2008) explored the functional and psychological impact of different cancer symptoms in 505 patients. Fatigue affected the patient's daily routine, social activities and relationships. The patients perceived fatigue as the symptom with the highest impact on their daily living and reported that it substantially affected their emotional and social activities. There was lack of monitoring

the patients as they completed the self-administered survey. Additionally, no resources were offered to assist them with their fatigue.

A survey totaling 1,933 breast cancer survivors were recruited from five large hospitals in Korea to examine the prevalence and correlates of fatigue and depression. They assessed the correlates for relevance to health-related quality of life. Results showed that fatigue and depression were influenced by sociodemographic factors, co-morbidity and symptom characteristics rather than cancer or treatment-related factors. Both fatigue and depression were negatively associated with survivors' health-related quality of life. The assessment scales utilized for fatigue and depression were appropriate; however, collection of data was not clearly delineated fully in the study (Kim et al., 2008).

A structured interview was conducted on 200 breast cancer patients two years after completion of therapy. The researchers investigated the relationship between cancer-related fatigue and clinical variables. In addition to interviewing the women, blood and urine samples were collected for hematological, biochemical, and cortisol analysis. The results showed that 30% of the women who had completed chemotherapy had significant negative changes in their quality of life and mood status. There was some evidence that the fatigue was related to sleep disturbance or to a persistent inflammatory or immune response (Alexander, Minton, Andrews, & Stone, 2009).

Further research demonstrates that cancer-related fatigue persists long after treatments are completed and greatly impacts the patient's quality of life. Meeske, Smith, and Alfano (2007) conducted a study on large cohort of disease-free breast cancer

survivors to assess the prevalence of fatigue, correlates of fatigue and the relationship between fatigue and quality of life. Results reflected that 41% of breast cancer survivors were fatigued two to five years post-treatments. Significant correlates of fatigue included cognitive problems, physical inactivity, pain, changes in physical appearance and use of antidepressants. Fatigue was associated with poor quality of life, mainly in the area of role changes and social functioning. Another study by Goldstein et al. (2006) further reinforced that psychological distress and fatigue persisted four years post-chemotherapy and radiotherapy in 176 breast cancer patients. These women also reported functional disability that was caused by their fatigue.

In summary, fatigue is one of the most pervasive symptoms experienced by patients with cancer. This symptom has the capacity to greatly diminish quality of life (Glaus, Crow, & Hammond, 1996) as well as negatively impacting treatment outcomes by reducing survival times (McDaniel, Musselman, & Porter, 1995). Data from Ferrell et al. (1996) secondary analysis of data determined that rather than being an isolated physical symptom, fatigue is a "force that has an impact on all dimensions of quality of life" (Ferrell et al., 1996, p. 1539).

Cella, Lai, & Chang (2002) further clarified this phenomenon by identifying a strong linear relationship between fatigue and quality of life in his investigation into factors impacting on the latter. Distress and disruption in patients' lives evoked by fatigue are evident in several qualitative investigations (Glaus et al., 1996; Ream & Richardson, 1997; Holley, 2000). In addition, two surveys conducted determined that fatigue causes more impairment to quality of life in patients receiving chemotherapy and

radiotherapy than other common side-effects of cancer therapy. Furthermore, there is a financial impact not only for the patient but also for the caregiver caused by cancer-related fatigue. Approximately 20% of patients needed to employ someone to help with household chores with 75% of patients having to change their conditions of employment as a result of fatigue (Breithart, Cella, & Curt, 2000).

Assessment of Cancer-Related Fatigue

Another important aspect in the study of fatigue is the measurement of this subjective phenomenon. To investigate more control of fatigue, there is the need for reliable and valid assessment measurements as there is a lack of consensus surrounding the optimal means of assessing cancer-related fatigue (Jacobsen, 2004). Piper and associates submit that they were the first to propose a multidimensional measurement model for fatigue manifestations (Piper et al., 1987). However, a critical literature review on cancer-related fatigue demonstrates that the measurement of fatigue has been restricted somewhat due to one-dimensional scales with limited reliability and validity (Irvine et al., 1994). Over time, approximately 18 instruments to measure fatigue have been developed. These myriad of fatigue assessment tools sometimes are only one-dimensional and tend to be much shorter and more clinically appropriate but do not take into account the multifactorial nature of fatigue. Conversely, multidimensional scales are mainly developed for research studies but the length and time required to complete them make them impractical to use in clinical screening or clinical evaluation. Additionally, the length of the tools tend to exhaust the patients. Consequently, the effective

management of fatigue is hampered by lack of a well-validated, sensitive and easily administered measurement tool (NCCN, 2009).

The Rhoten Fatigue Scale (Rhoden, 1982) is simple and easy to use but does not describe the fatigue experience comprehensively as it was not developed for measuring cancer-related fatigue. The second instrument, Profile of Mood States (POMS) is easy to use; however, it was developed to measure change in mood states in psychiatric outpatients, not fatigue in cancer patients. The multidimensional fatigue inventory (MFI-20) demonstrates good reliability in patients receiving radiotherapy. However, the instrument needs to be validated with other cancer populations (Smets, Garssen, & Bonke, 1995). The Functional Assessment of Cancer Therapy Fatigue Scale (FACT-F) has high internal consistency, is brief, simple and easy to use, but the length of the questionnaire could burden fatigued patients.

Other assessment tools serve as multidimensional measurements and, as previously mentioned, tend to be lengthy and more suited for research studies, such as the Piper Scale. It is the most comprehensive scale; however, it is quite lengthy and is not designed to be used clinically (Piper et al., 1987). The Multidimensional Fatigue Symptom (MFSI) has good psychometric properties and does not assume the presence of fatigue or chronic disease. It, too, is lengthy and could burden the patient (Stein, 1998). In addition, the Schwartz Cancer Fatigue Scale is highly recognized as it measures various dimensions of quality of life. It is simple and relatively brief. It has a validation limitation in that the patients had completed their cancer treatment. Therefore, it needs further tests of psychometric properties (Schwartz, Jandorf, & Krupp, 1993). Holley

devised the Cancer-Related Fatigue Distress Scale in 2000. Its strength is that the items were based on patient interviews and the content was validated by cancer survivors. The limitation is that it measures only one aspect of the cancer-related fatigue experience, distress, which may not capture the whole picture of the fatigue experience (Holley, 2000).

A study evaluating screening instruments for cancer-related fatigue in 200 breast cancer survivors was conducted. The study utilizing a diagnostic interview combined with a structured psychiatric interview was completed (Alexander, Minto, & Stone, 2009). The patients also were assessed utilizing the Bidimensional Fatigue Scale and the FACT-F. The researchers concluded that both assessment tools' cut-off scores can be used to identify breast cancer survivors at higher risk of significant ongoing post-treatment fatigue. Because the interviews were lengthy, they may not be conducive to utilize in fatigued cancer patients and would not be suitable for clinical use.

A recent study by Santana et al. (2009) assessed fatigue in 43 patients utilizing the FACT-F for the purpose of providing evidence on the magnitude of change in the fatigue subscale scores. The changes in the fatigue scores correlated with patients' perception of their fatigue worsening or improving. They also requested their participants to complete a battery of questionnaires, which possibly was exhausting to a fatigued patient.

A systematic review methodology was used to identify scales that have been validated to measure cancer-related fatigue. The reviewers identified 14 scales that met the inclusion criteria: validated for use in cancer patients and/or widely used in cancer patients. They concluded that the unidimensional scales are the easiest to administer and

have been used most widely. They recommended the use of the EORTC QLQ C30 (fatigue subscale) and the Fatigue Questionnaire (FQ). The remaining scales need further validation before using in the oncology patient (Minton & Stone, 2009).

In summary, there are several tools available to assess cancer-related fatigue. Despite efforts to produce fatigue instruments, no gold standard is available. From a clinical and research perspective, it might be more relevant to use a simple measure that clearly indicates the presence, absence and severity of cancer-related fatigue during and after treatment. Unfortunately, there is concern because of lacking uniformity among the elements that are assessed. In addition, most of the tools are quite lengthy, laborious and tend not to be user friendly for the patient who is experiencing fatigue. In addition, the utility of the assessment tools in the clinical setting is in question due to the inordinate amount of time required to complete them. Finally, due to the lack of uniformity among the various tools, the results leave the practitioner with a lack of clarity in how to implement strategies to manage patients who are experiencing the fatigue.

Management Stratégies: Cancer-Related Fatigue

Exercise

The most effective approach to symptom management is to identify the cause of the distressing symptom and correct it. However, in many patients with cancer, no cause for fatigue can be readily identified, and the approach to management is a general one. The most supporting evidence of effectiveness can be found for exercise as an intervention for cancer-related fatigue (Mock, Atkinson, & Barsevick, 2000). The theory

supporting exercise as a treatment for fatigue proposes that the combined toxic effects of cancer treatment and a decreased degree of physical activity during treatment cause a reduction in the capacity for physical performance. Exercise training leads to a reduction in the loss or even an increase in functional capacity, leading to reduced effort and decreased fatigue (Schwartz, 1999).

To date, there are approximately 11 published reports by four research teams of studies testing the effects of exercise on fatigue during active cancer treatment, and two additional reports of exercise programs after cancer treatment (Mock, McCorkle, Ropka, Pickett, & Poniatowski, 2002; Mock, Dow, & Meares, 1997; Mock, 2001). All indicate significantly lower levels of fatigue in individuals who exercised compared to the control group. Although the results have been consistent across studies, they are limited in number, their sample sizes are small, and there are methodological limitations associated with many. Furthermore, most studies have only included patients with breast cancer.

Two reviews of exercise studies in patients with cancer have also concluded that exercise reduces fatigue and improves quality of life (Courneya & Friedenreich, 1999; Pinto, & Maruyam, 1999). Results of a pilot study of increased activity in nine patients with advanced cancer also showed reductions in fatigue (Porock, Kristjanson, Tinnelly, Duke, & Blight, 2000). Only one small study (n=5) investigating the effects of exercise on fatigue involved instituting an exercise program for individuals complaining of high levels of fatigue (Dimeo et al., 1996).

A few studies have demonstrated that regular exercise improves mood, body image, self-concept, and sleep patterns (Crews & Landers, 1987; MacVicar &

Winningham, 1986). Crews and Landers (1987) conducted a meta-analysis of thirty-four studies including approximately 1500 subjects investigating aerobic fitness and reactivity to psychosocial stressors. Results indicated that aerobically fit subjects had a significantly reduced stress response when compared to control group or baseline values. A more recent retrospective investigation between aerobic exercise and quality of life in women with breast cancer was compared to a matched control group who did not exercise. The women who exercised had a significantly higher quality of life (Young-McCaughan & Sexton, 1991).

In contrast, Losito, Murphy, and Thomas (2006) reported there was no difference in fatigue in a prospective, pre- and post-test design convenience sample of 12 adults with various types of cancer. They observed that social interactions resulted in strong group cohesiveness. Limitations of the study included an inadequate power to demonstrate significant differences in outcome variables as well as lack of comparison groups, self-selected participation and lack of formal measurement of the group process.

Conversely, 113 breast cancer patients participated in a supervised exercise training program. Results showed that moderate intensity, individualized exercise improved cardiovascular and pulmonary function with reduction in fatigue. However, fatigue did not decrease on psychologically based domain of affective fatigue and cognitive/mood fatigue (Schneider, Hsieh, & Spoud, 2007).

According to Schwartz (1999), only a few published studies tested exercise interventions to manage fatigue during cancer treatment. These studies included radiotherapy patients participating in aerobic exercise. The results demonstrated lower

levels of fatigue in the aerobic group. Studies were done in small samples of patients with breast cancer.

Other studies of exercise during cancer treatment, while not focused on fatigue as an outcome, have demonstrated positive findings related to physical function during cancer treatment. Another study (Dimeo et al., 1997), studied the effects of exercise on bone marrow transplant patients who exercised with a bed exercise bicycle for 30 minutes daily. The results demonstrated increased physical performance and a decreased white blood cell and platelet count as well as a decreased length of stay when compared with the control group. Fatigue was not an outcome reported in this study. These studies do, however, suggest that patients receiving active cancer therapy can exercise safely.

A meta-analysis of exercise interventions for patients with cancer-related fatigue was completed by Conn, Hafdahl, Porock, et al. (2006). Results indicated that exercise interventions resulted in small positive effects on health and well-being. However, these findings suggested that breast cancer patients benefited the most from exercise. Improvement in mood was found only when exercise was done after completion of therapy. Limitation of the study included no report of patients dropping out of the studies.

A more recent study (Winters-Stone, Bennett, Nail, & Schwartz, 2008) conducted a cross-sectional study to determine whether clinical characteristics, physical fitness or physical activity predict fatigue in older, long-term breast cancer survivors. The sample included 47 women who were at least one year beyond treatment completion. Findings revealed that fatigue was significantly correlated with variables with the exception of

aerobic fitness. Fatigue was higher with lower age, greater body fat composition, fewer years after diagnosis, more adjuvant treatments, poorer lower-extremity muscle strength and less physical activity. Fatigue was linked to physical activity and muscle strength. Regard for the women being fatigued should have been taken into consideration as a two-hour testing session was completed.

Hanna, Avila, Meteer, Nicholas, and Kaminsky (2008) conducted a retrospective analysis of achieved data of 39 cancer patients who completed a 16-session comprehensive exercise program. The program consisted of low-to-moderate intensity aerobic and resistance exercise, education and support twice a week for eight weeks. Significant improvements in physical function, fatigue and mood were noted.

A biobehavioral model was proposed by Al-Majid & Gray (2009) because the majority of past exercise studies have not been guided by a consistent theoretical model nor have they examined biobehavioral mechanisms underlying cancer-related fatigue. As a result, the mechanism by which exercise reduces fatigue is not fully elucidated. This model will provide guidance for future research on exercise interventions for fatigue and will help to identify variables implicated in causing cancer-related fatigue.

Donnelly et al. (2009) conducted a study to establish physiotherapy exercise management of cancer-related fatigue in the United Kingdom. Results showed that the most common barrier to implementing an exercise program was lack of exercise guidelines. Their recommendation included not only teaching exercises to patients but including strategies to teach the patients' energy-conservation techniques.

The most recent study conducted by Adamsen (2009) included 296 patients with various types of cancer receiving chemotherapy. Both male and female patients in the Danish study were randomized to either standard of care or standard of care plus a multimodal high intensity exercise intervention. The exercise program included group exercise three times per week as well as low intensity training with 30 minute relaxation exercise four times per week as well as a 30 minute massage twice a week. Results demonstrated that there was a simple reduction in fatigue and improvements in other measures of well-being in the intervention group; however, these patients did not have an improved overall quality of life. The patients who completed the 6 week exercise program showed a 6.6 point decrease in the fatigue scale. The effect size of 0.33 suggested that a small to medium clinically important change in the study's primary outcome measure was noted. Not only was the patients' fatigue improved, but also improvement in physical functioning, vitality, and mental health was noted. The strengths of the study included a large sample size including both male and female patients. Additionally, the same results were noted in patients with advanced disease. Weaknesses of the study included lack of a blinded study as well as the control group was allowed to crossover to participate in the program. Approximately two-thirds of the participants in the control group switched over to the intervention group. Additionally, there were more female than male patients participating in the study.

Energy Conservation

Energy conservation is a frequent treatment recommendation for cancer-related fatigue. Patients with fatigue are often advised by health-care professionals to get

additional rest and sleep (Vogelzang et al., 1997). The relation between sleep disturbances and fatigue has been inadequately investigated (Berger, 1998). Results of two studies, which used actigraphy to measure activity and sleep, have shown that cancer patients spend more time resting and sleeping than healthy individuals, but the pattern of sleep is often severely disrupted with awakening almost every hour (Berger, 1998; Young-McCaughan, Dramiga, & Yoder, 2002). Berger, VonEssen, and Khun (2002) conducted a pilot project and found that patients who try additional rest and sleep to manage fatigue do not report it to be particularly effective.

The research being done to test rest or sleep to manage fatigue is in preliminary stages (Barsevick, Berger, Bakken, & Cetak, 2007). Although research is limited, results of a pilot study have been published by Barsevick, Whitmer, Sweeney, and Nail (2002), and a multicenter randomized clinical trial also has been published (Barsevick, Beck, & Sweeney, 2002). These studies were designed well; the results indicate a need for additional studies involving a larger sample of patients.

Stress Reduction/Cognitive Behavior Modification

Studies testing interventions to reduce stress and increase psychosocial support also have shown reductions in fatigue, usually as a component of mood state (Fawzy, 1995; Fawzy et al., 1990). Because these interventions did not have fatigue as a primary endpoint, fatigue measures are often limited to a subscale on an instrument to measure emotional distress, and the interventions generally did not attempt to elucidate a mediating mechanism of fatigue. In these studies, assessing the validity of the intervention in relation to effects on fatigue, the content of the intervention, and potential

clinical confounds that threaten the internal validity of the study were difficult. Because the original interventions did not target fatigue, the amount and type of information about fatigue and suggestions for self-care included in the interventions were not described or controlled, and use of these suggestions by participants was not examined. Interventions suggested by other patients were adopted during group interventions, or suggestions by the nurse were used during individual counseling sessions, making it difficult to assess the overall effect of a fairly broad psychosocial intervention (Fawzy, 1995).

Specific interventions tested have included support groups, counseling, and a comprehensive coping strategy (Hadorn, Baker, Hodges, & Hicks, 1996). In the studies of support groups, the experimental groups have shown less overall mood disturbance, less depression, less fatigue, and greater vigor than control groups on the Profile of Mood States scale (Fawzy et al., 1990).

A model of cognitive or attentional fatigue in patients with cancer has been described by Cimprich (2001). She developed and tested an attention-restoring intervention in post-surgical patients with breast cancer, involving restorative experiences with the natural environment. Participants in the experimental group showed enhanced attentional capacity on various neurocognitive tests and returned to work earlier than the participants in the control group. The research in this area is preliminary and needs further development. Also, the relationship between attentional fatigue and cancer-related fatigue is unclear, since no measures of self-reported fatigue levels were used in the studies (Cimprich, 2001). Neither was a link established between neuropsychologic function and the general sensation of fatigue.

Given, B., Given, C., and McCorkle (2002) conducted a randomized clinical trial to test a supportive care nursing intervention to manage pain and fatigue during chemotherapy in a sample of 113 cancer patients with mixed diagnosis, including stages 1-4. The intervention was tailored to patients' problems and included teaching, counseling and support, coordination, and communication. Pain and fatigue, as well as total symptoms, were reduced in the experimental group, and both physical and social role functions were significantly higher than in control group (Given et al., 2002). The study is well designed such that the researchers determined the effectiveness of the interventions. In addition, the sample size is large and stratified well.

Brown et al. (2006) conducted a randomized study of 115 participants to assess whether a multidisciplinary intervention helped to reduce level of fatigue in patients with advanced cancer receiving radiotherapy. The 8-session structured psychoeducational program included didactic and experiential sessions from a psychiatrist or psychologist collaborating with a nurse, physical therapist, chaplain or social worker, depending on the session's theme. Radiotherapy initially caused a worsening of fatigue but with time fatigue levels returned to baseline. Clinically, the structured multidisciplinary intervention had no impact on fatigue, and there was a suggestion the multiple sessions may have contributed to worsen fatigue during active cancer treatment. The fatigue assessment utilized was a one-dimensional tool and did not assess the various factors causing the fatigue. The sessions were 90 minutes in length which probably precipitated increased fatigue in the participants and subsequently affected their concentration levels to remember the information provided.

An exploratory study by Gielissen, Verhagen, and Bleijenberg, (2007) examined the long-term effect of cognitive behavior therapy in patients who completed the therapy. Sixty eight patients were assessed pretreatment, post-treatment and at follow-up ranging from 1- 4 years. The exploratory regression analysis showed that fatigue severity, psychological distress and somatic attribution at pretreatment contributed to persistent fatigue severity at follow-up. Cognitive behavior therapy, especially designed for cancer-related fatigue, was successful in reducing fatigue and functional impairment in cancer survivors. These effects were maintained after two years completion of cognitive behavior therapy.

