Coping with Cancer: Taking Action to Adapt to the Realities of Cancer and Treatment

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Dedication

This thesis is dedicated to my grandpa, George Yates, who is living with and courageously surviving cancer in spite of the odds against him. I attribute his survival to the strength of his fighting, often stubborn, character. I love you, Grandpa! It is also dedicated to the memory of my grandma, Annelies Sullivan. Cancer took her life when I was young; however, her life continues to guide and inspire me.
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Abstract

The purpose of this qualitative study was to explore and better understand problems and ways of coping with cancer and treatment and then identify interventions that nurses may use to address issues identified as problematic and assist patients to cope more effectively with cancer. Grounded theory methodology was used to analyze data obtained from audio taped and transcribed interviews with three individuals with cancer who were undergoing treatment. *Taking action* was the core category that described the experiences and problems facing patients with cancer undergoing treatment. The following seven supporting categories describe patients’ ability to take action, cope, and achieve personal control: (a) seeking information, (b) enduring physical symptoms, (c) maintaining hope, (d) finding meaning, (e) establishing social support systems, (f) accepting change and loss, and (g) acknowledging fear and emotions. These findings provide nurses with a basic framework for practice as well as a greater understanding of how patients with cancer cope.
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Introduction

Cancer is the second leading cause of death in the U. S. after heart disease. The American Cancer Society (2005) estimates that 570,280 men and women will die of cancer in 2005. The diagnosis of cancer is a life-altering event, but approximately 1.4 million Americans will be diagnosed in 2005. Cancer is a physically, emotionally, and socially devastating epidemic that every American will be faced with at some point, whether personally or with a loved one. One in two men and one in three women will have some form of cancer in their lifetime (American Cancer Society, 2005). Cancer has tremendous emotional and physical effects, and there are a multitude of ensuing issues involved with cancer and its treatment. The purpose of this thesis is to explore and better understand the experiences, problems, and ways of coping with the disease and treatment for patients with cancer and then identify interventions for nurses to minimize these areas recognized as problematic and assist patients to cope more effectively with cancer.

Etiology and Risks

Experts say that “although the precise biochemical cause is unknown, there are risk factors associated with increased incidence of cancer” (McCance & Heuther, 2002, p. 329). Genetic predisposition, hormones, ultra violet rays, ionizing radiation, human papilloma viruses, herpes viruses, and occupational exposure to asbestos, fossil fuels, dyes, rubber, and paint may increase cancer risk (McCance & Heuther, 2002). People are continually exposed to toxic, mutagenic, and carcinogenic chemicals, such as environmental and industrial contaminants, some artificial additives and preservatives in foods, compounds produced in the cooking of fat, meat, or protein, and certain prescribed and over the counter drugs (McCance & Heuther, 2002).
Ironically, “cytotoxic drugs used to treat cancers may damage chromosomes and occasionally cause secondary malignancies” (Venes, 2001, p. 311). Personal behaviors associated with increased cancer risk include smoking, chewing tobacco, alcohol abuse, risky sexual behavior, obesity, and high fat diets (McCance & Heuther, 2002).

Cancer is likely multi-causal, meaning that multiple factors interact in the development of cancer. Certain types of cancer are associated with carcinogens. For example, UV rays are related to cancers of the skin and eyes; benzene is associated with myelogenous leukemia, and tobacco is associated with lung, esophageal, oral, pancreatic, kidney, liver, stomach, and colon cancers, as well as leukemia (Ignatavicius & Workman, 2002). Genetics and physiological environment may facilitate cancer development, either alone or in association with carcinogenic or mutagenic agents.