Dirksen and Epstein (2008) studied the efficacy of cognitive behavioral therapy for insomnia on fatigue, mood and quality of life in 72 breast cancer survivors. The women were randomly assigned to either cognitive behavior therapy for the insomnia group or the control group. Findings revealed that the women who received the therapy for their insomnia had significant improvements in fatigue, anxiety, depression and quality of life.

A more recent study by Montgomery et al. (2009) evaluated the effectiveness of a psychological intervention combining cognitive-behavioral therapy and hypnosis to treat fatigue associated with radiotherapy. Breast cancer women scheduled for radiotherapy were randomized to receive standard care versus standard care combined with cognitive-behavioral therapy (including meeting with a psychologist) and hypnosis. The fatigue level was reduced significantly ($p = .05$) in the intervention group. The researchers concluded that the cognitive-behavioral therapy with hypnosis intervention was effective

in controlling and potentially preventing fatigue. Limitation of the study was a small sample.

Dolbeault, Cayrou, & Bredart (2009) conducted a multi-site randomized study to evaluate the effects of psycho-educational group intervention. Two hundred and one breast cancer patients were recruited and randomly assigned either to a treatment group, a psycho-educational intervention, or to a waiting-list control group. The eight-week program with two hour classes included thematic discussions and training on stress management. Results showed a significant reduction in anxiety as well as decreased anger, depression and fatigue among the group participants. The psychosocial intervention represents an excellent complement to medical oncology care. This intervention should be tested in groups with other types of cancer and other phases of their disease.

In summary, the result of studies utilizing psychosocial interventions portends lower levels of fatigue in cancer patients who are in active treatment as well as cancer survivors. Studies further suggest that psychosocial interventions are effective in managing cancer-related fatigue whether delivered individually or in a group setting (Given et al., 2002). The benefits of the interventions may continue for months after the program is completed. Conversely, lengthy interventions and excessive number of sessions tend to exacerbate fatigue, especially in patients receiving radiotherapy (Brown et al., 2006).

Pharmacologic Therapy

Several pharmacologic approaches potentially could provide relief for cancer patients dealing with fatigue. The most rigorously designed clinical trials to date have been conducted with colony stimulating factors, epoetin alfa and darbopoetin alfa. Five large community-based non-randomized studies (Demetri, et al., 1998; Gabrilove, Cleeland, & Livingston, 2001; Glaspy, Bukowski, & Steinberg, 1997; Littlewood, Bajetta, & Nortier, 2002; Osterborg, Brandberg, & Molostova, 2002) have shown a clinical benefit of epoetin alfa treatment for cancer-related anemia and fatigue. These studies experiential designs reflect significant findings. However, there are concerns that some of the non-responders were eliminated from the data prior to publishing the research.

A more recent study (Blair, Bardwell, Podbelewicz-Schuller, & Mortimer, 2008) assessed the correlation between hemoglobin and fatigue in women undergoing adjuvant chemotherapy without erythropoieten-agent support. Seventy-five women participated in the study using quality of life questionnaires to assess changes in the need for psychosocial support over time. Participants with high fatigue levels at 2 months had hemoglobin levels 13% lower than those with a low level of fatigue. A larger study group is warranted before suggesting that chemotherapy-induced decline in hemoglobin may be a marker of physiologic reserve.

In a small randomized study, amifostine administered with paclitaxel to women with breast cancer did not affect therapy-induced fatigue (Gutstein, 2001). A pilot study of 12 patients with melanoma who were receiving interferon compared methylphenidate

plus exercise to exercise alone to fatigue levels of historical controls. Fatigue was lower for the methylphenidate plus exercise group than for the comparisons group (Schwartz, Thompson, & Masood, 2002). Both studies include small numbers of patients in the sample and neither assessed the level of fatigue the patient was experiencing using a commonly used fatigue tool.

Few controlled studies have been done to investigate other pharmacologic therapies for cancer-related fatigue. Other classes of medications, such as CNS stimulants and psychostimulants have shown promise in open-label prospective designs, but evidence is lacking in placebo-controlled randomized trials (Burks, 2001). Several other classes of drugs, antidepressants and cholinesterase inhibitors, have been studied for the treatment of cancer-related fatigue. Methylphenidate has been studied considerably and seems to be effective and is tolerated well. Antidepressants studies have shown mixed results. It is suggested in some studies that Modafinil is helpful for patients experiencing cancer-related fatigue. Paroxetine has shown some benefit for fatigue, primarily when depression is present. Bupropion may be beneficial in treating fatigue, and Donepezil may be beneficial in open-label studies (Breitbart & Alici, 2008). NCCN (2009) does not advocate utilizing these agents except in cancer patients experiencing fatigue during terminal phase of illness. Further randomized clinical trials are warranted to determine the efficacy of these psychotropic medications.

Complementary Therapy

A pilot study by Barton et al., (2009) was conducted to investigate whether various doses of American ginseng would affect cancer-related fatigue. A secondary

endpoint was to assess toxicity. The study involved 290 patients and was double-blinded to three doses of Ginseng: 750 mg. 1,000 mg. or 2,000 mg. per day versus placebo; the various doses were administered twice a day for eight weeks. The researchers concluded that there was some activity at reducing fatigue in patients receiving 1,000 – 2,000 mg/day. There were no significant differences in toxicities based on various doses. Further study is warranted.

Role of Patient Education

Prior to 2003, no research addressed the adequacy of resources that have been developed for patients with cancer-related fatigue. A qualitative European study was undertaken to explore how useful educational materials dealing with the management of cancer-related fatigue would be to patients (Ream, Browne, & Glaus, 2003). In their study, focus groups with patients in the United Kingdom and Switzerland were conducted. Findings from the groups fell within two major themes: educational process and educational materials. In the educational process arena, patients voiced that information about cancer-related fatigue had not been provided to them. There also was a perception that healthcare professionals do not view fatigue as important. Participants also stated that education about fatigue should be delivered slowly and gently, allowing patients time to talk, reflect and ask questions. The importance of providing the material verbally was emphasized by the participants. They also stressed the importance of personal contact when providing the information, and suggested providing information on fatigue prior to the administration of the treatment. Participants perceived that

preparation prior to the initiation of cancer therapy would prevent their losing control and increase their motivation to manage their fatigue.

Evidence from the Ream et al. (2003) study also showed that unless patients had access to the educational materials before the session, their effect was "purely an academic issue" (p. 108). The majority of the patients felt that the material helped them; it provided good advice and reassured them that fatigue was not unusual. There also was a discussion of the strengths and weaknesses of various types of educational materials including written material, video resources, poster, and Internet materials. The groups recommended that quality of life issues be included as it was not advantageous to 'fight' fatigue; rather the patient should strive to remain motivated despite it. Ream et al., (2003) participants also felt strongly that healthcare professionals play a major role in facilitating patients' access to materials on cancer-related fatigue as patients were unaware of how or where to locate existing information. In addition, the patients valued the one-on-one teaching methodology as being pivotal to their understanding fatigue. A nurse-led educational session was preferred by the participants because of the therapeutic relationships that are often established between patients and nursing staff (Ream et al., 2003).

Summary

In summary, though several strategies have been studied and implemented in the management of cancer-related fatigue, there is no clear evidence that one strategy will prevent the number one symptom that cancer patients experience. Rather, a combination of various strategies seems to provide the best approach to the management of the

fatigue. Even with the implementation of the various strategies outlined, patients still experience the unrelenting symptom that impacts their functional capacity and their quality of life. Thus, with this evidence, it is imperative that cancer-related fatigue is studied from a phenomenological approach so that researchers have a better understanding of the experience of the fatigue that patients confront. The derived information will serve as the framework for future researchers to embark on more specific and appropriate measures to deal with the phenomenon. Without the answer to this much needed question: "What is it like to experience cancer-related fatigue and how does it impact on the quality of life?" healthcare professionals will continue to study cancer-related fatigue fastidiously, while remaining "blind-folded" to the "essence or meaning" of the experience for the cancer patient. Without this evidence, researchers will fail to understand what the patient experiences, thus preventing a protocol being established to address ways to abate and minimize this debilitating symptom.

CHAPTER III

METHODOLOGY

In this study the experience of breast cancer patients confronting fatigue will be explored and discussed. The existential phenomenologic approach is selected because there first must be an understanding of what the cancer patient experiences with their fatigue before a conceptual framework or practice guideline can be developed to treat and manage these patients. At present there is a lack of distinction between tiredness, fatigue, and exhaustion, despite conceptual differences (Olson, 2007). Therefore, it is important to go into the world of the cancer patient and hear what is happening to those who are experiencing the symptom in order to really understand the experience of cancer-related fatigue.

Existential phenomenology is chosen also because the framework seems to fit with the phenomena of interest as the way the cancer patient experiences fatigue depends upon many grounds, the world of objects and physical space, body, time and other people (Thomas & Pollio, 2002). The experiential meaning to the cancer patient as they deal with their unrelenting fatigue on a daily basis has not been revealed in previous research.

The philosophical perspective of Merleau-Ponty was introduced in Chapter 1, and will be further elucidated in this chapter. Additionally, the rationale for utilizing a qualitative approach to study this number one complaint among cancer patients will be discussed as well as the link between phenomenological philosophy and the method utilized in the study. The procedural aspects of conducting the phenomenological study, such as selection of the sample, data collection procedures, protection of the human

subjects, data recording procedure, data analysis and validating the accuracy of the findings also will be reviewed in this chapter.

Research Design

Characteristics of Qualitative Method

Qualitative research focuses on the naturalistic inquiry into everyday living. Qualitative researchers believe that gaining knowledge from sources that have intimate familiarity with their issues is much more meaningful than the objective distancing approach that characterizes quantitative approaches (Taylor & Bogdan, 1984). Only qualitative research reveals the meaning of what is occurring to those who are experiencing an event or situation. In other words, to acquire the meaning of human experiences, the qualitative method is warranted (Thomas & Pollio, 2002). Additionally, qualitative research views phenomena holistically.

Linking the Phenomenological Philosophy to the Method

To explore the phenomenon of cancer-related fatigue it is essential to understand what are the meaning, structure, and essence of the lived experience of the patient. It is important for the researcher to gain access to the individual's world of experience, and then search for the invariant structures of the individual's experience or their essence of the experience. To properly study human events, the research approach must be congruent with a philosophy designed to encompass human activities. The University of Tennessee approach is grounded in the philosophy of Merleau-Ponty. This approach enables the participants to describe who they are and how they live in their world; as

suggested by Merleau-Ponty, we should always start with the world because it is all we have. He also suggests that experience is the starting point rather than knowledge. Additionally, this approach allows consideration of both freedom, which has its own energy and difficulty, and the responsibility of individuals shaping the situation they are facing (Valle, King, & Halling, 1989). It thus allows patients with cancer-related fatigue to describe their experience of fatigue in their own and unique perspective, including those changes in freedoms and responsibilities that have evolved secondary to the development of fatigue.

History of Existential Phenomenology

The term "phenomenology" is derived from two Greek words: an appearance (phaninomenon) and a reasoned inquiry (logos). True to the origin of the term, phenomenology focuses on the essences of anything that is conscious to us. In other words, it is concerned with the way things appear to us. It is the "taken for granted" perspective which is generally unrecognized as part of the phenomenon. It remains with the person's experience and is often described in two stages: first, the individual providing a description of their experience, and second, the researcher capturing and explicating the experience through the interview and descriptive efforts (Ray, 1994).

The marriage of the two terms, existentialism and phenomenology, evolved from two philosophies that both were concerned about the existence of human beings. In the aforementioned historical perspective, one quickly recognizes that existentialism can be traced to Kierkegaard from the 19th century in which there was recognition that man's everyday existence is important. To further the amalgamation of questions pertaining to

human existence as well as a method to study existence, Merleau-Ponty further defined the path of existential phenomenology. He delineates his perspective by stating, "All my knowledge of the world is gained from experience of the world." "To return to things themselves is to return to that world which precedes knowledge" (Merleau-Ponty, 1962, p. viii-ix). Merleau-Ponty suggested that his perspective seeks to appreciate an understanding of a phenomenon in the everyday world as well as assessing experiences and meanings of these experiences of the subject of interest.

Important to understanding existential phenomenology, one must appreciate that human existence (consciousness) includes two features, figure and ground as well as intentionality. Intentionality is the fundamental basis of the world and humans; whereas existence always connotes that we are in the world, and in that setting is where we humans know ourselves. Furthermore, it is in that venue that we understand that man cannot be taken out of the situation.

Figure and ground are equally features of the human experience. "Standing out" is another way of defining existence. This emerges as a figure against the ground, which tends to stand out. As described by Thomas and Pollio (2002), when viewing the "face and vase" drawing, only one aspect of the picture is in focus at one time. Conversely, the area not in focus is the background. In other words, one does not exist without the other, but one seems to stay in the background until we have a direct experience with that particular subject, object or experience. Thereafter, we integrate that important item or experience into our armamentarium such that it becomes more figural for us. It becomes more meaningful for us because we notice it more frequently. It is important to recognize

that these concepts of figure and ground are fluid; sometimes the figural perspective retreats to the ground, a secondary position, and ground becomes figural. Whatever that person conveys important as standing out conveys what is meaningful to that person. Obviously, ground and figure are different components of the same experience; they do, however, provide a forum for describing and contextualizing a human experience (Thomas & Pollio, 2002, p. 18).

The researcher learns what is figural and what is contextual through face-to-face dialogue. In the following section, the procedure for conducting interviews is described.

Procedure

Interviews were conducted in a quiet, private place that was mutually acceptable to the participant and the researcher. The researcher was cognizant of the lack of energy these patients experienced; therefore, she offered to visit them in their home if that was acceptable to the patient. Emphasis was placed on the setting promoting a comfortable environment for the patient since fatigue was such a debilitating symptom. The patient was asked to describe how it is to live with being tired. An audiotape recording of the participant describing their experience of living with fatigue was recorded. At several times during the interview the researcher summarized what had been heard. The face-to-face interviews were conducted either in the participant's home or their office, lasting approximately one hour or until the participant had no further information to share. After the interview was completed, field notes were summarized by the researcher in the format of audio taping the experience. Thereafter, a paid transcriptionist who had signed a confidentiality form transcribed both the interview of the patient as well as the

researcher's field notes. Then the researcher and the Interpretive Research Group at the University of Tennessee read the transcript for meaning units; it then was reviewed with the interpretive process, using the part-to-whole process (Thomas & Pollio, 2002).

Sampling and Data Collection

The design included studying twelve breast cancer patients with stage I and stage II breast cancer that had completed chemotherapy regimens and radiotherapy. Participants who had co-morbid chronic diseases such as heart, diabetes, and autoimmune diseases were excluded from the study. Diversity in education, cultural background and age were considered during the accrual process. After five interviews were completed, there was evidence of redundancy. A sixth interview was completed to ensure that saturation had been achieved as described by Denzin and Lincoln (1998).

The study continued over a six month period after a pilot interview was conducted to test the question and to assist the researcher in identifying areas that needed to be rectified. As noted in Table I. the sample consisted of six women, ages 36 - 60 years. One-half of the women had stage I breast cancer and the remaining three had stage II. All participants were Caucasian and married; however, one participant divorced one year after completion of her treatments. Five of the women had children, and all the women worked outside the home. Their treatments had been completed from one to five years.

Table 1. Participants

Name	Age at Diagnosis	Stage of Breast Cancer	Number of Children	Occupation
Linda	48 years	Stage II	2	Owner Hair Salon
Beth	36 years	Stage II	2	Graduate Student
Judy	60 years	Stage I	2	School Teacher
Jan	49 Years	Stage I	0	Executive Secretary
Elizabeth	55 Years	Stage I	1	Business Executive
Susan	38 years	Stage II	3	Human Resource Associate

Participants

Each participant was very excited about sharing their experience of dealing with their fatigue. The women conveyed the importance of sharing their story in hopes of helping future breast cancer patients deal with the unrelenting fatigue they each continued to experience. As listed in Table 1, the participants included the following:

Linda is a 48 year old married female who owns a hair salon. She described herself as always being extremely healthy and was shocked when she received breast cancer diagnosis. She is the mother of two children and has two grandchildren.

Beth is a 36 year old divorced mother of two children. She also is a graduate student and continues to struggle with overwhelming fatigue five years after treatments were completed.

Judy is a 60 year school teacher, a mother and is married. She has two daughters and three grandchildren. She was overwhelmed not only with the diagnosis of breast cancer but the unrelenting fatigue that incapacitated her.

Jan is a 49 year old executive secretary who is married and has no children. Jan described the fatigue as devastating, but admittedly shared she should have taken more time off work because she did not function well.

Elizabeth is a 55 year old business executive. She is married and has one son in college. She described the fatigue experience as "devastating……and three years later, it continues to be devastating to my life".

Susan is a 38 year old mother of three. She is employed by a Human Resource Company. Although the fatigue was overwhelming to Susan, she attempted to incorporate her family and friends into helping care for her.

Bracketing

Prior to the interviewing process of the patients, a bracketing interview of the researcher was completed and the interpretive research group facilitated the bracketing by discussing identified assumptions made by the researcher. One interview was completed in order to "set aside" knowledge, proposed theories about cancer-related fatigue and various assumptions about the phenomenon. The presuppositions and biases held by the researcher about cancer-related fatigue are that it is the most debilitating symptomology the cancer patient experiences. It is also believed by the researcher that the phenomenon is multifactorial and impacts greatly on every domain of the patient's quality of life. It is

assumed that cancer-related fatigue is so overwhelming that the symptom of fatigue may be worse that the disease. It is also believed that unrelieved cancer-related fatigue leads to depression and despair and reduces the patient's will to live. It is also the researchers' assumption that minimal interventions can be done for the debilitating symptom, and that it is a most frustrating symptom not only for the patient but also for the family and the oncology healthcare team.

Protection of Human Subjects

Permission for the interview was obtained after the patient had completed both chemotherapy and radiotherapy. Since the debilitated patients were considered a high risk population, ethical consideration was given individually for each patient ensuring that if they were too fatigued to participate, they had the option to terminate their commitment. Assurance was provided to the participant that confidentially was maintained as they may voice discontent about their healthcare professionals for not addressing their fatigue. In addition, the researcher respected the needs, rights, values and desires of the participant (Creswell, 2009). With approval from the University of Tennessee Institutional Review Board, participants were recruited from local community support groups. An explanation of the study was provided to interested participants. If the patient was interested, a consent form was completed, and an appointment was set up to conduct the interview at the participant's convenience.

Data Analysis and Interpretation

The data was scrutinized for meaning units and metaphors. The data analysis proceeded through a methodology of reduction, the analysis of specific statements and a search for all possible meanings (Creswell, 2009). Then major themes were clustered, and the thematic structure was developed and refined. Subsequently, a general description of the experience was completed by bringing together these transformations. The thematic structure was submitted to the original study participants who determined whether the overall findings were reflective of their own individual experience. Then the findings were reported to the participants and the final report was completed (Thomas & Pollio, 2002). Since validation of the findings occurs throughout the research process, it is important to recognize the importance of rigorous implementation of this process.

Rigor of the Study

Since the premise of a phenomenological study is to search for understanding and meaning with the consideration that no truths or facts are separate from the experience, it is essential and logical to ensure rigor of the analysis of the phenomenological study. Ensuring rigor of the study of cancer-related fatigue includes a vigilant and systematic means of gathering the relevant data that are accrued from the interviews. In addition, there is a disciplined interpretation of the transcripts, not only interpreting them individually but also participating in the interdisciplinary phenomenology group that meets weekly at The University of Tennessee College of Nursing. In the group meetings, transcripts are read aloud, and tentative interpretations are offered. The perspectives of group members provide alternative ways to consider the words of the text. Through the

group interaction there is a confirmation of stable empirically derived results from the interviews.

There is credibility as the study is carried out methodically while conducting the interviews, collecting the data, transcribing and reviewing the data. Prolonged engagement and persistent observation to ensure sufficient time to collect the data and to understand the patient's perspective also produces more credible data. Additionally, the interviewer was vigilant and methodical in conducting the interviews and reviewing the transcripts and was available to be critiqued by the research team.

Dependability of the data was reflected as interviews continued to be completed until there was evidence of redundancy. In addition, to ensure the established criteria set up prior to the initiation of the study had been met and to guard against bias, an audit trail was done to include the collection of the transcripts and a record of meetings to discuss the transcripts. The group discussions about each transcript were recorded.

Validity was ensured by making sure the cancer patient's description about the phenomenon of fatigue was reported as "convincing evidence brought forth in favor of the description offered" (Thomas & Pollio, 2002, p. 41). The structure was similar from the standpoint of the researcher and the readers of the interviews (Creswell, 2009). Validation was confirmed by using the weekly interdisciplinary phenomenology group at the University of Tennessee to review the transcripts and ensure the interpretation as being valid and trustworthy. Members of this group had analyzed the researcher's bracketing interview and were vigilant regarding any possible evidence of bias.

The ultimate validation of a phenomenological study is its reception by the professional community. According to Thomas and Pollio (2002, p. 57), "validity depends on the significance of the information gleaned" and "how well it convinces the reader of its accuracy" (Thomas & Pollio, 2002, p. 41). As Sandelowski stated: "validity resides in the utility"; to be valid, it must be useful (Thomas, 2004, lecture notes).

Because the structure of the experience of cancer-related fatigue was identified, transferability to other breast cancer patients may be possible. Subsequently, the goal is to provide information which may be useful to healthcare providers in the clinical practice setting and help them develop strategies to help patients manage their fatigue.

Summary

The phenomenological approach to studying cancer-related fatigue provides an understanding, or the essence, of the unrelenting symptom. The outcome of the study is to equip the healthcare professional to better understand what it is like for the patient to experience cancer-related fatigue. With this understanding, strategies can be implemented to improve the cancer patient's quality of life. It is important to study the problem of cancer-related fatigue by entering the patient's world, seeing how they experience, live, and display the cancer-related fatigue as well as learning how they perceive the meaning of the experience of their fatigue. It is critical to understand from the cancer patient's perspective what it is like to experience cancer-related fatigue and, furthermore, what it is like to live with cancer-related fatigue and how it impacts on the patient's quality of life. Although we may be unable to fully understand the world of the cancer patient, with reflexivity and vigilance in the pursuit of qualitative research, we are

able to interpret what the world is like for the cancer patient experiencing the overwhelming fatigue if we are respectful of their language and story. It is hoped that pursuing a qualitative approach in seeking to understand the phenomenon of cancer-related fatigue, this research will speed knowledge development about this pervasive and distressing phenomenon. Thus, the findings may lead to nursing interventions that can enhance the cancer patient's quality of life.

CHAPTER IV

FINDINGS

While the cancer patients' specialists continue their vigilant watch to prevent recurrence of the malignancy post-treatment, patients share a totally different perspective on their primary focus as they navigate through the cancer trajectory. They continue their daily struggle of living with unrelenting fatigue, which impacts every facet of their lives. The lived experience of ongoing fatigue during and post-treatment greatly impacts the women's quality of life. These patients face profound physical, psychological, social and financial challenges as they continue to live with the most common and distressing symptom, fatigue, that seems to persist long after the treatments are completed.

We know that, for better or worse, cancer changes lives forever and in a multitude of ways. For these breast cancer women dealing with ongoing fatigue, their lives have been changed in dramatic ways, even causing some to question their identity. These women question, "Who am I?"; "It's not my life anymore." and "Where is my old self?" Questions like these were foreign to these participants prior to receiving the diagnosis of cancer. These women are married, have children, and work outside the home. They were very active and employed full-time, either professionally or as owners of businesses. They were very involved in their children and grandchildren's lives. These working mothers also were very involved in their communities, not only being soccer moms but some were active in church and school activities. Then there was a sudden shock and disbelief of receiving the news: diagnosis of breast cancer. Immediately their

thoughts focused on survival: “Am I going to die?” They also questioned who would care for my family if I die? There also were fears surrounding the treatments, perhaps including financial concerns about the inordinate costs of cancer care. There also were fears of pain and suffering….”not that I am afraid to die, rather how will I die?” There were concerns about dealing with the side effects of cancer treatment; however, these were fleeting thoughts as they were self assured that the side effects were short-lived and dealing with the symptoms would be well worth it to be cured of one’s breast cancer. Their healthcare professionals reinforced these sentiments; they assured the patients that supportive care would minimize/alleviate the side effects from the therapies. This, however, was not the lived experience for these women. Yes, their lives did change…..never to return to the pre-cancer status of their life’s course.

Figure 2. depicts the figural themes of the women’s experience of fatigue. Before explaining the figural themes, the contextual ground “Shadow of Death” will be described. Dealing with the prevailing and profound fatigue has entrenched these women’s lives with an overarching sense of living in the “Shadow of Death” (the contextual ground). Surrounding their daily lives are constant reminders of their cancer and the sequalae of their treatments.

They search for meaning and freedom from being “exiled on an island with their fatigue” and hope to regain some normalcy in their lives. Yet, as much as five years later, these women struggle with the one symptom that connotes that “They saved my life, but it’s not my life anymore…..I am never going back to my ‘old self’.”

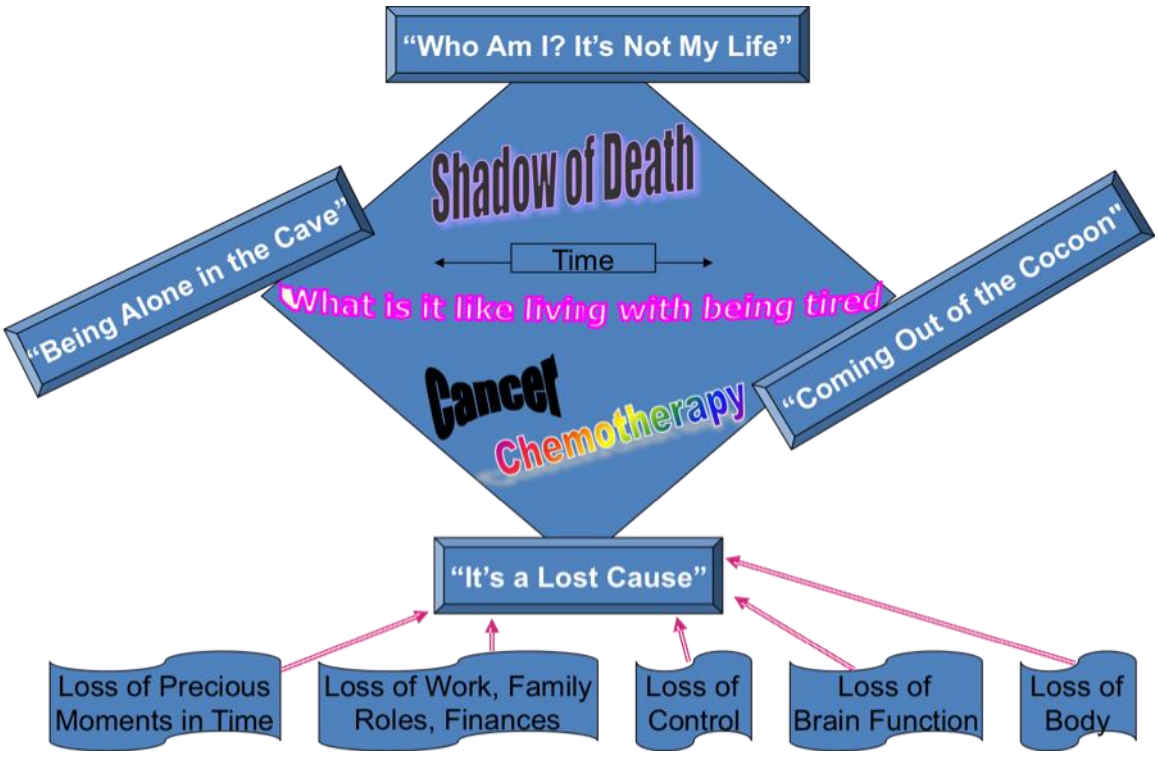


Figure 2: Contextual Ground of the Experience of Fatigue: Shadow of Death

The constant reminder of the "death of my body I once knew" is promulgated by the treatments the women received. They conveyed that they were not worried about their breast cancer, rather, the way the treatment made them feel. The treatments were described as terrible and were characterized as "brutal and violent." Their descriptors of the experience were: "chemotherapy poisoned me," "it robbed me of my body," "Chemotherapy was not my ally," "Chemotherapy and radiation therapy beat me down." In the words of one participant, "My body knew chemotherapy had tapped every single piece of me…there was nothing left of me." They also resented what the treatments did to their body as well as how it impacted them financially: "It wiped me out financially and I probably will never recover!"

The patients felt their bodies deteriorating as they dealt with the fatigue. The effects were all inclusive: "Besides tapping on my whole body, it plays with my head also." In addition, they questioned the residual effects from the unrelenting fatigue: "Since it lasts forever, does it increase my risk for a recurrence?" It is noteworthy that these women conveyed a sense of appreciation for surviving this catastrophic event; however, there is a lack of gratitude for the oncologists treating their breast cancer successfully. As one patient shared: "I am grateful for the era (21st century) in which I received my treatment, but I am coping with it for the rest of my life."

While the completion of therapy is an important milestone in the successful treatment of cancer, these survivors find themselves facing a variety of challenges as they continue dealing with their fatigue. These women had confronted the stark reality of possibly dying from their breast cancer. Fortunately, they survived without any recurrences. Yet, though survived, they question, "Who am I?" They described themselves:

> I look like walking death and Frankenstein's bride." Another patient described herself as "scary with no hair, eyelashes, eyebrows…..my breast had been taken off…..I was pale…..I was no longer a woman….I kept telling myself: "self, don't think about it."

As another patient described her experience of "trying not to go stir crazy" it becomes apparent that the patients had sensed a level of death as they viewed their bodies differently and questioned their own destiny and identity.

Though the physical body was insulted greatly by the fatigue as they mourned the loss of what the body was to what it is now, their world and their relationship with others as they once knew it also was greatly impacted in the daily lives of these women. As described by one of the younger mothers:

> Living with fatigue is part of the weaving of the fabric of my life; while weaving, it is never a complete tapestry….there are lots of holes and imperfections in the weaved fabric…there are lots of unusual colors of thread woven in certain parts of the fabric…some are pink…some are green….and they really are not part of the selected threads to weave the tapestry. Yet, there is a common thread that runs through the fabric….that common thread is the "Sisters in My Sorority" that belongs there. These sisters understand me because they, too, are living with the fatigue that impacts our daily lives in ways that I cannot even describe how horrible the fatigue is (Beth).

These "threads" that appear to be woven throughout the fabric of the lives of these fatigued breast cancer patients emerge as four figural themes. The themes are: "Being Alone in My Cave," "Coming Out of the Cocoon," "It's a Lost Fight," and "Who am I Now? It's Not My Life"

Themes

Theme One. "Being Alone in My Cave"

Participants described overwhelmingly loneliness and despair experienced during their fatigue, and these feelings served as reminders of how sick they were. Their fatigue made them feel "insecure, dependent, self-doubting and incompetent." They felt "beaten down" and "kicked in the butt" and made to feel that a "Mack truck had run over me" as well as being "rammed into a brick wall." They often described the fatigue as the "walls were coming down" and "it made me stop in my tracks." There also were feelings of "insecurities, ineptness, guilt, helplessness, defeat, worthlessness, incompetency," and a sense of "being out of control." Coupled with these overwhelming concerns, patients felt their fatigue was not fixable because it made them feel horrible. Additionally, women reported that their healthcare professionals did not assess their fatigue nor did they offer assistance when the patient mentioned their fatigue.

The unpredictability of the fatigue often made the patients cry and "feel bummed out." Because of the sense of "permanent exhaustion" the patients felt a sense of "doom and gloom"…sensing that death had occurred to a part of their life. There was a sense that "I should be doing better" but there was an "on and off switch" that impeded the patients doing anything other than vegetate. There also was a sense of "being on a roller coaster" with the evolving emotions precipitating "sadness, disappointment and depression."

Participants reported sleeping the majority of time. Their sleep patterns varied widely; some patients slept a two-day stint and others slept eleven days at one time. One

patient described “Getting chemotherapy on Monday and waking up on Friday.” When they were not sleeping, they described the fatigue as “making me just sit and stare at the wall” or the “fatigue was so overwhelming it was indescribable.” They also described “going to my cave as I was down for the kill.” The majority stayed in bed the entire time while undergoing treatment, whether they were asleep or not; it was their way of “dealing and surviving the ordeal.” They voiced concern that often they were so exhausted that they were “unable to talk, eat or even keep their eyes open.” They often became angry with their family because of their exhaustion:

> I was angry with my three-year-old daughter because I was so exhausted; all I wanted to do is sleep. I would put a movie in DVD player and hoped she would be entertained while I slept.

Most patients described receiving their chemotherapy and “staying in my cave” for several days until they felt better. While in the cave, time surfaced as very important to these women. The fatigue was described as “lasting forever; it seemed like an eternity.” Days were described as “like a million years” and “nights were even worse” with darkness being described as “being in a tunnel” and “even getting in and out of bed took me a half day.” Some described the exhaustion as being so overwhelming that “I knocked myself out most of the time”; “it lingered on and on and I could not shake it.”

It is noteworthy to appreciate these women never felt normal as their lives evolved from being “a normal working mom” to a woman dealing with fatigue on a daily

basis…this became commonplace for them. They always felt their life had been taken away from them because of the unrelenting fatigue. They described feeling that "I will never return to normal; I feel defeated, it is a lost fight."

The women also retreated to their cave because of their disappointment in self. They sensed their body being recalcitrant as they described "my body not responding and not holding up its part of the deal." Mundane physical activities became overwhelming as one patient shared, "It was a huge effort to crawl into my recliner; I had expectations of myself but could not do them because I had no energy."

The world became restricted with the women retreating to their caves. The narratives of the women reflected loneliness and despair as they moved to their caves: "I wanted to be alone; I cried when I was alone; my bedroom was my cave." Linda also related, "I didn't care…I was in my cave and I would sit and stare…I just wanted to forget it…I needed space from other people."

The existential ground of "other people" also became restricted as the women described "feeling totally alone with no one there to help me through the ordeal; it was my battle and I felt closed off from my family." It also affected the family system as Susan and Linda described, "being removed from family and friends and sensing a terrible heaviness and burden to carry all the time." They also shared a sense of frustration that they were unsure others recognized how badly they felt.

Participants also "felt out of control" in everything that happened they had "no control of the situation." In many ways that felt robotic as they described "having an on and off switch" and "I had a 'turn off' mode, and my family knew to leave me alone so I

could get plenty of rest." They also felt out of control emotionally as the young mother described her fatigue: "The more fatigued I became the more moody I became….I would eat people for lunch and then feel very guilty about it."

The patients viewed their fatigue as a "permanent visitor" and as "a new way of life." In essence, the patients summarized the fatigue as "changing my life; it is not the same, not in any form or fashion as it was before, not physically, emotionally, spiritually, socially or financially." To deal with these life-changing events, often their only recourse was to retreat to a quiet place, "being alone in my cave."

Theme Two. "Coming Out of the Cocoon"

As the overwhelming fatigue began to lessen, the patients described beginning to engage in the outside world, though they were trapped in bodies that were not working as they would have liked to participate in life. As they began to integrate back into "being a human being again," they described the experience as "coming out of the cocoon." They were the first to admit they were not fully recovered as one patient shared, "I still felt subpar, I was below baseline." While functioning minimally, they were nonetheless elated to begin integration into society. Often they described looking for "small windows of hope," such as watching children get off the school bus or listening to birds singing. Beth even questioned how fatigue had affected her motivation in some activities as she described:

> Feeling warped because I 'enjoyed' going for my chemotherapy treatment because someone was taking care of me without me having to ask for

everything…it also was the only time that I could rest for 4-6 hours without feeling guilty that I couldn't do things….it was a respite for me….I didn't feel incompetent during this time.

The patients recognized their limitations as they transitioned into previous roles. One patient described feeling like a "rubber band…I made an effort to help my son with homework, but I could not do it….I kept bouncing back like a rubber band into my wiped out mode." Others described the ongoing fatigue as "a wave…my body wants to move forward and in doing so, it is washed back…..I just wanted it to move forward but the waves kept getting bigger and bigger and pushing me back."

Quickly the women recognized that increased time was required to complete minor tasks. One patient described the feeling as "being in catch-up mode all the time." Another patient, Linda, described, "It's taking me five times longer than normal to complete things." Even completing personal hygiene was difficult for the majority of the women. Some stated they were unable to complete simple tasks, such as shampooing hair, and others shared that an inordinate amount of time was required to shower because they had to sit down and rest several times before they were done. Three women shared that after showering they slept for the rest of the day.

The women discovered that their level of enjoyment had changed while they were hibernating in their caves. One patient described the change as "What typically was pleasurable or comforting….now it is a burden or energy draining." She continued by sharing the example of always enjoyed attending her children's soccer games but found

them to be overwhelming even if she only attended the game and skipped the pre- and post-game activities. Another patient related an instance of taking her niece to an amusement park they visited frequently; while there, the participant became so exhausted she could not pick up her foot to take another step; subsequently, she lay on a bench in the park for several hours while the family enjoyed the activities. Other patients felt it was not worth "getting dressed and going out" as it demanded too much energy.

Though the fatigue persisted, women exhibited fortitude and tenacity. One of the participants, Linda, shared that though she could hardly walk into the grocery store with her husband, "I refused to ride in a cart." She also shared how "peering through the window panes" helped her to have hope; however, though she was becoming integrated back into the world she still removed herself from being active in the world. Examples cited were taking a ride in a car and watching the children get off the school bus or driving along the street enjoying the beautiful spring flowers. She also enjoyed doing mundane activities such as riding to Wal-Mart and the drive-in at Sonic. Her appearance was extremely important to her; therefore, she did not get out of the car as "I looked like death warmed over." She protected herself from the world, at the same time peering into it…..through a "window of hope".

In the throes of what they perceived as being "permanent exhaustion," these women conveyed an inordinate level of motivation and persistence. They described having layers and levels of being tired. They shared how they kept peeling the layers off to find that fatigue was still there. Once the last layer was removed, there was a huge

disappointment to realize the fatigue was "lingering on" and sadly they admitted, "I never knew how tired I was until I dealt with this unforgiving exhaustion."

Even in the midst of "being wiped out with fatigue" those who spoke persevered. Jan shared:

> My boss depended on me; I am unsure he could do anything without me. I somehow drove to work totally exhausted, walked into the office, collapsed at my desk and sat there all day. I think he knew I was wiped out; so he assigned my work to my colleagues. The only thing I had to do was answer the phone….I could not even pick up the phone…..it was too overwhelming. I only missed 29 days of work during my treatments; in all honesty, I should have not worked at all because I didn't feel like it.

Though the interviewed women continued to work, there was a sense of "not caring" about the quality of their output because they felt so exhausted. One of the patients, Judy, shared that in the past, when she assigned her educator colleagues to help with a project, "I am standing over them like a hawk ensuring that everything is perfect." In contrast, she admitted, "While I was undergoing chemotherapy I would pass projects off to them and never checked with them to ensure everything was going OK because I really did not care!"

As the women "transcended from the cocoon" there was a sense of disconnect. Beth shared that she felt disjointed and there was:

> A separation of my body and me…..I didn't feel like myself….I am struggling to regain but no matter what I do, I am unhappy with myself…I am very disappointed that self will not do anything…I wanted to cook but I was too tired to even think about it.

Others questioned how this persistent fatigue had overtaken their body. They conveyed feelings of "what once was" to "what it is now." They shared, "How can this be happening to my body?" Judy shared, "I have always been extremely motivated," a "workaholic", a "big driver," and proud that I could multi-task while teaching in high school and caring for my family.

A subtheme that emerged as these women were reintegrating into their roles is "the desire to but cannot muster up the energy to do." Several of the women shared stories of their attempts to participate in activities that were "near and dear" to them. A young mother, Susan, shared her disappointment in being unable to shop with her children at Christmas. She continued:

> It was Saturday morning and we all were so excited about shopping…I attempted to get out of bed and my body would not budge…I attempted again to no avail…I spent the entire day in bed crying…

> Normally, I sang in the choir…I could not sing during the Christmas Cantata because I felt that I was drawing attention to myself as my choir colleagues were so concerned about my energy level…they thought I would literally crumble to my feet during the performance!