Prevention. Cancer is not predictable, but it can often be prevented. One third of the cancer deaths that occur annually are related to diet and other lifestyle factors; thus, they could have been prevented (Venes, 2001). The Center for Disease Control recommends eating a diet low in fats, high in fruits, vegetables, and other plant products, exercising, maintaining a healthy weight, quitting smoking, avoiding second hand smoke, limiting sun exposure, and having regular cancer screenings for early detection (2004). The other two-thirds of malignant diseases, however, are idiopathic, in which the exact cause is unknown. A woman who has led a healthy life of proper diet and physical activity may die of cancer, while a man who smokes two packs a day his entire life may never get cancer.
Pathophysiology

While more than 200 types of cancer have been identified, the most common types in the U. S. are cancers of the lungs, breasts, colon, prostate, and skin (Venes, 2001). A malignant tumor or cancer is caused by the uncontrolled growth of cells, often with invasion of locally healthy tissues, and it may spread or metastasize throughout the body (Venes, 2001). Cancer development is a result of malfunction or mutation of genes that regulate division and proliferation of cells. There are two possible routes: a proto-oncogene, that codes for normal growth stimulation may become mutated or malfunction. It becomes an oncogene, which codes for hyperactive growth. The second possibility is that a tumor suppressor gene controlling abnormal growth may mutate or malfunction, allowing for hyperactive cell proliferation: “Carcinogenesis involves inactivation of tumor suppressor genes and/or activation of oncogenes” (McCance & Heuther, 2002, p. 308).

Cancer cells are independent from other cells and from normal control; they produce their own growth factors. They have no differentiation, which is the process of developing specialized function and organization, such as brain or liver tissue. Cancer cell characteristics include an increase in cell numbers, varied size and shape, unorganized arrangement, and a tendency to invade surrounding cells. Cell membranes change, causing decreased intercellular communication, and they no longer anchor to other cells in tissue, allowing them to travel and metastasize (McCance & Heuther, 2002). A tumor may cause compression, obstruction, stretching, invasion of, and damage to the surrounding tissue, as well as inflammation, all of which may contribute to pain.

Signs and Symptoms
There are several general clinical manifestations that are commonly associated with cancer: “Usually little or no pain is associated with the early stages of malignant disease, but pain occurs in 60% to 80% of individuals who are terminally ill with cancer” (McCance & Heuther, 2002, p. 341). Fatigue is the most frequently reported symptom of cancer and cancer treatment (McCance & Heuther, 2002). Cachexia syndrome is a collection of signs and symptoms which include early satiety (filling), anorexia, change in taste, weight loss, anemia, marked weakness, altered metabolism, and a general sunken and emaciated appearance (Ignatavicius & Workman, 2002). This syndrome may actually cause death before a malignant tumor does. Anemia is another disorder commonly associated with cancer caused by malignancy of blood-forming organs, iron deficiency related to chronic bleeding, malnutrition, and medical therapies and treatment (McCance & Heuther, 2002). Usually in relation to depressed bone marrow, decreased white blood cell count, and decreased immune system function that results from the cancer and/or treatment, “infection is the most significant cause of complications and death in persons with malignant disease” (McCance & Heuther, 2002, p. 344).

Treatment

The most common conventional medical treatment options include surgery, radiation, and chemotherapy. Surgery involves the removal of diseased tissue. If the cancer has not spread and all cancerous tissue is removed, surgery can result in a cure. Many cancers have already spread too far for surgery alone to be curative; however, it still may be useful for diagnosis, determination of therapy effectiveness, reconstruction or rehabilitation, or palliation (Ignatavicius & Workman, 2002).
The purpose of radiation is to locally destroy cancer cells while limiting normal cell exposure to the damaging effects of radiation. Adverse effects of radiation include fatigue that can be debilitating, taste changes, damage to normal tissue in the area of radiation, and impaired skin integrity (Ignatavicius & Workman, 2002).

Chemotherapy consists of a regimen of drugs and chemical compounds effective in killing cancer cells; “its effects are systemic and thus provide the opportunity to kill metastatic cancer cells that have escaped local treatment” (Ignatavicius & Workman, 2002, p. 430). The cell damaging effects are not necessarily selective of cancer cells; healthy cells, especially those that divide rapidly, are profoundly affected. Adverse effects of chemotherapy include bone marrow suppression, compromised immune system, nausea and vomiting, mucotitis/stomatitis, and alopecia.