The women who spoke were proactive in attempting to manage their fatigue as their body attempted to recover. Elizabeth described frustration in trying to exercise to reduce her fatigue:

> Walking, as I understand it, helps those of us who are fatigued….let me tell you….when you are so exhausted you cannot even think…..exercise is not possible…..I tried real hard to walk everyday and I crashed every time.

Even doing activities to enhance one's sense of well-being seem to minimally improve their fatigue. Another patient shared: "I tried to feel better by getting regular massages but I was still tired when I finished; it may have taken the edge off a tad, but I still was just as exhausted." Others described that no intervention helped them: "Nothing helped the fatigue…I mean nothing overcame it…I progressively worsened at times and had to go back into my respite spot, my bedroom."

Most, even while attempting to recover from the fatigue, described it as "being overwhelming in every aspect of life….even eating out…..shopping…it was a disaster….looking at racks of clothes, trying to figure out the correct size, color…..I just

could not do it!" Though they left their cave and emerged from the cocoon, life and living had changed dramatically….and the majority stated that perhaps for a long time.

Theme Three. "It's a Lost Fight"

There were significant and major losses identified among the breast cancer patients as they dealt with their persistent fatigue. They lost their freedom, as they could not make choices because of being too tired. They had no drive to fight their cancer, as typically one would expect in an oncology patient. In fact, "this permanent visitor called fatigue" had caused them to lose control. The fatigue impacted every facet of their life, including physical, mental, emotional, spiritual and financial aspects. No matter how small the task to complete nor how hard they worked to accomplish an assignment, they did not succeed. In other words, it seemed their "losses" filled their days with disappointments and despair. The fatigue seemed sequential and eternal as the patients worked to overcome the challenges. The losses were so overwhelming this major theme is foundational to all other identified themes. Because of the prevalence of the losses, subthemes emerged and are identified as: *"Loss of Body," "Loss of Brain Function," "Loss of Control," "Loss of Family Roles, Work, Financial Status" and "Loss of Precious Moments in Time."*

Subtheme One. "Loss of Body"

The women graphically described how riddled their bodies became as the treatments usurped every tiny molecule of energy their body produced which resulted in only "gas fumes in my tank." They described themselves as having no energy, not

enough to open their eyes or to lift a glass of water from the bedside table. One patient shared: "I had no energy to talk; I didn't even want to think; everything required more energy than I had; I didn't want to do anything."

Another patient described not being able to function: "I was so exhausted I could not even make a grocery list for my husband." Yet another patient described the fatigue as "unbearable"; "it is really extreme"; "I planned a Christmas party and my family had to do everything….I could not even mail one Christmas card." Their lack of energy caused them to be unable to participate in activities with their family, including dining with their loved ones at mealtime. The majority of the patients preferred to "remain on the sofa rather than eating…that's how tired I was." They admitted to consuming minimal food, as the fatigue was so severe, "it took my appetite away."

They viewed the body as betraying them and being left with a recalcitrant body that could not be controlled; it made "me feel like I was not even a woman."
One patient, Beth, stated:

> My body said: you can push me so far and then I am shutting down…This prevailing tiredness caused an "extreme heaviness on me…I felt like I had twenty pound weights on my extremities.

The patients also were concerned about long-term effects of the fatigue and whether it potentially increased their risk of a recurrence. Beth continued by questioning:

> How incompetent is my immune system? ...I am so afraid of succumbing to some overwhelming infections because the fatigue has affected their immunity big time.

Their bodies not only deceived them but their independence was taken away causing them to feel "helpless and defeated." They also felt worthless because their "permanent exhaustion" interfered with their completing their normal activities. Not only did their bodies fail them but not matter how hard they tried, they could not overcome the fatigue. They talked of struggling to fulfill their role as a mother, to complete an important project at work or to drive to the grocery store. One of the patients, a student, shared that her exhaustion caused her to fall asleep in class. She continued by stating she pushed herself, and it required an inordinate amount of effort just to make it through class.

They also experienced ambivalence about their bodies, especially when their bodies failed them. One of the patients described "loving my body at times, and at other times I wanted to leave it…all I got out of the treatment was this fatigue…I cannot determine whether the treatment was worth it…my body is not holding up its end of the deal." Another patient stated: "I am very disappointed because self will not do anything."

Because of the overwhelming fatigue, the women were emotionally exhausted. Their fatigue was onerous; there was nothing that either helped nor was anything pleasurable in life, mainly because they were constantly fighting to overcome their tiredness. They admitted to struggling to become happy but were unsuccessful in

achieving this goal. They also shared that many of their feelings were kept secret because "no one understood me." In fact, one of the patients admitted to "being lost and having no feelings."

It is paramount to appreciate that no matter how much energy was exerted by these women in an attempt to complete tasks, all failed! Their failure to perform activities precipitated more feelings of self-doubt and defeat. In addition, their inability to remain active caused them to feel guilty, worthless, and helpless as they became weaker. They described these feelings as making them feel "stuck" and realized that "no matter how much mind over matter you tried to do you couldn't master it," Susan shared a story of how her husband attempted to improve her well-being but did not help her:

> Bob played easy listening music to help me relax. The lit candles were nice but really didn't help and neither did the lavender bubble bath. Even with these niceties I still was too tired to sleep. I couldn't concentrate on TV or reading…so I would lay and stare at the walls.

Subtheme Two. "Loss of Brain Function"

The impact of the cognitive changes these women experienced during and post-treatment affected them immensely. In fact, all study participants spent more time discussing their fears and concerns about changes in their memory than all other issues combined. These changes affected their decision-making and problem-solving ability as well as made them question their confidence, competence and self-esteem. Several of the women described themselves as "going crazy because I could not remember," and found

these changes to be very frightening. Cognitive impairment impacted greatly on their quality of life. Not only did it affect them physically but also emotionally, socially and financially. Beth shared:

> My thinking was affected big time…I was and am in a fog and I finished all my treatments two years ago…to this day, I blame my memory on chemotherapy.

Another patient, Elizabeth stated:

> Oh, it is really scary, that's scary because I'll think of one word but sometimes another word comes out. My friends always try to make me feel better by saying, "Oh, we can't think at times either." But honestly, I think it's really, really worse, I do. And sometimes it scares me, I think, oh my gosh, I think I'm in early Alzheimer's. I think my husband recognizes it too; he never says anything. I am losing my keys often and he just quietly starts looking for them and when he finds them he doesn't say anything…I remember the first time I wrote a contract after I finished chemotherapy. I ask my co-worker to check the document because I was not sure my thinking was good enough to do something so important. So I really lost confidence doing everything, even driving. It took me several months to start feeling more confident enough to drive, even locally, and two years later, I am still uncomfortable driving out of town, though I may be familiar with the area I a

going…..its like I don't have a recall of places I used to drive to all the time.

Beth shared the changes in memory that affected her greatly, especially while attending school:

> My eyebrows and eyelashes started to grow back and I kept thinking, OK, you ought to feel good…and it would be, you tell me something and if it didn't have a long-term memory attachment to it, I couldn't remember…and sometimes just trying to remember stuff, I became exhausted…like studying for an exam…I shoved information in my brain and it wouldn't stay…like I have taken the Graduate Entrance Exam three times and cannot pass it…I have problems with holding on to memories, remembering to go to grocery store to get milk…to, to try to remember all that was exhausting….it was like mental fatigue…And it is scary, if I already have all these memory problems at my young age, what will I be like with age dementia?...So I am already doing things that stroke patients do to remember…like making checklists in the morning. I find myself asking, "What has happened to my neurons?...What have these drugs done to my brain and how can we train my neurons to hold on to information again?...What happens if my body doesn't rejuvenate…its not functioning like it did before they dumped that entire toxin inside of me…If we hadn't done it, there may be a chance I wouldn't see my daughters walk down the aisle…So I'm not saying I shouldn't have done what I did…But there's a level of, was it worth it when I think how it has affected

my memory."

The patients describe their daily activities being affected by everything "slowing down" with their thought processes being significantly affected. They often described cognitive effects from the chemotherapy and coined the term "chemo brain" because they felt "fuzzy about details" and "everything was hazy and blurred." They shared that the brain only "functioned partially at times."

Another patient, Susan, shared how difficult her daily life was dealing with the "chemo brain":

> There were things I could not think through…even a menu…I couldn't think through what to do once I got to the grocery store….I would just wander around for an hour and finally go home without groceries…It definitely affected my thought processes…It made it real hard to think all the way through things…Most of the time I could think but I had to do it more methodically, more deliberately…much more slowed than before…it was terrible… It was like I was always looking through a fog…So, you really had to concentrate on who's talking to you and what they're saying to you….otherwise you would get lost.
>
> It wore me out to concentrate…I couldn't think through long enough to help my children with their homework…My mind would get tired…To really describe the true impact of my fatigue is impossible…I couldn't concentrate long enough to read a whole book…I ended up reading short stories, devotion books, Reader's

> Digest…After reading the last chapter in a book, I couldn't recall how the story ended…I couldn't even concentrate on watching my favorite TV shows, not even commercials.

Not only were their daily activities affected as their cognitive status continued to change, some of the patients shared experiences of having total lapses of memory. Judy shared the following story of her family planning their traditional Christmas party in which they invited several family and friends. She recalls being totally exhausted though she rested throughout the party. Several weeks after the holidays were over, her husband shared the photographs of the party. Judy questioned the taking of the photographs. Not only did she have no recall of photographs being taken, she did not remember having a Christmas party! Other patients shared driving to and from their physicians' offices and not recalling how they got home.

The women discussed the difficulties with having memory problems. They described themselves "as looking ok" but, instead, they shared they were so exhausted they could not think. They also described as "getting lost because I was trying to think…it was too fatiguing to think...I could not focus; I was at a level where I consciously had to think about thinking, such as holding on to a thought." The only way they managed their memory problem was to make lists, even to manage their doctor's visits. One patient graphed her lab values and test results as she felt that was the only recourse she had "to keep things straight in my mind." They continued by sharing how they "felt like I was going crazy because I could not remember things." Several shared

that their body was not as tired as the mind. Others described not feeling coordinated, coherent or connected. It was hard for "words to come….I did not want to think…it was too exhausting."

Subtheme Three. "Loss of Control"

The patients perceived that the chemotherapy administered for their breast cancer violated their bodies in many ways. As a result, their body's integrity was not intact and had resulted in impacting various aspects of their life. They lost control of their body, their relationship with others, their ability to fulfill previous roles as well as their inability to complete their job responsibilities.

First, they lost control of their bodies. The women described their bodies not functioning properly by stating, "My body does not respond and it is not holding up its part of the deal." Another patient remarked: "My body says I am shutting down because I have pushed me too far." "There was desperate isolation and betrayal by my body" shared another patient. "I am very disappointed that self will not do anything." As mentioned previously, regardless of how committed these women were to "making their bodies work" they were unsuccessful. They pushed themselves, trying to fight the overwhelming fatigue. They also restricted what they did in order to conserve energy. They activated the self-protective mechanism by choosing not to think and trying not to feel guilty when they did nothing other than rest. As the body continued to deteriorate with the unrelenting fatigue, it seemed the body became foreign to self and further promoted the sense of living in the "Shadow of Death" as their bodies became

recalcitrant and subsequently lost control of the body they once knew. One patient describes the change as: "It is a new way of being…where is the old self. I thought I would return to my old self but it is gone."

The loss of control in relating to families and friends is a significant area of concern for these women. Inability to maintain relationships and fulfill roles and responsibilities greatly impacted how these women perceived their well-being. Ms. M. related:

> I had a hard time doing things with my children…I struggled with that all the time. My family and friends had a hard time adjusting to my level of energy…They also were bothered that my alertness varied. I dealt with that by removing myself from them….I needed space in order to deal with this…I could not go out with family and friends…it was so frustrating.

One of the young mothers shared her feelings:

> My mother role was removed…my total life was disrupted…My husband became mother and father…It impacted my entire family…that was very upsetting to me because I could not participate in outings with my family because I was a party pooper.

Subtheme Four. "Loss of Work, Family Roles, Financial Status"

The loss of various roles, responsibilities and time impacted greatly on this group of women. As their fatigue worsened their identity was affected as they relinquished their roles as mothers, wives, daughters, sisters and friends. Their relegation to a non-participative role in social activities with family and friends further ostracized them. Subsequently, they retreated to their cave. These feelings of isolation and guilt were apparent among all women as they described the various losses they experienced. Elizabeth shared the following:

> Being the only daughter in my family, I was used to taking care of other people….now my role has changed…people are taking care of me. That made me feel badly. My fatigue affected my family system…it affected everything and everyone. It was a terrible heaviness and burden to carry all the time.

> I tried to make myself feel better snuggling with my three-year-old daughter because I felt so alone. At the same time I needed to sleep because I was so wiped out but felt very guilty about it. I could do nothing but sleep. I couldn't come to the table to eat. I needed to be fed for physical reasons but the aura part of me needed to be fed also. The fatigue made me sad and disappointed. I could not do things I enjoyed with my two daughters, agrees three and six. It was hard to give these things up. I struggled with that constantly. I was so alone…I often

went to my cave.

Work and school continued to be very important to these women. Though they admitted to not feeling like continuing employment/attending school, they displayed a tremendous fortitude in remaining committed. Each of the women modified their work schedules to accommodate their days of not feeling well enough to work full-time. Their employers were extremely supportive of providing a flexible schedule as well as reducing their workload. Unanimously, they acknowledged their work performance as being "lackluster" and "only going through the motions of work." Admittedly, they did not care their performance was below average because the fatigue was so consuming.

The fatigue experienced by the women also impacted their careers negatively. One patient has been unable to complete graduate school; therefore, she has taken an inordinate number of student loans out in order to work toward a degree so she can become gainfully employed. Another patient shared that her ongoing fatigue has incredibly affected her financially. Elizabeth related how difficult the financial impact continues to be:

> My fatigue impacted my work tremendously…I think that year I was on chemo, I think it was probably going to be one of the best years that I ever had in my business because of my referrals…So I just knew that I could not meet with clients and show houses when I was so fatigued…There was just no way…So I'd have to refer them…Then to make things worse, my referrals stopped from three

> different companies… They went overboard not wanting me to have customers…not wanting to send me customers because I was going through this process…And everyone said, "Well, you know, the most important thing is for you to get well"…well of course it was…but financially its, its devastating…So, since being diagnosed with breast cancer it has been my fatigue that has financially impacted me unbelievably…It has been absolutely devastating, and it is devastating to this day…I will never recover from it!

Another patient, Judy, related how being unable to work full-time affected her:

> I think I have pretty high-esteem, but the fatigue almost makes me feel worthless because I had just always worked, and all of a sudden, you know, I'm not working…So it makes you feel like you're supposed to be doing something but you don't know what it is that you are suppose to do…Because, I think in this particular business, you have to kind of keep that going, and I would be so tired sometimes you just don't care. I just didn't care whether I met with a client or not because I was so zonked.

Subtheme Five. "Loss of Precious Moments in Time"

The inability to recuperate time lost during the periods of overwhelming fatigue was paramount in the minds of the women interviewed. The memory of losing precious time with loved ones was almost unbearable to the majority of these patients. They spoke candidly about the difficulties, even today, they confront while realizing they lost huge

"chunks of time"….time that is irretrievable. Their words reflected sadness and regret as all five women's narratives conveyed:

> I lost lots of time…..time that was very special to me….it is time I will never get back. But at the time I was so exhausted I really didn't care what I was missing. There are many regrets but there isn't anything that I can do to make it different.

> I lost one year of my life…that is really bothersome to me because I don't recall my grandson being born and the first year of his life…That saddens me tremendously.

Another patient, Susan, shared:

> I lost six months of healthy living…Not only that, I gained 45 pounds staying in bed all the time…So that really made me feel even worse about how I look.

Theme Four. "Who Am I; It's Not My Life"

Over time, the breast cancer patients initiated the transition from their "cave" into the "cocoon" as they revivified into a person who had undergone an incredible metamorphosis. As a result of the major insults to the "old self" (pre-cancer treatment state) to the "new self" (post-cancer treatment state) these metamorphic changes have emerged as major changes to "who the present person is." Undeniably, these women shared stories of how they searched for the "old me"… never to find her. The changes

that brought these women face to face with their "Shadow of Death", and to face the "new me," were precipitated by the major losses engendered during their tenure of cancer therapy. Not only did they lose attributes of their body and its functioning, but they also lost what they considered major: loss of brain functioning. To further add insult, they also lost control of their life as well as their work, family, friends and financial security. In time, these women recognized they never would be the person they once were. They talked about "then and now" and "before and after." They acknowledged they would "never be returning to me." Life as they knew it was over. They searched for the old self and finally acknowledged that "my life was saved but it's not my life anymore." Their perspective about life correlated with Heidegger describing "being thrown into the world" which involves redefining the self (the patient) as living with fatigue and wanting to be the "old self" again. The person and the world "co-create" each other (Heidegger, 1962).

These women stressed that it is impossible to really describe the pervasiveness of the fatigue and how it impacted their lives. They described the fatigue as a "permanent visitor." Admittedly, their words richly conveyed their sentiments though they are pale compared to how they lived their lives from day to day as they dealt with this devastating symptom. Several patients shared the following:

> Before, I had a purpose. Now I am uncertain I know who I am. I finished my treatments about 13 months ago and to be honest I am still exhausted. At first I

thought once these treatments are over I will be my old self again and so far that has not happened at all. I still have the fatigue today (Elizabeth).

My life was saved but it's not my life anymore. I am still stuck and it makes me feel worthless because I don't have the same stamina I once did. I finished my treatments two years ago and I still have significant fatigue (Linda).

There is no return to normal for me. I still don't have the 'good energy' I used to have. I have learned to adjust to a new way of life. I have to be more disciplined and think about everything I do so I can conserve my energy for things that are important (Susan).

Life is not like it used to be…not in any form or fashion…not physically, emotionally or spiritually. My old self is gone. I question what others expect of me since I have a new self. I am convinced I will never go back to my old self (Beth).

The patients conveyed a sense of not recognizing their body as they talked about the "new me." Not only did they not feel "like a woman" because their appearance had changed but their roles had been relinquished to family and friends. The majority of the patients felt they never recuperated the life they once enjoyed. They described their body as an "object for others" and the "dark night of the soul"; the "body for others"

disappeared at night, and they were able to become their "self," especially as they retreated to their cave and dealt with the "Shadow of Death."

Summary

The four themes that evolved from the richness of the words the breast cancer patients shared about their debilitating fatigue evoke an overwhelming sense of isolation, despair, disappointment, and a subsequent sense of living but losing one's life as it once was. The fatigue experienced by the women was abrupt and incapacitating in every aspect of their life, including physically, emotionally, psychologically and financially. This devastating symptom caused betrayal of the body, role changes, both personally and professionally, as well as permanent adjustments to how their future lives will be lived.

Because of the overwhelming sense of their body reverting to a survival mode of being "alone in the cave," these women experienced a sense of exile, "being on an island by myself." In time, often described "as feeling like a million years" elapsed, these women began to emerge from their morphologic state, "coming out of the cocoon," to discover an overwhelming life full of losses. The losses were overwhelming and devastating to these women. Not only did they lose their bodies to the fatigue but also their focus, memory and ability to concentrate. As the patients moved from disengagement to engagement they also discovered that there was loss of control. In other words, the "fatigue is not fixable." No matter how much one places "mind over matter," the fatigue cannot be mastered. Therefore, it becomes a "permanent fixture" in these women's lives and affects every remnant of their life.

As the body transforms and adjusts to the many changes in their life, the women quickly understand that their lives have been changed permanently. Often they questioned, "Who am I now?" and "What is the meaning of my life?" As they surveyed the many changes in their life and made subsequent adjustments in their personal and professional life, there was a major question ensuing: "What is the meaning of my life now?" For all, the fatigue seemed permanent, and adjustments in their life appeared challenging. Roles changed, traditions were altered, and professional responsibilities were adjusted to accommodate their fatigue. Admittedly, the patients continued their adjustments to the losses on a daily basis. The greatest challenge they faced each day was living in the "Shadow of Death" and questioning who they were as they adjusted to the new life cancer and cancer treatment had handed them.