Hormone therapy, colony stimulating factors, and interferon are less common, but are still considered conventional medical cancer treatments. Depending on the treatment location, there may be various clinical trials available to the patient based on new research. There are numerous complimentary and alternative therapies a person with cancer may choose from as well, which include vitamin and herbal therapies, massage, and prayer to name just a few that may be used in conjunction with or instead of conventional cancer treatment.

Impact on the Person

A cancer diagnosis is a crisis and a life-changing event, which affects every aspect of a persons being. Patient’s lives will forever be changed, if for no other reason than that they were faced with a crisis, which forced them to come to terms with life and death, no matter what the prognosis. A woman with cancer describes the impact cancer
has had on her: “Having cancer changes everything. . . . Nothing, your daily routines, your relationships, or beliefs, or your future will ever be the same again. Cancer has meaning in relation to all events in its vicinity, and its influence permeates a person’s entire life” (Utley, 1999, p. 1523).

*Psychosocial impact.* Cancer is a disease that can cause a high level of psychological distress, from the initial diagnosis, as one is making decisions regarding treatment, to actual treatment, and afterward. The uncertainty one faces, along with the psychological distress and physical anguish experienced throughout the process can lead to fear and anxiety, depression, hopelessness, social isolation, and many more psychosocial dilemmas (Ignatavicius & Workman, 2002). A person must go through a process of coming to terms with the cancer and accepting it. Patients will call upon their past coping mechanisms to deal with their distress, whether mechanisms are effective or not. Effective coping strategies function as “sufficient regulators to reduce the stress of cancer” (Wonghongkul, Moore, Musil, Schneider, & Deilmling, 2000, p.427). It is part of a nurse’s role to assess coping, and to help patients find effective coping mechanisms when those they are using are ineffective. Social support systems also play a major part in managing the stress of cancer, by providing comfort, encouragement, and presence. Wonghongkul et al., (2000) found that “social support can prevent the perception of uncertainty by supplying feedback on the meaning of events” (p. 427).

*Physical impact.* As discussed above in the section on signs and symptoms, there are many physiologically uncomfortable symptoms that a person with cancer may endure. Depending on treatment choices, one may face a number of other physical discomforts, treatment complications, and risks. Cancer treatment is harsh and extremely stressing
physiologically. There are many adverse effects and complications associated with cancer treatment, which include pain, fatigue, nausea and vomiting, stomatitis, alopecia, diarrhea, constipation, anemia, leukopenia, thrombocytopenia, infection, and paraneoplastic syndromes (McCance & Heuther, 2002).

**Ethical impact.** There are a variety of difficult decisions that a patient with cancer will have to make following diagnosis. With the advice of their health care providers, patients must decide first the route of treatment, if any, they will undergo depending on advancement, prognosis, type of cancer, and personal preference. They may also need to consider a living will, which may include advance directives and a Do Not Resuscitate order. Nurses must advocate patients’ needs and wishes throughout the process of their cancer from diagnosis through end of life care. The ethical implications of cancer require nurses to use a high level communication and provide support for the patient and family to ensure that they understand their options, to support their decisions, to document accurately, and to ensure patient privacy and confidentiality (Christensen, 2002).

**Financial impact.** Cancer screening, advancing medical treatments, and new technologies mean more people than ever are surviving cancer. According to the American Cancer Society, 50% of those diagnosed with cancer will be cured (2004). However, survival may come at a high price. The National Institute of Health estimates the overall cost for cancer in the U.S. in 2002 was $171.6 billion (PR Newswire, 2003), and this cost is surely rising.

Major medical insurance will pay for most of the medical care and treatment of cancer, but the medical expenses not covered by insurance, such as deductibles and coinsurance can still be overwhelming; for instance, one may be expected to pay a 10%
co-payment for treatment costs in the tens of thousands of dollars (PR Newswire, 2003). Major medical insurance may not cover out of network care if one needed to go to a regional or national treatment center. Non-medical expenses such as lost wages, travel expenses to treatment centers, lodging and meals, child care, special diets, and home modifications, to name a few, may also overwhelm a patient with cancer and his or her family (PR Newswire, 2003). The financial burden of cancer treatment and care as well as the immense impact on physical and psychological well-being are stressors that require a high degree of coping.

Summary

It is crucial that nurses involved in the care of patients with cancer have a broad understanding of the various aspects of the disease and treatment and the effects of these aspects on the person. Nurses will encounter patients with cancer in many areas as these patients’ care extends across various areas of healthcare. Consideration of the tremendous emotional and physical effects that cancer has on the person can help the nurse to better understand the necessity of effective coping for these patients and positively influence nurses’ overall care of patients with cancer. The interventions nurses use can promote effective coping that will ultimately lead to more positive outcomes and improved quality of life for the patient with cancer regardless of the prognosis.

Purpose. The purpose of this thesis is to explore and better understand the experiences, problems, and ways of coping with the disease and treatment for patients’ with cancer and then identify ways for nurses to minimize areas identified as problematic and assist patients to cope more effectively with cancer. The study was designed to answer the following questions: (1) What are the problems and experiences of patients
with cancer? (2) How do patients with cancer cope with the disease and treatment? (3) In what ways can nurses assist patients to cope?

Assumptions.

- People with cancer are willing to share their cancer experience with a student nurse.
- People with cancer have problems and/or issues related to their disease and treatment.
- Coping influences people’s outlook, quality of life, and health outcomes.
- Coping will vary among individuals and individuals’ coping will vary from day to day in relation to circumstances.

Limitations. The sample consisted of only three individuals with cancer, each with a different type of cancer and in different phases of the disease. Due to the small sample size, saturation of all categories was not achieved. While categories or themes emerged portraying similar issues or experiences of the participants, findings would likely vary with more participants in a specific population or a more diverse sample. All participants are from rural geographical settings. The results cannot be taken as an attempt to generalize the experiences and issues of all patients with cancer. Carroll College does not have an Institutional Review Board. Informed consent was obtained, however, and the standards of confidentiality have been upheld, which include assurance that participants’ identities and research records remain confidential (see appendix A).

Chapter II
Review of Literature

Coping is a complex process that involves every dimension of the human being—physiological, psychological, sociocultural, and spiritual. Moreover, quality of life is perceived as “the net physical, psychologic, social, and spiritual well-being” (Ream, Richardson, & Alexander-Dann, 2002, p. 300). From this it can be assumed that coping and well-being are inter-related. Coping with cancer involves the human dimensions and is associated with many outside factors as well. Nurses need to understand the various aspects affecting coping in order to gain a better understanding of the phenomenon of how a population facing the uncertainty of this dreaded, potentially devastating, and possibly fatal disease adapts to living with cancer and endures the exhausting and sometimes debilitating therapies through various means of coping.

Physical Symptom Distress

The physical symptom distress of patients with cancer is often rooted in the tumor. Because of the differing locations of their tumors, patients with cancer experience different physical and emotional symptom distress. For example, a person with lung cancer may experience difficulty breathing, coughing, and anxiety (Ting-Ting & Fung-Chi, 2002). It is known that various “cancer related symptoms can be alleviated or even eliminated by reduction in tumor size through therapy; however, treatment brings with it side effects that are another source of symptom distress for patients” (Ting-Ting & Fung-Chi, 2002, p. 310). Common side effects that occur with multiple cancer treatments include decreased white blood cell counts, nausea, vomiting, loss of appetite, constipation, hair loss, skin sores, mouth sores, taste changes, pain, fatigue, (Chernecky,
1999), as well as “changes in activity levels and sleep disturbances, which often occur simultaneously” (Young-McCaughan et al., 2003, p. 442).

Estimates on the prevalence of cancer and treatment related fatigue range from 65% to 100% (Ream, Richardson, & Alexander-Dann, 2002). Ream et al.’s study on fatigue (2002) found that “patients perceive fatigue as one of the most troublesome and distressing symptoms associated with cancer and its treatment” (p. 301). Fatigue associated with illness has been defined as a subjective, unpleasant symptom that includes total body feelings ranging from tiredness to exhaustion; fatigue creates an unrelenting overall condition that interferes with an individual’s ability to function. The psychological implications of such physical limitations are individual, but can include feelings of uselessness, reliance on others, feelings of fear, frustration, depression, and compromised socialization (Ream, et al., 2002).