CHAPTER V

DISCUSSION

The purpose of this study was to understand the meaning of the fatigue experienced by breast cancer patients who had undergone chemotherapy and radiotherapy. Utilizing a phenomenological approach based on the works of Merleau-Ponty, the researcher conducted six interviews with stage I and stage II breast cancer patients who received both chemotherapy and radiotherapy post-mastectomy. A bracketing interview was completed prior to the interviews with the patients to identify the researcher's preconceived impressions and suppositions. Each patient was asked to share their experience of living with the fatigue that occurred during and following their cancer treatments. Each interview was audio-recorded and then transcribed verbatim. Each transcript was analyzed using a hermeneutic method developed by Pollio (Pollio, Henley, & Thompson, 1997) and then brought before and reviewed by the Interpretive Research Group at The University of Tennessee chaired by Thomas and Pollio (Thomas and Pollio, 2002). Each transcript was studied and reviewed with the interpretive process using the part-to-whole method as well as within the context of all the interviews with subsequent themes identified throughout the documents.

The interviewed patients described the meaning of fatigue they experienced during and after the completion of chemotherapy and radiotherapy. Their treatments had been completed from one to five years. Interestingly, all the patients continued to experience the fatigue, regardless of the time lapse since the completion of their therapy. During active treatment, the fatigue was more acute and more overwhelming; however,

with time, the fatigue lessened to some degree, but remained a constant reminder of their cancer and treatment sequelae. It is noteworthy to recognize that the patients had an immense recall of the experiences and continued to converse about the residual fatigue that persisted long after their therapies were completed. Obviously, this connotes a significant meaning attached to these experiences as they vividly shared the major changes that occurred in their life secondary to the unrelenting fatigue.

The majority of the focus was on the impactful side effect of the therapy causing this persistent fatigue. The discussion centered around the effects of the fatigue on their body and mind with significant losses of control as well as negative effects on family roles, work, finances and quality of life. Additionally, they shared how the fatigue had affected them personally, especially the effects on their body as well as the significant losses experienced from the fatigue. The end result is a major and persistent insult to their recalcitrant body that consequently cause the patients to question who they are, as a person, and will they ever return to their "old self."

Relevance of Study Findings to Phenomenology of Merleau-Ponty

Human Experience of Human Body

The body of the cancer patient is viewed through the world of major changes in body image as effects from the disease and treatment have played havoc on the integrity of the human body. Because of the many body image distortions, the patients' self perception of their body is often devastating to them as they potentially have lost major body parts, such as a breast, as well as body functioning. These feelings of loss are often

intensified in the patient who is dealing with cancer-related fatigue as they are unable to manage the side effects of treatment and deal with their losses due to the overwhelming fatigue. This disabling phenomenon also is overwhelming to the patient because of the fatigue often being equated with that they are doing poorly and thus reflects a poor prognosis.

In addition, the cancer patients' life world is virtually restricted to their body experiencing the overwhelming fatigue. As such, this pervasive fatigue affects every facet of their life including their world and the people within in their world. As described from Merleau-Ponty's perspective, the element of time and the non-human world are also affected. Each of these perspectives will be described in the forthcoming section.

The Experience of Other People

The "human experience of other people" becomes an extremely important topic of interest when studying the phenomenon of cancer-related fatigue. According to Thomas and Pollio (2002), when significant relationships are lost, feelings of loss and defeat manifest. The breast cancer patients' social role enactments are affected greatly when fatigue is present. Though the patients fully understands their role and wishes to fulfill that position, whether as an employee, a mother, a wife or a friend, they may be unable to fulfill that because of the incapacitating fatigue. The fatigue affects the three domains of role performance as they may be unable to meet the mutual goals of role for themselves as well as others. The fatigue also affects how the breast cancer patient will feel about their body when they are attempting to move to enact their role. Because of the lack of energy manifested with the fatigue, often the patient cannot physically enact the role. In

addition, Merleau-Ponty proposes that there are important benefits to connecting with other people and suggests that reciprocity exits. Unfortunately, because of the fatigue, often these women are unable to connect to the people important in their lives. As a result, lack of fulfilling their role and being unable to connect socially may lead to depression, despair, isolation and a fading will to live.

Human Experience of Time

The "human experience of time" is a critical aspect of the breast cancer patient's life. Merleau-Ponty proposes that we look at the past and anticipate expectation of the future. The fatigued breast cancer patients' perception is skewed by the meaning of what their life was like prior to the fatigue and perhaps what it will be in the future (Thomas & Pollio, 2002). In addition, time becomes paramount in their lives due to the fear of dying because of the disease being incurable. Often the cancer patients views their lives from a Heideggerian's perspective in that the meaning of time from a futuristic point of view is with certainty. They are well aware of their morbidity and recognize they may die from their disease (Thomas & Pollio, 2002). This overwhelming sense of doom and gloom is exacerbated in patients who are experiencing the incapacitating fatigue.

In addition, the experience of time is greatly affected in the breast cancer patients with fatigue who are experiencing cognitive dysfunction. Both clock time and lived time become important as these patients require increased time to complete tasks, experience the inability to complete executive decisions, and tend to have poor memory and forgetfulness.

Human Experience of Non-Human World

Whether the breast cancer patient experiencing fatigue is considered from an objective point of view or from the perspective of being found and understood only as "meaningful being-in-the-world," it serves as the fourth contextual ground of human life. Merleau-Ponty proposes that we capture the meaning of special places in our lives, as these women resorted to "caves" as their respite place (Thomas and Pollio, 2002). The breast cancer patient with fatigue experiences changes in relationships of people in their lives and often these changes result in the patient feeling very insecure and thus affecting their space and place. As the study participants shared their stories, it became evident that major changes occurred in every aspect of their life. In the aforementioned paragraphs Merleua-Ponty's philosophical perspective about the human experience to the body, others, time and the non-human world are described. As illustrated in the following section, the human body was affected in drastic ways. Additionally, how they dealt with "other people" and "their world" were greatly changed as was the element of time.

Overview of Thematic Structure

Each patient shared stories of their life before being diagnosed with breast cancer. They were working mothers, soccer moms, students, professional and businesswomen. They were involved in church and community activities and seemed to be enjoying life to its fullest potential. Suddenly, a "lightning bolt" flashed before them as they received the most frightening three words one can ever hear: "You have cancer!" Being totally devastated with the overwhelming news, these tenacious women sought the best medical

and surgical oncology treatment available, with some seeking second opinions at major cancer centers. After the initial shock and disbelief, with great fortitude the women underwent breast cancer surgery, received chemotherapy with subsequent radiotherapy. It was during the treatment phase their lives further fell apart as they described their chemotherapy as "toxins being poured into my bodies."

Understandably, during this active phase of their breast cancer treatment the fatigue surfaced. The life of the patient transformed substantially with major changes in their quality of life. It was at this point in the cancer trajectory that a fourth word, fatigue, was added to their repertoire of their cancer experience. This was the turning point; their lives changed dramatically…never to return to the life they once enjoyed. Because of the radical changes associated with being diagnosed with breast cancer and having received cancer treatments, the experience of the patient was grounded in body and time as previously described. Out of these experiences, the meaning of their fatigue unfolded and the thematic structure evolved as: "being alone in the cave," "coming out of the cocoon," "it's a lost fight," and "who am I now, it' not my life."

During this experience of transitioning from a "normal working mom" to a person cloaked with a new body lacking vitality, a "subpar" level of cognition as well as newly defined roles, these women quickly saw their life being lived in the "Shadow of Death." Pollio, Henley, and Thompson, (1997) propose that according to Heidegger, when one faces death, the impossible possibility of "not being in the world," is when a person chooses to live an authentic life. Therefore, one could propose that "being in the world" is a "being toward death." For these women being in the world reflected this position as

they dealt with their pervasive fatigue of being in two worlds as they faced the "Shadow of Death."

The first world was very hard and demanding. In this world, they tried to fulfill roles and responsibilities to no avail. The harder they tried to complete various duties and responsibilities, the more difficult the tasks became. Their energy waned and eventually became nonexistent as they described themselves as "looking like death warmed over." This was followed by despair, disappointment, despondency and isolation. Food became unimportant, donning clothes and applying makeup were too exhausting, and socializing with family and friends was overwhelming. Subsequently, the participants described "running on fumes" as they succumbed to defeat and resorted to a safe place, their refuge. Each theme will now be further elucidated.

Theme 1. "Being Alone in the Cave"

Resorting to a cave, their refuge, is the second world, which is safe and one in which the patient felt secure though they still described it as being exiled from everything important in life. The patients shared "looking through a window" as they viewed the outside world; however, it was a vicarious experience for them as they could look out but no one could see inside their room, the cave, because they were disappointed in their physical appearance. They enjoyed the mundane scenes of everyday life, such as watching children get off the school bus, listening to birds sing outside their bedroom or enjoying a ride in the neighborhood. Their stories reflect the poignant experiences they endured:

> My fatigue affected everything about me and around me; I wanted to be alone. At this point I went to my little cave…I was in my cave….my own little cave… I just crawled in it and stayed there. I cried once I was by myself. While I was in my cave I could see the world but it could not see me. I looked and felt terrible; I didn't want anyone to see me. I looked through the little windowpanes from time to time so I stayed connected with the outside world.

The participants also questioned the entire ordeal and asked why they were dealing with this catastrophic event. They questioned why the rest of the world didn't feel like they did. At times they displayed anger as one patient, Linda, described the following:

> I was in my cave…all alone…I could not sleep at night. I just stared at the walls. I really couldn't watch TV because I couldn't concentrate, but in the middle of the night TV got my attention. Those infomercials or people exercising or trying to sell weight loss stuff…that drove me crazy! Every time I heard the advertisement, I wanted to slap those feisty young girls who were wiping me out just watching them. I hated it. It reminded me what I had lost and probably was not going to get back.

As the women continued to hibernate in the cave, their temporal world broke down. They described the fatigue as lasting forever and that time was running together.

For these patients, time was a benchmark to normalcy. Time was very heavy. Before being diagnosed with cancer, the tempo was great because they felt well. When they became ill, time was blank as they "sat and stared at the walls." In addition, the tempo was lost, and nighttime became an existential crisis, as they described not having to be strong for anyone. Linda shared the following:

> The days were like a million years long, and the nights were even worse. I remember laying in the darkness and just thinking, oh when will the daylight ever get here? Because darkness, I don't know what it is about darkness, but you seem to be worse at night than you are in daytime. I guess the light coming through the window helps. But you think you are never going to get through the darkness.

In addition to their feeling of the fatigue lasting "forever," the patients lost orientation in time as the hours ran together. When they were "down for the kill" time ran together as there was no purpose. Time also fell apart when the patients had a sense of "not caring" because nothing helped the fatigue. Whereas, when they began to feel better they left their cave and came out of their cocoon.

Theme 2. "Coming Out of the Cocoon"

As they began feeling better, time became more important and was more structured. In addition to time becoming more important as they were transformed from the cave to the cocoon, they became more engaged in themselves and others. Because of the continued lack of vitality, the patients often described their "bodies were for others"

as they attempted to dress and apply makeup so that did not "look like walking death," They often described not appearing as a female. In contrast, some women preferred the night as "my body for others disappeared…I was able to be myself."

These women also discussed the difficulties of having "others in their life" as they dealt with their fatigue. Some family and friends actually did not acknowledge how badly these women felt. The patients stated that they "looked OK"; so people did not realize how exhausted they were most of the time. They also shared that their loved ones were not very helpful at times nor were they empathetic; perhaps they did not know how to help, they suggested. The patients embraced major changes as their roles changed. In essence, the women did not convey a substantial degree of others being important as they dealt with their fatigue. Rather, it was not about others, it was a lost fight these women experienced, as the fatigue was meaningless. Also, it precipitated a lack of freedom as well as loneliness and a meaningless existence. Making choices did not change the outcome; these women were impotent in changing the outcome of the level of exhaustion as nothing helped their fatigue! One of the participants, Susan, shared the difficulties she experienced as she dealt with fulfilling her role as a mother while being fatigued:

> It was a very hard time for my children. I lost my role as a mother; I continue to struggle with that, even today. Our total life was disrupted. It is very upsetting to me as it has impacted the entire family. It was hard on the children to adjust to the unpredictability as my level of alertness and activity varied widely. It was a very hard time for me and probably always will be as I feel like I have lost a big chunk of my children's life. I felt exiled from the family. The entire family system is

affected. It affected everything and everybody. It's a heaviness, and I have to deal with it because it will not go away.

The fatigue also affected how the patients interacted with people; they felt they were always in "catch up "mode. The patients compared themselves to other patients as well as healthy individuals. They felt there was a perception from the healthcare professionals that they "looked OK"; as long as their blood counts were normal the physicians were not interested in talking about their fatigue. The healthcare providers also offered no strategies in helping to manage the fatigue.

Theme 3. "It's a Lost Fight"

As the patients dealt with their fatigue, they experienced an overwhelmingly sense of loss. The encompassing theme of the study, "it's a lost fight" reflects major losses including physical changes but also cognitive aberrations as well as role changes, both personally and professionally. Their quality of life was affected physically but also functionally, cognitively, psychologically and socioeconomically. These losses serve as the foundational basis of the study results and are interrelated with the other themes. This thematic structure emerges as the patients deal with their ongoing fatigue. Not only are they dealing with being alone in the cave but also experiencing an inordinate level of lost time. There also is a major offense to the patients' body integrity. As alluded to, the patients are completely unable to will their body to do things. No matter how hard the patients attempt to conquer their overwhelming fatigue, the body is flattened and will not respond. One of the young mothers, Beth, described the effects fatigue had on her body:

> My body knew when it has tapped every single piece of my energy. I was so wiped out I could not stay awake though I had 2 young children to care for. I felt my body had betrayed me. In fact, I felt disjointed; there was a separation of my body and me. I mean I could not function; I could not even make a list for someone to grocery shop for me.

Another patient, Linda, describes how energy becomes relative to the tiredness and the difficulties of dealing with the fatigue:

> Tiredness is an understatement! It's not like being tired after a busy day. When you wake up, you are just as tired as you were when you went to sleep. It is totally overwhelming; I really cannot think of words that really describe it. You run out of steam. You literally run out of energy. I don't know what else to say other than it is the worst thing that I have ever dealt with and the problem is that I don't think it is ever going away…that is scary.

As cited in a study by Breithart et al. (2000), 91% of breast cancer patients reported their fatigue prevented them from having a "normal" life. Interestingly, the women's stories conveyed a powerful description of the difficulty living each day knowing they would not feel like doing things they wanted to accomplish. Obviously, this defeat led to feelings of isolation and loss of control and function. The furtherance of feeling a sense of loss and their bodies conquered by their fatigue, these women dealt

with an indescribable change in their cognitive functioning. This loss of memory and concentration was and still is very frightening to these women. In fact, it is the most prevalent symptom the women continue to experience. Their concerns are expressed as they share their daily living with these changes:

> I feel like am I am out there; I am not with it. I am not competent and I cannot problem-solve as I once could. There is nothing connected; I got lost when I tried to think…so all I did was sit and stare. I am in a fog; I think there is only one piece of my brain that comes and goes. My mind is hazy and blurred….I cannot concentrate and hold on to any thoughts. Sometimes I have problems getting home from work (Jan).

All the patients conveyed their concern about their memory being affected permanently. They acknowledge that forgetfulness, poor memory and lack of concentration continue to be apparent, and they fear for their future. They recognize their cognitive functioning has deteriorated since receiving chemotherapy, and half of the patients mentioned their "brain needed to be retrained." Conversely, the patients also acknowledged that as they began recovering from their fatigue, they began to "think" first and then they "got a little energy and then could do a little more." As they continue to improve slightly, they move into a new phase of their life, "Who Am I Now."

Theme 4. "Who Am I; It's Not My Life"

As these women began to slowly improve, there were glimpses of freedom and normalcy. While the patients evolved from a sense of being alone with a meaningless life, there was a sense of relinquishing the bondage they had experienced since the inception of the fatigue. The changes that brought these women face to face with their "Shadow of Death", and to face the "new me", were precipitated by the major losses engendered during their tenure of cancer therapy.

Not only did they lose attributes of their body and its functioning, but they also lost what they considered major: loss of brain functioning. However, they continued living in the throes of coming "face to face" with the "new me" which was precipitated by my major losses engendered during their tenure of having cancer. Therefore, they often described living in the "Shadow of Death" which represents the ground. This prevailing theme is woven throughout their stories. The end result is that though they survived their cancer and the cancer treatment, the subsequent fatigue rendered their bodies, mind and lives different. Their voices convey a question of asking "where is the old me" and "will I ever be the same; is the old me gone….never to return again?"

The patients' stories parallel closely to Viktor Frankl's, *Man's Search for Meaning*, (Frankl, 1992), in which he discusses the experience of the incarcerated prisoners in the Nazi death camps attaining freedom in the midst of despair and desolation, though the possibility of death still existed…yet, that was the ultimate horizon they sought. As Frankl argues, suffering cannot be avoided but we choose how we cope with it, finding meaning in our suffering and then move forward with renewed purpose.

This position is similar to the experience of these breast cancer survivors who were weighted down with their fatigue. Their experiences were similar as both the cancer survivors and Frankl describe the experiences of loneliness, desolation and despair. They questioned their existence many times as they sought answers, as their lives had no meaning while they fought the demons bestowed upon them. Though they faced the "Shadow of Death" every day of their existence, they eventually sensed freedom. Though their bodies and minds were not the same, there is the possibility of perceiving freedom to discover and pursue what is personally meaningful to them. With the "new me," these patients could continue to strive and pursue worthwhile goals…goals with meaning and a desire to find significance in their future lives and, hopefully a feeling of nirvana.

Albeit the breast cancer patients surviving the many catastrophic events leading up to the phase, "Who Am I, Its Not My Life Anymore?" in their cancer trajectory, the majority of the women admit they have yet to identify new personal goals. They are still dealing with what they once were and attempting to negotiate how to deal with their losses. Similar findings are noted in several cross-sectional studies as well as a study by Byar, Berger, Babken, and Cetak (2006), and in which breast cancer patients' fatigue did not return to low levels after active treatment after completion of therapy. The problematic symptoms associated with the unrelenting fatigue were sleep disturbances, anxiety, depression and poor quality of life.

A paucity of qualitative studies has studied the meaning of the fatigue experienced by cancer patients and even less in breast cancer patients. There are no

studies identifying the losses revealed in the interviews of these women. Neither has the questioning of identity been noted in prior studies, as seen in these patients who confronted evolving into a new person. It is not surprising that previous research has failed to reveal these concerns; the focus on cancer-related fatigue research for the past 25 years, for the most part, has been on quantitative studies focusing on measurement of fatigue, causes of fatigue and interventional approaches in the management of fatigue.

Implications for Theory

When comparing cancer-related fatigue to normal fatigue that is experienced after a busy day, they are very different. Cancer-related fatigue is more intense and pervasive and tends to be persistent for an indefinite period of time. Generally speaking, rest does not lessen the symptomatology of the exhaustion experienced in the cancer patient. The cancer-related fatigue also tends to impact more on the patients' quality of life and may extend for months to years after the therapy is completed. Because of the challenges in managing this type of fatigue as well as the impact cancer-related fatigue has on quality of life issues, nurses should explore the following models that may be helpful in attempting to better understand and manage cancer-related fatigue.

Nurses continue to be at the forefront in addressing these various issues precipitated by the cancer patients' fatigue and actively utilizing the conceptual frameworks identified while managing their cancer patients' fatigue. Using the models in their clinical practice may contribute to improving the patients' quality of life through direct care but also will address issues for ongoing research in the field. From the findings of the study, there are five theoretical models that may be consistent and

relevant: Ferrell's Quality of Life Model, Levine's Conservation Model, Roy's Adaptation Model, Neuman's System Model, and Dodd's Conceptual Model of Symptom Management. These models not only address the quality of life issues that confront the patients but also serve as conceptual frameworks to pursue future research studies for the furtherance of better understanding the meaning of the fatigue these women eloquently shared. Moreover, middle-range nursing theory could be derived from these theories to apply to cancer patients in both in-and-outpatient treatment.