In their qualitative study to understand the correlation between symptom distress and coping strategies in patients with lung cancer, it was found that “physical symptom distresses interact with psychological symptom distress” (Ting-Ting & Fung-Chi, 2002, p. 315) and “severe physical symptom distress is worsened by psychological symptom distress” (Ting-Ting & Fung-Chi, 2002, p. 310). In this study correlations showed that the degree of physical and psychological symptom distress was lessened with the use of effective coping strategies and adaptive behavior (Ting-Ting & Fung-Chi, 2002, p. 314).

Psychological Symptom Distress

Psychological distress encompasses a series of negative emotions, such as anxiety, fear, anger, confusion, and depression that are the end states of a maladaptive process (Zabalegui, 1999). As discussed above, and proven in study, physical and
psychological cancer distresses are related (Ting-Ting & Fung-Chi, 2002; Zabalegui, 1999; Uitterhoeve, Duijnhouwer, Ambaum & van Acterber, 2003). The physical symptoms are stressors that contribute to the psychological distress of cancer. However, there are many other stressors contributing to psychological distress for patients with cancer, such as initial diagnoses, confusion about diagnoses and treatment, fear of treatment side effects, uncertainty whether treatment will be effective, metastatic spread, the need for further treatment, family members responses, the impact of cancer on daily lives, poor prognoses, and fear of the unknown to name a few (Uitterhoeve et. al, 2003). However, there appears to be inconsistency in the amount of attention that patients with cancer receive in the psychosocial area of their health.

Psychological needs. In a quantitative study by the Dutch Oncology Nursing Society seeking to explore differences between perceptions of cancer patients receiving chemotherapy and their caregivers, it was found that medical specialists and nurses pay much attention to medical aspects and to ensuring that the patient understands these medical aspects, but rarely address the psychosocial sequelae of the treatment (Uitterhoeve et al., 2003). There is little importance placed on care of the psychological aspect of the person in regards to the emotional stress that cancer invokes, and the coping and adaptation that is necessary to forgo the physical distress caused by cancer treatment (Uitterhoeve et al., 2003). The fact that severe physical symptom distress is worsened by psychologic symptom distress and is lessened by effective coping and adaptive behavior (Ting-Ting & Fung-Chi, 2002), as discussed earlier, proves that much more attention needs to be given to the psychological well-being of patients with cancer and facilitating coping.
Nurses can impact coping and adaptation, divert psychological crisis, and improve quality of life by caring for patients with cancer holistically (Chernecky, 1999). Nurses need to address more than physical symptoms and complications; they need to also address the patients’ emotions and perceptions, their psychosocial and spiritual needs. A nurse’s role in caring for patients with cancer should include close regard to any psychological issues or distress, and evaluating and facilitating effective coping to lessen psychologic and physiologic distress to promote well-being. According to Ting-Ting & Fung-Chi, “Use of coping alleviates the effects of stress on an individual’s physical and psychologic symptom distress” (2002, p. 310).

**Factors Influencing Coping**

Coping has been defined as “an individual’s attempt to manage stress and adapt to the demands of added problems” (Ting-Ting & Fung-Chi, 2002, p. 310). Lazarus, a prominent figure in coping research and theory, proposed that individuals use coping as a primary mechanism to adapt to their illness, which helps to alleviate a stressful situation (Ting-Ting & Fung-Chi, 2002). Patients differ in their reaction to the stressors of cancer and its treatment. Their level of stress is based on their adaptive resources, which “to a certain extent is determined by psychosocial factors, such as the ability to cope with the illness, the availability of social support, and the nature and impact of this type of crisis on daily functioning” (Uitterhoeve et al., 2003, p. 19).

The process patients with cancer use to cope is complex and is influenced by many factors including available social support, stage of cancer, prognosis, treatment regimen, expected outcome, previous coping mechanisms (Hee-Seung, Hye, Young-Sun, Nam-Cho & Yang-Suk, 2002), and their perceptions of meanings, uncertainty, and hope.
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(Ramfelt, Severinsson, & Lutzen, 2002; Wonghongkul et al., 2000). It is important that
the nurse continually assess coping so that he or she may support and encourage
continued effective coping or teach coping techniques that might increase the
effectiveness of adaptation to cancer, realizing, however, that “a coping strategy that is
effective at one time may not necessarily be effective in another situation or a different
time” (Ting-Ting & Fung-Chi, 2002).