Ferrell's Quality of Life Model

Ferrell's Quality of Life Model consists of four domains of quality of life that are interrelated (Ferrell, 2008). They include physical well-being and symptoms, such as functional activities, fatigue, strength, sleep, rest and overall physical health. The second domain is psychologic well-being and includes control, anxiety, depression, enjoyment/leisure, and cognition/attention. The third domain is the social well-being, which addresses role/relationships, family distress, appearance, isolation, enjoyment, finances and work. The fourth domain is spiritual well-being and includes meaning of illness, hope, uncertainty and inner strength. These domains address the issues that the participants shared about their lives. Their shared experiences about these issues reflected how much their quality of life was affected with the major changes that occurred, including physical, psychologic, social and spiritual changes. Interestingly, this model can be expanded to address survivorship issues that are also pertinent to this group of women as five years post-therapy they voiced major concerns about persistent fatigue.

Levine's Conservation Model

The second theory selected to discuss the patients' perception of cancer-related fatigue and quality of life is Levine's Conservation Model. The model is an adaptation model that portrays the maintenance of life by conserving individual integrity (Fawcett, 1999). Three major concepts form the basis of the model and its assumptions: conservation, adaptation, and wholeness. Levine proposes that individuals continuously defend their wholeness. Conservation connotes the keeping together of the life system. This maintenance promotes a proper balance between the nurse's intervention and the patient's participation. The patient interacts with the environment on a continual basis. In order to maintain this integrity, the individual is continually safeguarding his integrity by choosing the most economical and energy-sparing options.

Levine proposes that adaptation is the ongoing process of change; as a result, individuals maintain their integrity (level of energy) within the realities of their environment. Every individual possesses a range of adaptive responses that is unique to that person (Fawcett, 1999). When dealing with an illness, such as cancer, these ranges may vary.

In the Levine model, redundancy represents the physiological and psychological options available to the patient to ensure continued adaptation. When an interaction or constant adaptations to the environment permits the assurance of integrity, the wholeness exists, thus allowing the individual to become the focus. This wholeness occurs when there is recognition of an open, fluid, constantly changing interaction between the environment and the cancer patient. When the patient is diagnosed with cancer, there is a

maladaptive interaction with the environment. As a result, cancer-related fatigue evolves and thus produces the potential of functional disability.

The cancer patient adapts to forces surrounding him as he deals with the internal environment (the malignancy) that combines the physiological and pathophysiological aspects of the illness. The internal environment (accumulation of metabolites from the tumor, changes in energy and energy substrate patterns caused by anemia, psychological patterns and symptom patterns) is constantly challenged by the external environment (life event patterns, social patterns, environmental patterns), which includes those factors that impinge on and challenge the individual. According to Fawcett (2004), the Levine model purports that health and disease, such as cancer, are patterns of adaptive change, the goals of which include well-being. In addition, nursing is to promote adaptation and maintain wholeness. Through the conservation of energy as well as through the structural, personal and social integrity, this goal is met for the cancer patient (Alligood & Toomey, 2006).

Four conservation principles underlie the model and include: conservation of energy; conservation of structural integrity; conservation of personal integrity and conservation of social integrity. Conservation of energy relies on an exchange between free energy and the living systems that are continually replenishing their energy supplies. Conservation of energy is critical to the cancer patients' range of adaptive responses to the fatigue. The conservation of structural integrity relies on an intact defense system of which exercise plays a key role. This system repairs and heals, and it is responsive to the challenges from the internal and external environment. The conservation of personal

integrity recognizes that the cancer patient maintains his physical stamina through exercising on a regular basis, thus reducing his level of fatigue (this establishes his wholeness in response to the environment). It acknowledges that the patient strives for independence and self-awareness. The conservation of social integrity acknowledges that the functioning society the person cancer lives in is part of the patients' established boundaries. This includes the impact the cancer diagnosis has on work, finances, leisure activities, family roles and relationships, affection and sexual function.

The fourth conservation principle focuses on the patients' perception of fatigue and quality of life, while maintaining social integrity. Conservation of personal integrity is demonstrated when a cancer patient reports low levels of emotional distress and high levels of quality of life, which conceivably could occur as physical activity is increased. Conservation of social integrity is represented by the maintenance of social functioning, which may improve as fatigue lessens (Fawcett, 1999).

Roy's Adaptation Model

The third model to consider in the context of understanding the meaning of the patients' fatigue is the Roy Adaptation Model. Roy describes humans as biopsychosocial beings who are in a constant state of adapting to external and internal environmental stimuli. The cancer patient functions as a unity and has an innate or acquired way of dealing with the fatigue while utilizing various coping processes. The person and environment are based on the cancer patients' ability to adapt to his diminished energy level. According to the Roy Model, the cancer patient initiates the adaptive process and is not passive in the process. To help the cancer patient cope with fatigue, he subscribes

to the subsystems of the coping process: regulator (chemical process of the tumor burden), cognator (cancer patient's level of consciousness), stabilizer (accomplish primary purpose of social system for the cancer patient and significant others) and innovator (structure and process changes for cancer patient after performing an activity, such as walking). Adaptation is an active process, which is initiated by the individual, of adjusting to environmental changes through physiological and psychosocial modes, and in turn, affecting the environment (Fawcett, 2004).

The physiological mode is associated with physical responses to stimuli. For cancer patients with solid tumors, such as breast cancer, physiological adaptation often includes recovery from surgery and physiological responses to radiotherapy and chemotherapy. Psychosocial modes defined in the Roy model are self-concept, role function, and interdependence. Self-concept is a composite of the individual's beliefs and feelings about the physical self and psychological state. In patients with cancer, self-concept is characterized by emotional reactions and often alterations in body image that may occur secondary to their fatigue. Role function and performing behaviors that are expected because of one's position in society, are reflected in the level of functional status in relation to job, home, and significant others. The functional status may be affected significantly in cancer-related fatigue. The interdependence mode focuses on affectional relationships with significant others and support systems and thus involves maintaining nurturing relationships with the partner, family, and close friends. In cancer-related fatigue patients, the interdependence mode is severely affected because of the diminished energy level. The stresses associated with a cancer diagnosis and treatment

may affect psychosocial adaptation by threatening the patient's ability to maintain employment, perform home and child care functions, or communicate affection to his/her partner.

Environmental stimuli may arise within or around the person and may be focal, contextual, or residual. Focal stimuli, those that most immediately confront the cancer patient, are diagnosis and the treatment regimen, as well as the treatment-related symptoms such as fatigue. Contextual stimuli are other contributing factors that influence the situation. For the cancer patient, contextual stimuli include the social support, perceived prognosis and coping strategies. Residual stimuli have undetermined effects and may include factors such as age, developmental stage, culture, and health beliefs (Alligood & Toomey, 2006).

In the Roy model, health is a reflection of successful adaptation to the fatigue with the goal of being and becoming an integrated and whole person. Adaptive responses are those that promote this integration. The goal of nursing is to promote adaptation to the fatigue in physiological and psychosocial modes, thereby contributing to the person's health and quality of life.

Neuman's System Model

The fourth model for consideration in explaining cancer-related fatigue is Neuman's System Model. Neuman proposes that the model presents a structure consisting of parts as well as subparts that are interrelated. As a result, the patient is considered as a whole in a complete system (Alligood & Tomey, 2006). Neuman purports that environmental stressors constantly bombard the cancer patient. In

Neuman's model, the individual cancer patient is considered an open system that experiences stressors developing from an internal environment (the malignancy itself as well as the side effects from the cancer treatment, such as fatigue) or an external environment (the life event patterns and social patterns). The cancer patient is constantly confronted with various stressors including a deteriorating disease state, changes in blood counts, interruption of sleep and rest patterns, symptom patterns and psychological patterns. This model suggests that while these stressors are constantly bombarding the patient, who is protected by a series of concentric buffers that minimize the impact of stressors. The cancer patient is equipped with various concentric circles that interact simultaneously and ultimately could impact on the patient's level of energy. The level of energy is affected as the patient system experiences disequilibrium, which occurs when there is a disruption in the basic structure that houses the energy resources (e.g. the central core of the patient's system). This interruption of the patients' energy resources can be affected by physiological, psychological, sociocultural, developmental and spiritual variables. The physiological variables include changes in the energy and energy substrate patterns level secondary to cancer treatment (causing nausea, vomiting, pain, cachexia, anemia and drug interactions) as well as accumulation of metabolites. These variables result in a decrease in the synthesis of protein and muscle contraction with a resultant muscle loss and extreme weakness. The psychological variables include anxiety, frustration, and fear of the meaning of fatigue, coping and acceptance, loss of independence, cognition and depression. The sociocultural and developmental variables include impact on work/finances, family roles and relationships and sexual function. The

spiritual variable includes changes in spirituality, altered priorities to balance diminished energy, hopelessness and meaning of fatigue. Consequently, these variables impact greatly on the patient's level of fatigue as the protected concentric buffers are ineffective due to the impact of the stressors. According to the Neuman Model, as the protective mechanisms are breached, the intrapersonal stressor (cancer) precipitates the fatigue experienced by oncology patients. Nurses are considered healers and have a goal of conserving the patient's energy to keep the system harmonious, while facilitating change toward optimal health (Fawcett, 2004).

Wellness is a central focus of the Neuman Model; therefore, prevention of the cancer-related fatigue becomes paramount in the model. The strategy includes primary prevention of the fatigue through various approaches including exercise and secondary prevention in which exercise could decrease the level of disequilibrium (fatigue). The tertiary prevention goal is to restore equilibrium to a seriously impacted system. This becomes the challenge as these women continue to experience the unrelenting fatigue.

Dodd's Conceptual Model of Symptom Management

Dodd's Symptom Management Model (Dodd, Janson, & Facione, 2001) focuses on symptom management strategies for the oncology patient. The model encompasses three interrelated dimensions: symptom experience, symptom management and symptom outcomes. The symptom experience component is very pertinent to the study as the focus is on understanding the symptom, such as fatigue, from the patient's perspective. Components of the symptom management strategies are factors to be considered when designing, delivering and prescribing interventions for the fatigue in order to achieve a

desired outcome. Adherence to a selected intervention for the fatigue can be influenced by different factors and ultimately affect the outcome. For the patients in this study, their overwhelming fatigue obviated most interventions during the acute phase of their fatigue (Dodd et al., 2001).

Practice and Policy Implications

The breast cancer women in the study reported their physicians did not assess their level of fatigue. In fact, physicians did not question whether they were experiencing fatigue. Neither did they offer suggestions once the patient complained about their overwhelming fatigue. The patient's impression was that "as long as my blood count was OK, the physician was not concerned about my fatigue." From the study results, it is clear that education of physicians about fatigue is warranted. These findings are substantiated by a recent NCCN survey (NCCN, 2009) of a convenience sample in which 1,000 oncology clinicians responded to a questionnaire assessing their knowledge and management strategies for cancer-related fatigue. Though the NCCN provides evidence-based practice guidelines utilized by oncologists in their practice, approximately one-third were not aware of the cancer-related guidelines, while only 17% of advanced practice nurses were unfamiliar with the guidelines. This recent survey further substantiates that medical schools, training programs for interns, residents and oncology fellows as well as healthcare institutions implement a curriculum that includes the importance of understanding and managing cancer-related fatigue. This becomes extremely important as studies show there is a disparity between physicians' and patients' perception of fatigue. More than 60% of cancer patients cite fatigue as their most

important symptom and only 20% of patients cite pain as a major concern. However, physicians rank fatigue only slightly above pain as the most important symptom, and they further minimize the importance of the patient's fatigue (Einhorn, 2009). The NCCN panel recognizes that education and training programs are needed to prepare oncology experts in fatigue management. Institutions must become involved in ensuring these professionals become skilled in managing cancer-related fatigue (NCCN, 2009).

Since cancer-related fatigue is the most prevalent symptom experienced by cancer patients, national guidelines should be implemented to promote understanding and treatment of the fatigue. The Joint Commission of Accreditation Hospital Organization (JCAHO) should include cancer-related fatigue as a standard just as pain is a recognized standard. Subsequently, institutions and practitioners would be held accountable. Institutions should hold physicians with hospital privileges accountable for implementing the NCCN Guidelines on Fatigue. Additionally, the institution's continuous quality improvement (CQI) committee should identify quality of fatigue management as a clinical focus and implement a CQI plan hospital-wide. Monitoring of adherence and progress with the guidelines could be evaluated using a CQI plan. As a result, evidence-based practice guidelines on management of cancer-related fatigue could be implemented in both in- and out-patient oncology programs.

Additionally, cancer-related fatigue should be included in clinical health outcome studies, and assessment of fatigue levels should be included in outcome research (NCCN, 2009). Institutions should develop comprehensive exercise programs using cancer-

related resources and collaborate among departments to mitigate short and long term effects of fatigue with resultant improvement in the patients' quality of life.

The NCCN Cancer-Related Fatigue Guidelines (NCCN, 2009) recommend education and counseling as central to effective management. Therefore, the nurse's role is pivotal in ensuring these strategies are implemented in all healthcare settings. Nurses should serve on key committees that address clinical practice issues related to fatigue in the in- and out-patient setting. Because of their patients' stories about their fatigue, the nurses are key to recognizing provider and system-related barriers that exist. Because of the knowledge the nurses have about the patient's fatigue, they are equipped to work with other healthcare professionals and administrators in a systematic and collaborative fashion within the system to address the various issues pertinent to improving the patient's fatigue. Nurses serve in a pivotal role to assist hospital administration and clinical cancer boards to understand how to effectively manage cancer-related fatigue. An informed and supportive oncology care team that assesses the patient's fatigue, counsels and educates patients regarding strategies for coping with their fatigue is essential. The oncology team must recognize when to refer patients with unresolved fatigue to experts. The team also must identify the patient, system-related and provider behaviors that may impede effective fatigue management. They should be proactive in provider policy making to ensure that diagnostic related group (DRG) includes the sequalae of treating cancer-related fatigue. Included in the policy coverage is screening for the fatigue, treatment strategies as well as the myriad of other symptomology associated with cancer-related fatigue, such as depression, sleep and cognitive

dysfunction, built into healthcare plans. The nurse helps the team to understand these barriers can be reduced by using available resources and evidenced-based guidelines for patients with fatigue (Piper et al., 2008).

Nursing Implications

In 2009, cancer-related fatigue is still highly under-recognized, under-reported, under-diagnosed and under-treated. This fatigue is identified as a lasting and debilitating health problem that affects a substantial number of cancer patients and may persist long after treatments are completed. This most pervasive symptom may affect cancer treatment by compromising the timing or completion of treatment regimen, either because fatigue is a dose limiting adverse effect or because it reduces the patient's willingness to adhere to the treatment (Hofman, Morrow, & Roscoe, 2004). It has a strong and direct negative impact on all aspects of the breast cancer patient's quality of life that may persist in 34% - 40% of breast cancer survivors for 5-10 years after completion of treatment (Bower et al., 2006; Servaes, Verhagen, & Bleijenberg, 2002). Not only does it greatly impact their physical well-being but also diminishes their ability to participate in leisure activities, to sustain meaningful relationships with their family and friends, to work, and to engage in social activities. They also become dependent on others for assisting them with personal activities and often succumb to having to rest and nap frequently in an attempt to cope with their fatigue. Because of the changes in their daily lives, the patients may feel very discouraged and experience psychological distress as they deal with a significant financial burden with their limiting ability to work.

Many healthcare professionals admit that fatigue is perhaps even more difficult to treat than other problems experienced by cancer patients. Admittedly, these professionals continue to be challenged in their efforts to assist patients manage this distressful symptom and to help them remain fully engaged in life. At present, there are several facts known about cancer-related fatigue. Cancer chemotherapy not only eradicates malignant cells but also causes deleterious effects on healthy tissue, resulting in acute and chronic side effects. Fatigue is one such side effect that is precipitated by several proposed causes, including both physiologic and psychological factors. It also is suggested the causes of the fatigue may even be multifactorial in nature. It is a known fact the majority of patients' fatigue cannot be explained nor successfully treated.

It also is recognized that for the past several years research has been conducted on cancer-related fatigue. The focus of the research primarily has been on causation of cancer-related fatigue, assessment of fatigue, development and utilization of various screening instruments as well as management strategies for fatigue. Interventions to assist patients in dealing with this most common complaint affecting as many as 96% of cancer survivors (Nail et al., 1991) has fallen short of expectations. Researchers have demonstrated that fatigue has significant effects on physical functioning during treatment, and there is uncertainty that patients regain total functioning when treatments are finished (Mock, Pickett, & Ropka, 2002). For many reasons, fatigue continues to be the most prevailing side effect of the patients' experience. Though committed researchers continue to search for ways to prevent or at least minimize this overwhelming side effect

that creates functional, cognitive, psychological and socioeconomic issues in patients, our patients continue to struggle.

With cancer-related fatigue being a subjective experience, it becomes extremely important the oncology team appreciates there is a discordance in perception of cancer-related fatigue between the patient and the healthcare professional team. Therefore, we must listen to their words to better understand the meaning of their fatigue. After listening to the captivating stories shared about the breast cancer women's experiences with fatigue, it is the researcher's belief, unequivocally, that until we learn to appreciate the words of the patient as they describe this unrelenting symptom, further research will not discover what is needed to obviate the patient's suffering. The first step to understanding the direction that research should be directed is to listen to the voice of the patients from the lived world of their fatigue. As healthcare providers, we must learn to bring the patient's own voice into both the nursing and physician encounter. We must understand the meaning of the lived experience of this overwhelming symptom that greatly impacts the patient's quality of life. Our patients can be real-life teachers and can help the healthcare professional understand what it means to live daily with the fatigue. Listening to their experience helps the healthcare team to delve deeper into understanding their fatigue, and then work toward establishing an evidenced-based practice to manage cancer-related fatigue.

Presently, treatment strategies in place to reduce fatigue at best are elusive. According to the Oncology Nursing Society's resource, "Putting Evidence Into Practice," the only intervention considered "recommended for practice" is exercise (ONS, 2006).

Though several studies support that exercise is recommended for patients suffering with fatigue, the participants in the present study conveyed that exercise did not relieve their fatigue. At best, the exercise may be therapeutic physically and mentally. Admittedly, even with the most researched management strategy not working effectively, we must commit to first understand what the patients are telling us about their fatigue. We must understand their experience before a framework for treatment strategies can be researched, developed, tested and implemented. Because of the researcher's passionate commitment to this cause, it is the belief that the oncology nurse serves in a pivotal role to search for the meaning of fatigue as he/she enters into a dialogical encounter with the patient. Through practice, education and research, the oncology nurse will pave the way in searching for understanding the meaning of the patient's fatigue and then establish a framework to identify management strategies.

Awareness of patients experiencing fatigue is imperative to be recognized by the patient, their families and healthcare professionals if successful quality of life and clinical outcomes are to be obtained. Nurses can be leaders in ensuring that fatigue is addressed and managed because they often are the most present and available healthcare professional on the healthcare team. Perhaps fatigue should be anticipated in each patient. Then the nurse could conduct preemptive planning with each patient as the patient meets with their oncologist to discuss an initial treatment plan. Doing so would equip each patient then to deal with the symptom as it occurs. Therefore, the nurse would play an integral role in fatigue screening and assessment as well as management and evaluation of interventions to manage the fatigue (Cleeland & Wang, 2001). Typically,

oncology nurses have a natural propensity to express concern and empathy for patients (McDonald et al., 1999). Their primary goal is not only to recognize fatigue and screen patients for their level of fatigue, but they are also responsible for management of the patient's fatigue throughout the illness trajectory. Nurses serve an important role assisting other healthcare providers realize the prevalence and significance of cancer-related fatigue. Additionally, nurses can help cancer patients/survivors articulate the impact their fatigue has on their quality of life as well as their significant others. Nurses are the key to empowering the patient to report they are receiving inadequate information about how to manage their fatigue. Patients report difficulty in accessing information on how to manage fatigue and typically resort to resting and sleeping more or curtailing their activities in an attempt to conserve energy (Messias, Yeager, Dibble, & Dodd, 1997).

Having fatigue may adversely affect general well-being and quality of life. It is incumbent for the nurse to recognize if these patients become too exhausted to participate in activities or to fulfill their roles that make life meaningful as quality of life may be impacted greatly. Nurses remain in the forefront of patient care and should become advocates for patients. As Newman proposes in her model nurses are considered healers and have a goal of conserving the patient's energy to keep the system harmonious while facilitating change toward optimal heath (Fawcett, 2004). They are positioned to identify patients who are struggling with fatigue early in the cancer-treatment process and should become the voice of the patient. Therefore, nurses need to ensure that all healthcare professionals recognize fatigue as a significant symptom, similar to how pain is addressed today. Their role also is very important as they ensure teamwork, patient

assessments and evaluation methods are in place when addressing fatigue management with the team (Jakobsson, Ekman, & Ahlberg, 2008). A comprehensive multidisciplinary treatment approach should be used to determine the best intervention for the patient. Treatments should be based not only on physical examination and laboratory values but also cognitive and psychosocial assessments of the individual.

The nurse plays an integral role to ensure that the patient's fatigue is addressed. Every cancer patient should be screened for fatigue. If present, this subjective experience should be systematically assessed using patient self-reports as well. Because fatigue is perceived by the patient, it is a symptom that is described most accurately by self-report (NCCN, 2009). Additionally, a quantitative or semiquantative assessment should be performed. According to Jean-Pierre et al. (2007), it may be more relevant, both clinically and for research purposes, to use a single measure that could clearly indicate the presence and absence as well as the severity of fatigue. The fatigue assessment should begin before treatments are initiated, utilizing a 0 – 10 visual analogue scale, with 0 being no fatigue to 10 being the worst fatigue ever experienced. Fatigue studies in cancer patients have revealed a marked decrease in physical functioning at a level of 7 or more (Cleeland, 1999). With each patient encounter there must be an assessment completed as symptoms may be underreported because fatigue often is expected and accepted. An assessment of the patient's fatigue should be taken, much as pain is assessed today. In fact, assessing fatigue could become the sixth vital sign as pain is considered the fifth vital sign (Given, 2007). Part of the assessment should include assessment for poor sleep patterns in patients who report fatigue of 4 or higher. Wielgus,

Berger, and Hertzog (2009) concluded in a randomized study that patients who have good sleep each night experience less fatigue. Encouraging the patient to keep a self-report diary throughout the course of cancer therapy also helps the healthcare practitioner to assess not only fatigue but also sleep (Wielgus et al., 2009).

In addition to assessment of fatigue, a focused history including an in-depth fatigue history should be conducted for a fatigue level of 4 or more. Assessment of treatable contributing factors, such as anemia, pain, depression, anxiety, sleep disturbances, nutritional assessment and activity level should be completed. An assessment of side effects of medications the patient is consuming is also important to determine. Co-morbidities also should be assessed as part of the evaluation of the patient as various health conditions and medications may precipitate significant fatigue (NCCN, 2009).

Subsequently, the nurse must communicate the assessments to the practitioners as the study participants conveyed their physicians did nothing to manage their fatigue. Nurses must advocate with physicians to seek better ways to address the patient's fatigue. A recent survey showed that although patients continue to have unmet communication needs related to fatigue, patients find these discussions extremely useful when they occur (Butt, Wagner, & Beaumont, 2008). Educating the patients about the importance of communicating their level of fatigue to their healthcare professional is of paramount importance. The patient should describe specifically their fatigue so the healthcare team can explore possible etiologies. Their fatigue tends to be underreported because patients often do not want to "bother" healthcare providers nor do they want to be labeled as a

complainer. They also worry that the symptoms may delay their staying on schedule with their cancer treatments, thus allowing their tumor to recur. Complaining about their fatigue also may imply their disease is worsening; therefore, patients may prefer not to inform their healthcare professional. The patients may believe their fatigue is an inevitable part of their cancer trajectory and must learn to live with it. They also may not realize the importance of reporting their fatigue or they may feel that nothing can be done to help; therefore, there is no reason to report it (Borneman, Piper, & Sun, 2007).

Nurses are the voices for their patients, especially as it relates to their fatigue. It is important for the nurse to assist the patient in removing the communication barriers that may impede the patient from talking about their fatigue with their healthcare professional. Coaching the patient and family to initiate the discussion about their fatigue with the practitioner is very important. Helping the patient to recognize that nurses are as interested in their fatigue as pain will improve the patient's comfort level in reporting their fatigue. Encouraging patients, caregivers and family to access the patient dedicated NCCN website will provide essential information on cancer-related fatigue. The goal of the website is to educate patients to become engaged in more informed conversations with their healthcare provider (NCCN, 2009).

The Oncology Nursing Society identified strategies for management of cancer-related fatigue that reflect evidence-based practice. These strategies include screening, exercise, energy conservation and activity management, measures to optimize sleep quality, education, counseling, relaxation and massage, and correction of anemia. Interventions for which there are insufficient data or inadequate quality research evident

include individual and group psychotherapy, expressive writing, yoga, acupuncture, distraction, nutritional counseling, reflexology and/or aromatherapy (Mitchell, Beck, & Hood, 2007). Albeit some management strategies may have no scientific basis, the researcher will cover the majority of these approaches in the following section.

Advocating for the cancer patient with fatigue is very important also. Referrals to programs that will assist patients in dealing with the physiologic and psychosocial changes are very important. Consultative services for nutritional support are pertinent as the women lost and gained considerable weight while in were in "their cave" and "their cocoon". A nutritional counselor ensures that the patient receives adequate caloric intake, proteins and fluids to help prevent fatigue and increase energy level.

Emotional distress was very apparent both during the acute and chronic fatigue these women still experience. Quality of life improves when distress is alleviated (Sloan et al., 2002). Therefore, counseling including stress reduction and management of depression and anxiety can be useful in reducing fatigue (Stark, Kiely, & Smith, 2002). Kim, Hickok, and Morrow (2007) further substantiated that stress reduction ameliorates high levels of fatigue. The researchers examined 549 patients undergoing chemotherapy. The purpose of the study was to assess the degree to which two dimensions of emotion assessed as psychological factors, arousal and violence, served as predictors of change in fatigue and depressive symptoms. Findings demonstrated that fatigue is associated with increases in anxiety and confusion. Recommendations for the healthcare professional to help cancer patients with increased anxiety are guided imagery, relaxation and use of positive coping strategies. The researchers also suggested special guidance and education

about self-care as well as other strategies targeted at restoring direct attention and capacity for concentration in order to minimize cognitive impairment.

Randomized trials have demonstrated that cognitive-behavior strategies, such as relaxed breathing or progressive muscle relaxation, may improve fatigue in patients with cancer (Kim & Kim, 2005). Support groups also would be very beneficial in helping patients cope with the major changes they have experienced. Referrals to the American Cancer Society and Wellness Community for local support groups in the patient's area also helps the patient deal with their emotional issues and subsequently fatigue. `

Nurses are in a key role to educate patients and caregivers about potential cognitive dysfunction post-chemotherapy. Because of the cognitive changes experienced by these women, the nurse's goals for the patient include increasing the patient's functioning to the highest level feasible, follow-up with a multidisciplinary team including a neurologist, counselor and a neuropsychologist. A neuropsychologist is skilled in the administration and interpretation of neurocognitive tests which link behaviors to underlying normal and abnormal brain processes. Their role is very important in assessing, diagnosing and counseling the patient with cognitive impairment. The neuropsychologist can facilitate psychosocial support to improve the patient's coping with lifestyle changes. They also can serve as a guide in cognitive retraining. Cognitive and vocational rehabilitation can be very helpful to this group also (Meyer, 2000).

The effects of cognitive behavioral therapy in severely fatigued patients was studied by Gielissen, Verhazen, & Witjes, (2006). The researchers randomized 112 cancer survivors to either an intervention arm (cognitive behavioral therapy) or a control

arm (standard care). Patients in the intervention group reported significantly greater reduction in fatigue severity than the control group. It also is noteworthy to recognize that quality of life is negatively affected when patients with cognitive dysfunction do not have access to a multidisciplinary team (Grober, 2002). Therefore, the nurse should identify support groups and cognitive retraining programs for these patients. These nurses also should be instrumental in the development of clinical pathways to identify patients experiencing cognitive changes.

The nurse also can provide information about attention restorative exercises to help increase memory and concentration (Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005). Involvement in activities that engage patients' fascination or have other restorative properties that improve attentional capacity may be helpful (Page et al., 2006). Engaging in renewal through nature activities such as sitting near water, gardening, walking, bird-watching, and arts and crafts can improve concentration and problem-solving skills (Syrop, 2008). In a randomized study of 157 women with newly diagnosed breast cancer, Cimprich and Ronis (2003) reported that regular exposure to the natural environment demonstrated improved attentional fatigue. Though limited, existing data indicate that restorative therapy provides benefits for the sensory dimension of cancer-related fatigue. Cimprich (1992) noted improvement in attentional fatigue in a randomized controlled trial involving 32 women after breast cancer surgery.

Educating the patient about expected treatment plans, support groups and counseling can be very beneficial to the patient. Educating the patient and caregiver about web sites that provide information on chemotherapy-related cognitive impairment

resources is also helpful. Additionally, training programs that focus on cognitive behavioral treatment have been used to treat breast cancer patients. Ahles and Saykin (2007) piloted a study that included four cognitive areas of study, including memory and attention education, self-awareness training, self-regulation with a focus on relaxation training, activity scheduling and pacing and strategies to compensate for cognitive dysfunction. Five neuropsychological tests were completed on all 29 breast cancer patients who completed chemotherapy 8 years ago. Results showed improvement in self-report of cognitive function, quality of life and neuropsychological test performance. Generalizability of the study is limited because of the small sample size. Additionally, only one type of cancer was studied. There also was a high level of education among the participants.

In an effort to alleviate fatigue and improve the patient's quality of life, yoga is another integrative intervention that may be useful. Cohen, Warneke, and Fouladi (2004) reported that 39 lymphoma patients participated in a randomized study including an intervention group of yoga, postures, visualization, breathing and mindfulness. Participants in the control group had increased fatigue compared to the intervention group. Though the results are encouraging and suggest that yoga may be a viable intervention for improving cancer-related fatigue, the evidence is preliminary.

Danhauer et. al. (2009) conducted a pilot study of 44 breast cancer patients post-treatment to assess if restorative yoga improved emotional, health-related quality of life and symptom outcome. The women were randomized to a treatment group and a control group. Group differences favoring the yoga group were seen for mental health,

depression, positive effect and spirituality. The yoga group demonstrated a significant improvement in fatigue. Study limitations included small sample size and the participants were at different points of time post-chemotherapy completion.

Another intervention that may be helpful to the patient with cancer-related fatigue is mindfulness-based stress reduction (MBSR) (Mustain, Katula, & Zhao, 2007). The program consists of yoga, mediation, group processing and discussion as well as educational materials related to mindfulness, relaxation and yoga. A study conducted by Carlson, Speca, and Patel (2004) reported improvement in cancer-related fatigue in the MBRS intervention group of 59 breast and prostate cancer patients compared to the control group. While the results are promising there is a need for more appropriately powered randomized clinical trials.

Polarity therapy is another intervention that may improve fatigue in the cancer patient. The therapy employs a gentle human touch in an effort to balance the electrical energy fields. A randomized, controlled pilot study conducted by Roscoe, Matteson, and Mustain (2005) investigated the efficacy of polarity therapy for improving cancer-related fatigue. The results demonstrated that breast cancer survivors receiving the interventions during the course of radiotherapy demonstrated significant reductions in their fatigue level compared to the control group only receiving radiotherapy. Since this is the only published study investigating the efficacy of polarity for controlling cancer-related fatigue, further research is warranted.

The question of whether Reiki is effective in decreasing fatigue levels in cancer patients was studied by Tsang, Carlson, Crossover, and Olson (2007) in a pilot study

including 16 patients. Results suggested that Reiki was effective in decreasing fatigue. Pain and anxiety also decreased cumulatively over the course of five sessions. Overall quality of life also improved among the study participants. The researchers suggested that Reiki is an ideal intervention for patients with limited energy. Limitations of the study include a small sample and lack of a control group

Mao et al. (2009) conducted a clinical trial to determine the feasibility of acupuncture preventing cancer-related fatigue in patients undergoing radiotherapy. Patients received up to 12 treatments of acupuncture over the course of their radiation therapy. Thirty-seven percent of the patients had improvement in their fatigue. Researchers concluded that acupuncture has the potential to prevent radiotherapy-related fatigue. Limitations included a small sample size, and the study was not a randomized controlled trial.

In assessing patients with cancer-related fatigue, it is important to differentiate between fatigue and depression. Assessment of mood changes that persist for 2 weeks or more and cause distress, impair functioning or are associated with other symptoms such as poor sleep or feelings of hopelessness should be included in the evaluation for depression. Cancer patients whose depression is characterized by the presence of somatic symptoms, such as fatigue and sleep disturbance can make the differential diagnosis of depression more challenging. Though it is noted that depression alone does not entirely explain feelings of fatigue in cancer survivors, referral to mental healthcare professional for evaluation and treatment is recommended for patients who exhibit symptoms of depression (Bower et al., 2000). Additionally, distraction, relaxation therapy, educational

and support group interventions are shown to be beneficial for fatigued cancer patients who also experience depression (Bower, 2008).

Assessing for distress in the cancer patient is also important as distress may precipitate fatigue. According to the NCCN Guidelines, distress represents a complex, multifactorial experience that include depression and anxiety (Mock et al., 2000). Assessing for levels of distress using the distress thermometer is important in determining the level of fatigue. It is recommended by the NCCN guidelines that a score of 4 or higher (moderate to severe distress) warrants a referral to a specialist. If the distress in mild (less than 4), the oncology team can provide supportive care (Holland, Andersen & Breitbart, 2007).

A higher level of cancer-related fatigue that occurs before and during chemotherapy treatments in patients with breast cancer may be related to less robust circadian activity rhythm (Ancoli-Israel, Liu, & Marler, 2006). Therefore, improving sleep disturbances is also important in managing cancer-related fatigue. ONS guidelines for pharmacologic management of sleep-wake disturbances specify that clinicians and patients should carefully weigh the benefits and potential harmful effects of pharmacologic sleep interventions (Page, Berger, & Johnson, 2007). Minimal evidence exists to support the effectiveness of herbal supplements (Berger, Parker, & Young-McCaughan, 2005). Because cancer-related fatigue and sleep disturbances are closely linked in terms of prevalence, often occurring as part of a multisystem cluster, both need to be addressed with the patient. According to Hickok et al. (2005) the close association

between fatigue, drowsiness, and sleep disturbances, interventions to improve sleep may also alleviate drowsiness and fatigue.

There needs to be a better understanding of the nature of sleep disturbances, the complex relationship seen with sleep and fatigue and the association with other symptoms commonly reported by the patient, such as anxiety, pain and depression. Assessing for these symptoms and suggesting interventions targeting disordered sleep and daytime sleepiness should be a primary focus of the nurse (Savard & Morin, 2001).

Berger, Kuhn, and Farr (2009) conducted a randomized-controlled trial on 219 breast cancer patients to determine whether sleep quality and fatigue associated with chemotherapy treatments can be improved with behavioral therapy (individualized sleep promotion plan, including modified stimulus control, modified sleep restriction, relaxation therapy and sleep hygiene). The intervention group showed improved sleep quality over time and better sleep. Perceptions of improved sleep quality did not result in lower fatigue.

Berger (2003) recommends improvement in sleep hygiene as a critical intervention in managing sleep disorders. The behavior sleep intervention program includes sleep restriction, stimulus control, relaxation therapy and sleep hygiene counseling (Wielgus et al., 2009). Evidence-based practice guidelines for improving quality of sleep include following sleep hygiene: going to sleep at same time each evening and rising at similar time every morning; limiting time spent in bed; utilizing bed only for sleep and sexual activity; eliminating evening stimulation, such as intake of caffeine, nicotine and alcohol and exercise within four hours of bedtime; exposure to

bright lights and sun upon wakening; and routine times for meals and exercise (Berger et al., 2002). Relaxation training, such as a warm bath, massage, reading and relaxing music, also is an evidence-based practice that helps to optimize sleep quality. Replacing the mattress every 10-12 years also improves the quality of sleep (Berger and Mitchell, 2008).

In addition to sleep hygiene, stimulus control and sleep restriction are important cognitive behavioral therapies to enhance sleep. Stimulus control includes encouraging the patient to go to get out of bed after 20 minutes being unable to go to sleep (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007). Sleep restriction includes avoiding long naps and limiting time in bed (Bootzin, Epstein, & Wood, 1991). In a pilot study by Berger, VonEssen, and Khun (2002) these behavioral therapies were implemented in women during adjuvant breast cancer therapy. The sleep and wake patterns remained consistent with normal values except for increased periods of nighttime awakenings (Davidson, Waisberg, Brundage, & MacLean, 2001). Several studies show that cognitive-behavioral therapy interventions designed to promote quality sleep in cancer patients may also improve fatigue (Savard, Simard, Ivers, & Morin, 2005; Quesnel, Savard, Simard, Ivers, & Morin, 2003; Davidson, Waisberg, Brundage, & MacLean, 2001). Patient education to promote quality sleep should be implemented prior to the first cancer therapy. Additionally, an intervention that is evidence-based, such as behavior sleep intervention, should be initiated in women who label themselves as "poor sleepers" prior to the initiation of cancer therapy. There is minimal empirical evidence for pharmacologic agents to be used to help manage sleep disorders (NCCN, 2009).

Several aforementioned studies substantiated that enhancing the quality of sleep tends to reduce the level of fatigue. Other researchers' findings do not support this position. Fernandes, Stone, Andrews, Morgan, and Sharma (2006) determined that fatigue was significantly correlated with low quality of life, depression and diminished self-reported physical functioning. However, despite the patients having greater impairments of sleep and circadian rhythm, the severity of fatigue did not appear to be related to these impairments. There is an accumulating body of evidence that the elusive concept of symptom clustering is becoming more evident as fatigue, insomnia, pain and depression are further studied in the oncology arena. There is now moderate evidence and the research is sufficient to accept that symptom clustering has validity as a scientific construct and is a clinically relevant problem. There is less evidence indicating an underlying mechanism as well as lack of validity that a few treatments would address all the symptoms (Barsevick, Berger, Bakken, & Cetak, 2007).

Additional integrative non-pharmacologic behavioral treatments should be implemented for the effective management of cancer-related fatigue. A wide range of interventions including educational programs and counseling are particularly beneficial to cancer patients experiencing fatigue. Education about fatigue and its natural course should be offered to all patients, especially as therapy is initiated (Roscoe et al., 2005). It should be stressed to patients that fatigue is not indicative that treatment is not working nor that the disease is progressing (Cella, Peterman, & Passik, 1998). Several studies support the role of educational interventions, such as providing physical sensory

information, anticipatory guidance, coping skills training and coaching to reduce fatigue levels (Allison et al., 2004; Fawzy el al., 1990; Given et al., 2002; Yates et al., 2005).

Additional interventions include supportive-expressive group therapy, supportive intervention therapy including psychosocial support, monthly home visits by support nurses to assess fatigue, provide psychological support and coach participants in self-care may be helpful. Ream, Richardson, and Alexander-Dann (2006) evaluated a supportive intervention for fatigue in patients undergoing chemotherapy. Approximately 100 patients were stratified to either an intervention group (fatigue packet, fatigue diary, support nurses to visit monthly in home to coach patients on self-care) or standard of care. The intervention group reported significantly less fatigue, lower distress and less impact of fatigue on valued past times than the control group. They also reported less anxiety and depression and displayed more adaptive coping.

Studies testing psychosocial interventions to increase psychosocial support and reduce stress in cancer patients have shown decreased levels of fatigue. Interventions included education, support groups, stress management program, individual counseling and a tailored behavioral intervention (Given et al., 2002). Therapies to relax the patient such as breathing control, progressive muscle relaxation, relaxation and guided imagery techniques have been evaluated as effective in controlling fatigue in the patient. Cohen and Fried (2007) conducted a study in which patients were randomized to either imagery/relaxation or a control group with a cognitive behavioral plan. Levels of fatigue and sleep difficulties decreased in both intervention groups; however, there was only a significantly difference noted in the relaxation and guided imagery group. Armes,

Chalder, and Addington-Hall (2007) conducted a randomized controlled trial to evaluate the effectiveness of a behaviorally oriented intervention for cancer-related fatigue. Sixty-four patients were randomized to receive an intervention consisting of education on cancer-related fatigue, self-monitoring of fatigue and a cognitive approach for helping patients clarify the meaning of cancer-related fatigue and the effectiveness of current coping strategies. The intervention group showed significant improvement in physical functioning and indicated a trend toward improvement in their fatigue. There was no effect on distress, anxiety and depression. The power of the study was low because of sample size.

Activity enhancement, such as exercise interventions, exercise conservation and energy management may also be helpful. There is strong evidence to support the benefits of exercise for cancer-related fatigue management. Patients benefit from a low-intensity exercise program as well as aerobic interval training with appropriate monitoring. Strength resistance exercise also may be beneficial to these patients. A home-based exercise program would be beneficial to the cancer patient. Mock et al. (1997) conducted a study that showed a home-based program exercise programs was beneficial during chemotherapy and radiation therapy. A more recent meta-analysis review of 19 articles by Kangas, Bovbjerg, and Montgomery (2008) reported the effectiveness of physical exercise on fatigue-related outcomes. Exercise interventions were more effective when administered during therapy as opposed to after completing therapy. Patients with breast cancer had a better response than other types of cancer.

In addition to implementing an exercise program to reduce fatigue, energy conservation also is an important intervention in the management of cancer-related fatigue. Strategies utilized to teach coping with fatigue include energy conservation and activity management. Barsevick et al. (2004) conducted clinical trials that showed patients with cancer benefit from learning energy conservation. Energy conservation includes teaching the patient about one's planned management of activities and personal energy resources. Rest and activity are maintained while participating in activities important to the patient. Planning, pacing, scheduling and prioritizing activities, delegation and resting are important strategies to include in the management plan. General strategies, such as purchasing labor-saving devices and postponing nonessential activities help to conserve energy. Naps should be limited to 20-30 minutes or less in order to prevent interference with sleep (NCCN, 2009).

Complementary therapies and supplements, drug treatments including hematopoietic growth factors in the anemic patients may also play a role in controlling the cancer-related fatigue. ONS guidelines for fatigue management emphasize that clinicians and patients should carefully evaluate potential benefits and harmful effects of recombinant erythropoietin for individual patients (Mitchell et al., 2007). A recent meta-analysis including 10 studies indicated that treating anemia with erythropoieten did improve the level of fatigue (Minton, Richardson, Hotopf, & Stone, 2008).

Stimulants, such as methylphenidate hydrochloride has been tested in clinical studies for use in relieving cancer-related fatigue. Evidence is inconclusive and future research is warranted (NCCN, 2009).

Depression and distress identified as a contributing factor to fatigue must be treated. Andrykowski, Curran, and Lightner (1998) conducted a study with breast cancer patients to ascertain the correlation between depression and fatigue. Results demonstrated that the breast cancer group demonstrated significantly higher levels of fatigue than the matched group of participants with benign breast problem. However, the two groups did not differ with respect to the amount of depression reported. A study by Servaes et al. (2002) concluded that there was no causal relationship between anxiety/depression and fatigue. The two phenomena are closely related, but it appears another variable might be causing the increase in cancer-related fatigue.

Pharmacologic management of depression may be effective in controlling cancer-related fatigue (NCCN, 2007). Combining antidepressants and counseling may benefit the cancer patient with fatigue. Counseling strategies should include education and behavioral therapy. Counseling becomes very important in helping the patient with fatigue because in clinical studies indicates that serotonin reuptake inhibitors have no significant effect on fatigue in the absence of depressed mood (Morrow, Hickok, & Roscoe, 2003; Roscoe et al., 2005). Antidepressants are not recommended to lower fatigue (NCCN, 2009). Studies utilizing paroxetime showed that the antidepressant had no effect on fatigue in patients receiving chemotherapy (Morrow, Hickok, & Roscoe, 2003; Roscoe, Matteson, & Mustain, 2005).

In addition to the various treatment strategies outlined in the aforementioned section, nursing leadership also serves a pivotal role in recognizing the prevalence and significance of cancer-related fatigue. Fatigue must be recognized as a serious clinical

issue that is highly prevalent in this population and is associated with decreased quality of life. They must understand that the etiology remains to be fully elucidated, and, to date, there is no universally accepted standard. Healthcare leaders also need to believe that fatigue is important to assess and manage in both in- and out-patient settings. Infrastructure and personnel issues need to be controlled in these settings so that strategic plans can be implemented to assess and manage cancer-related fatigue. Cancer-related fatigue needs to be made a clinical priority just as pain was several years ago. Healthcare administrators should be proactive in implementing the National Comprehensive Cancer Network (NCCN) Guidelines and work with other key leaders in recommending the guidelines become legally mandated, as with the assessment and management of pain. Unfortunately, assessment and management of fatigue are not viewed as practice priorities despite its prevalence. It is incumbent for nursing and hospital administrators to recognize that managing the cancer patient's fatigue will require a team approach as well as a system that will support understanding and listening to the words of the patient, assessment of the fatigue and the creation of an environment that encourages individualized patient care with appropriate staff available to manage the patient's fatigue.

Leadership needs to ensure that the healthcare teams takes deliberate steps to assess and intervene in improving quality of life beyond the acute stage of illness and into survivorship. These key leaders also need to take the lead with the oncology healthcare team in helping cancer patients obtain and retain disability benefits from insurers. The team also should advocate for cancer patients who require disability. Insurers need to be

educated about the sequalae of cancer-related fatigue and extend healthcare coverage to patients experiencing long-term fatigue, such as referrals to physical therapists, occupational therapists and dieticians. Additionally, disability insurance and coverage should be available to patients whose fatigue persists with subsequent disability. They should provide ongoing holistic care including rehabilitation to these patients along with disability compensation.

Nursing Education Implications

Students as well as professional nurses need to be educated about the severity and prevalence of cancer-related fatigue. Nursing educators need to increase their focus on teaching fatigue assessment and management as a way to increase the knowledge and skills of nurses who can then better manage fatigue. Educators need to teach students to develop care plans that use evidenced-based interventions for cancer patients experiencing fatigue. Understanding how pervasive fatigue is among cancer patients is extremely important to the nursing student. They also must have an understanding that cancer-related fatigue has a more rapid onset, is more intense, persistent, exhausting and longer lasting and not relieved easily. Additionally, there needs to be an understanding that fatigue is not routinely assessed in many clinical settings and often goes unreported, undiagnosed and untreated. They also need to appreciate that cancer-related fatigue is different from other types of fatigue and should be assessed and managed differently.

Faculty in schools of nursing also play a role in educating future nurses about the importance of listening to their cancer patients as they share their stories about their fatigue. The undergraduate curriculum should include undergraduate nursing students

being mentored by graduate students in phenomenology studies. This would encourage a comfort level in interviewing patients in the clinical setting after graduation. Helping students become proficient with supportive skills to help the patient cope with their fatigue by listening, clarifying concerns, encouragement, reassurance and demonstrating empathetic responses is important. Additionally, plans of care should be developed by the student that include interviewing patients about their fatigue and then developing a plan specific for the patient's story. Additionally, role-playing with students may be helpful in promoting a comfort level as they initiate a discussion about the fatigue.

Additionally, educators need to integrate the importance of patient education in the oncology curriculum with a focus on management of cancer-related fatigue. Godino, Jodan, Duran, Martinez, and Schiaffino (2006) conducted a study to determine whether patient education decreased perception of fatigue in cancer patients. Results reflected that individualized and structured patient education reduced the patient's level of fatigue. They also concluded that individualized education and counseling, as well as individualized support by a trained nurse, provided patients with an effective tool to manage their fatigue.

In addition, nursing students should be encouraged to utilize non-traditional approaches in dealing with the patient's fatigue. Encouraging patients to journal would be helpful as well as imagery and relaxation. Visual journaling that allows the patient to combine words with images would be helpful to the patients in dealing with their feelings and stress related to their fatigue.

Both nursing students and nurses should be educated on the various resources available to both them and their patients. In addition to the Oncology Nursing Society and the National Comprehensive Cancer Network being resourceful, there are several websites available that address cancer-related fatigue, both for the professional as well as the patient (Piper et al., 2008).

Nursing Research Implications

Cancer-related fatigue continues to be a complex phenomenon without a widely accepted definition. The NCCN has attempted to define cancer-related fatigue but has failed to recognize that experienced fatigue is disproportionate to the patient's level of exertion. Neither does the definition include that rest does not relieve the patient's fatigue. Therefore, cancer-related fatigue remains one of the least explained phenomena in oncology. It is the most frequently anticipated side effect of cancer treatment. Approximately 95% of patients scheduled for cancer treatments expect to experience some level of fatigue. Cancer-related fatigue also continues for months and even years following completion of therapy in one-third of patients (Hofman et al., 2004). The findings of this researcher's study revealed that as much as one to five years later, all patients were continuing to experience fatigue that impacted their physical and cognitive functioning. Additionally, the findings revealed there were considerable psychological distress and social isolation as well as significant financial burdens by limiting the patient's ability to work. While understanding the prevalence and chronicity of the fatigue as well as the impactful effects on the patient's quality of life, it is incumbent that

research continues at full speed ahead in order to relieve suffering associated with this devastating symptom.

Healthcare professionals have become increasingly aware of the clinical relevance of cancer-related fatigue and its debilitating effects on the patient. Albeit with this knowledge, the effect of fatigue on the patient's quality of life underscores the need for more effective management strategies to control the symptom. Essential to the investigation of better control of this pervasive symptom is the need to understand the patient's perception of their fatigue. In other words, their voices establish the platform from whence the research begins in understanding what is fatigue, how it affects their lives and what management strategies need to be developed. Before a standard methodology to measure fatigue is established, we must understand the words of the patient. Furthermore, before conceptualizing the definition of cancer-related fatigue, we need to listen to the words uttered by the patients who endure cancer-related fatigue today, tomorrow and interminably. Before formulating a comprehensive, multidisciplinary plan of care for breast cancer patients to help maximize their quality of life, we must hear their words. Obviously, when there is a better understanding of the phenomenon by understanding the meaning of fatigue to the patient, then and only then evidence-based clinical practice guidelines for the management of cancer-related fatigue will be successfully developed. Until the patient's words are heard and understood, this first step in reducing this unrelenting symptom will not occur.

To further develop nursing science, future studies would be helpful in determining the usefulness of the themes about the fatigue in clinical practice. By understanding the

meaning of the symptoms fatigue precipitates will help tailor interventions to the individual patient population. To increase theoretical understanding and improve therapeutic nursing interventions, further research on understanding the experience of cancer-related fatigue with resultant identification of strategies to minimize or ameliorate the fatigue is warranted. In addition, further research is needed to document the progression of fatigue over the course of a cancer treatment, such as radiotherapy and chemotherapy. A nursing theory about fatigue that examines the relationship between the cancer patient's fatigue, the perception of the patient's quality of life (subjective) and various changes in interleukin-6 and /hemoglobin level (objective) responses also would be useful to healthcare professionals.

Further research is needed to identify a standardized way of measuring fatigue as well as strategies to prevent physical deconditioning thereby allowing patients with fatigue to continue engaging in meaningful activities. Also additional research is needed to develop effective strategies that help patients to decrease barriers to exercise and to increase adherence to exercise programs. Further research is needed to test the efficacy of self-care activities that may reduce the fatigue and thus improve quality of life of the cancer patient. Research also is needed to evaluate whether reducing depression and changing coping strategies improve cancer-related fatigue. In order to assess cancer-related fatigue more in-depth, additional research involving the trajectory preceding adjuvant chemotherapy and longer study periods after completion of chemotherapy is warranted.

The strategy proposed by the researcher identifies themes about the experience of cancer-related fatigue which will serve as the basis to develop strategies for reducing the patient's level of fatigue. The findings of such research provide nurses with a sound empirical basis for recommending effective self-care activities to relieve the fatigue.

Given the magnitude of the women's complaint about changes in cognitive functioning and the significance of cognitive dysfunctioning post-chemotherapy in the oncology literature, the oncology nursing community must remain up-to-date in its knowledge of cognitive changes in this patient population. Appropriate assessments, interventions, patient education and referrals to specialty services are paramount for the nurse to implement with these patients. To better understand cognitive dysfunction, the nurse should spearhead clinical studies to address specific assessments and interventions. Subsequently, the results could be implemented into evidence-based practice and clinical pathways to enhance the patient's quality of life while they are dealing with both fatigue and cognitive dysfunction. Additionally, further phenomenological studies are warranted to specifically address the cognitive changes in fatigued cancer patients since this was such a major concern for the breast cancer patients in the study.

Continued research is warranted in understanding the etiologic factors that cause fatigue as well as management strategies. However, as mentioned previously, to successfully address this debilitating symptom, the research focus also must change. Conducting phenomenological studies in order to understand the patient's perspective is the first step before further qualitative and quantitative research should be embraced and pursued. Understanding the meaning of the fatigue for each patient is necessary before

there can be a furtherance of controlling and managing the patient's fatigue. Understanding the experience of the patient's fatigue serves as the foundation from which other research studies can evolve. It is felt that researchers will continue, "to spin their wheels" until we have a clear understanding what it is like to walk in the patient's moccasins.

By looking through the lens of the patient's experience, nurses can began to articulate those findings to practitioners and other healthcare team members as well as hospital administrators. Sharing those findings with reimbursement specialists also will reinforce the major problem to third party reimbursement companies. They, too, need an appreciation of the problem as the debilitating fatigue increases healthcare costs as well as impacts not only the patient but also family members who cannot remain fully employed as they care for their loved one with ongoing fatigue.

In addition to understanding fatigue in breast cancer patients, it is also important that further research is needed to address patients with different types of cancer. To appreciate the true experience of the cancer-related fatigue phenomenon, further studies need to be conducted with other groups of patients, not only including different cancers but different age groups. Studies are also warranted in long-term survivors as well as patients at different points in the illness experience including both male and female participants.

Understanding the level of fatigue in patients prior to the initiation of therapy would also be beneficial. Understanding the patient's health status at the beginning of treatment may be helpful to the healthcare provider. Listening to the words of the patient

as he/she describes the meaning of the onset, duration and pattern on the fatigue may help identify treatment strategies early in the treatment continuum. Not until we have a fuller understanding of the phenomena can we began to appreciate what cancer-related fatigue is and neither can we begin to identify interventions nor develop evidenced-based clinical practice guidelines. Without the patients sharing their stories about their experience of fatigue, these goals are non-existent and at best, are only words. They are only words written in textbooks and journals to perhaps help healthcare professionals feel less guilty and more confident as they address and manage the number one complaint cancer patients have had for the past 25 years.

In summary, cancer patients perceive fatigue as the symptom with the highest impact on their daily living as well as substantially affects and creates functional, psychological, cognitive and socioeconomical issues. This symptom is deserving of clinical attention and clinicians must be aware of this phenomenon and undertake methods of amelioration. This debilitating symptom, without a doubt, is one of the most discussed and researched topics in the specialty of oncology, but only from a quantitative perspective. Despite the plethora of studies focused on answering the question of how to manage fatigue, inconsistencies still prevail and a general conclusion cannot be made. Unfortunately, these studies have not translated into improved management strategies for the suffering patients with diminished quality of lives secondary to their fatigue. Despite efforts to determine causative factors and to identify better treatment strategies, fatigue remains the most common and pervasive symptom cancer patients experience. To address these issues, we must listen to the words of our patients:

Being tired is an understatement! My tiredness was not the tiredness I had after a busy day. It was like you stayed up all night and then heavy weights were placed on your entire body. I would try to lift my left arm and it would take everything in my body to slightly raise it and then it was so hard to put my arm back down. My legs were so heavy…it took everything in me to take a few steps. Just putting my makeup on literally wore me out. I was so tired I could not even button my shirt or zip my pants. I was even too tired to sing a song. I could not even eat. The thought of eating made me tired. I was too tired to pick up a glass of water at my bedside….it was the worst thing imaginable….I cannot describe how awful it was. The worst part was that it affected my mind. I couldn't remember things. I couldn't balance my check book. I forgot how to get home one day….that was really scary to me. Though the tiredness was overwhelming I could not let it consume me…I could not let it get me down. I kept up the faith by peering through my window pane and having "small windows of hope".

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APPENDIX

Informed Consent Statement

Understanding the Meaning of Fatigue Experienced by the Breast Cancer Patient: A Phenomenological Study

You are invited to participate in a research study. The purpose of this study is to explore the experience of having cancer-related fatigue. If you agree to participate, an experienced interviewer will conduct an audio taped interview with you that will last approximately one hour in a place of your choice. You will be asked to share your lived experience of being a cancer patient who is experiencing cancer-related fatigue. The nature and direction of the interview will be determined by you and the investigator and will unfold as the interview progresses. The interviewer may ask you to clarify or elaborate on your comments. This interview will be audio taped so that the investigators can use your exact words to understand your experience. These interviews will be transcribed into written form for analysis by an interdisciplinary research group. You will be asked to complete a demographic sheet indicating age, race, educational level, and date of cancer diagnosis.

Your name will not appear on the tape or the transcript. Tapes, transcripts, and consent forms will be kept in a separate locked file drawer in the Principle Investigator's office. Tapes will be destroyed after the interview is transcribed. For further study, transcripts will be archived in a locked drawer in the researcher's office.

In appreciation of your time and effort in participating, a handout on ways to manage fatigue will be provided. Participating in this study is strictly voluntary. You may contact the investigator following the interview and during the analysis to clarify the interpretation of the experience. You may experience some fatigue as a result of the length of the interview. Should you become tired during the interview, the interview can be terminated and a follow-up interview can be completed at a time and location convenient for you. You are free to choose not to participate in this study and you can withdraw at any time, before, during, or after the interview. Should you feel sad or anxious during the interview, you may request the interview to be terminated. Available resources to assist you with the sadness or anxiety will be offered to you. Your audio tape and/or transcript will be destroyed upon your request.

Any and all information will be kept in confidence. Neither your name nor any identifying information will be used in any reports although your words may be used to support the interpretation and analysis. Your transcribed words will not be traceable to you in public reports or articles resulting from the study.

Questions about this project can be directed to:

Lois Doane, MSN, RN, AOCN. (865) 384-8586

Sandra Thomas, PhD, RN. (865) 974-7581

University of Tennessee College of Nursing

1200 Volunteer Blvd.

Knoxville, TN. 37996-4180

I give permission to be interviewed.

_____ _____

Signature Date

I give permission for my transcribed interview to be archived for further study.

_____ _____

Signature Date

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Confidentiality Pledge of Group Member

I, _____, a member of the Phenomenology Research Group at the College of Nursing, University of Tennessee, pledge to maintain confidentiality of this audio taped research interview following discussions of the transcript in the research group. I will not discuss the contents of the transcripts outside the research group.

Date: _____

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Confidentiality Pledge of Transcriptionist

I, _____, as a transcriptionist for this study, pledge to maintain confidentiality of this audio taped research interview during and following transcription. I will not discuss the transcripts with anyone other than the Principle Investigator and the faculty advisor.

Date: _____ Signature: _____

VITA

Lois Starnes Doane was born in Rogersville, Tennessee on January 12, 1949. She graduated from Rogersville High School. She received her Diploma of Nursing from the University of Tennessee Medical Center in 1970 and BSN and MSN in 1975 and 1978 from the University of Tennessee. She is certified as an advanced practice nurse in oncology by the Oncology Nursing Society. She is a member of Sigma Theta Tau.

Lois has enjoyed over 34 years in oncology nursing in which she has been a clinical specialist, a manager and an educator. She also served as an adjunct faculty at the University of Tennessee College of Nursing for several years. She was named the recipient of the Alumni Award in Nursing Education.

Lois has volunteered with the American Cancer Society over 30 years and has served as a local, state and Mid-South board member as well as a delegate to the National Assembly. She is co-founder of a cancer support group, CancerNet that has been meeting monthly since 1985. Lois is the recipient of various American Cancer Society awards including Volunteer Leadership Award, the National Divisional Award, St. George Medal, and the Lane Adams Award.

Lois has conducted clinical research in oncology and has presented papers at national and international cancer congresses. She also has conducted poster presentations at state, national and international professional meetings. She has served on several national nursing committees and oncology advisory boards She has several publications in peer journals. Lois received her Doctorate of Philosophy in Nursing from the University of Tennessee, Knoxville in December, 2009.