Types of coping. Coping has been defined as a person’s “cognitive and behavioral
efforts to manage demands imposed by the person-environment transaction” (Chernecky,
1999, p. 268). The two major paths for coping, as classified by Lazarus and Folkman, are
emotion focused coping and problem focused coping (Zabalegui, 1999). Lazarus and
Folkman’s “problem focused coping is an effort to control the stressful situation by
altering the original source of stress by changing behaviors or environmental conditions,
whereas emotion focused coping is an effort to control stress-related emotions by
avoiding the stressful situation or reconstructing the context cognitively” (Ting-Ting &
Fung-Chi, 2002, p. 311). Patients with advanced cancer tend to use more emotion-
focused coping than those with early cancer, who tend to use more problem-focused
coping (Zabalegui, 1999); however, “neither of these two coping strategy types is
superior to the other” (Ting-Ting & Fung-Chi, 2002, p. 311). Because coping is
individualized and dynamic, it can only be evaluated by its short and long-term
effectiveness. Short-term effects include alleviating the demands of a particular stressful
situation and allowing one to adjust his or her own emotional reaction to the stress. In the
long-term, he or she might maintain and improve personal health and social function
(Ting-Ting & Fung-Chi, 2002).
Effective coping. Effective adaptation and coping by patients with cancer to their illness and to the stress of treatment “increases the feeling of control, fills the patient with hope, gives the patient goals for the future, and enables him or her to interact in society to seek related information and make positive lifestyle changes, and enables appropriate emotion expression” (Ting-Ting & Fung-Chi, 2002, p. 311). The nurse can play an important part in cancer patients’ coping and adapting by providing emotional support, training in coping techniques, decreasing patients’ symptom distress, and increasing the effectiveness of adaptation to stress (Gaston-Johansson et al., 2000). Providing preparatory information to increase control, cognitive restructuring, which includes positive coping statements and avoidance of negative statements, and methods of relaxation are strategies that have been proven effective to reduce physical and emotional distress related to cancer treatment (Gaston-Johansson et al., 2000).

Coping Strategies

Positive or effective coping strategies are internal thoughts and behaviors used to manage pain and physical symptoms, emotional reactions to symptoms, and to reduce emotional distress (Gaston-Johansson et al., 2000). On the other hand, “catastrophizing, a negative coping strategy, is defined as a method of cognitive coping characterized by negative self statements and thoughts about the future” (Gaston-Johansson et al., 2000, p. 279). It has been proven that negative thoughts are associated with negative health outcomes (Gaston-Johansson et al., 2000). Effective coping strategies differ from person to person based on individuality and from day to day due to changes in health. It is the role of the nurse to continually assess patients with cancer psychologically to evaluate the effectiveness of coping strategies.
Social support. The coping strategies one employs to manage stress may be effective or ineffective. Effective coping, as previously discussed, allows for acceptance, increases feelings of control, hope, and emotional expression. Patients with cancer use a combination of coping strategies to deal with the stressors associated with the disease (Zabalegui, 1999). Seeking and using social support is the effort to establish personal interactions with people who could provide informational, physical, or emotional support (Zabalegui, 1999). Support and assistance from family members is important to helping the patient cope with stress resulting from the disease and treatment (Ting-Ting & Fung-Chi, 2002).

Effective avoidance strategies. Distancing is dealing objectively with the problem by minimizing its significance (Zabalegui, 1999). Another example of an effective avoidance strategy is "focusing on the positive, the effort to approach the situation with a constructive attitude" (Zabalegui, 1999, p. 1512). Behavioral escape-avoidance is the effort to physically avoid confronting the stressor or to flee from it through delayed or risky behavior, and "cognitive escape-avoidance is the effort to mentally avoid confronting the stressor or fleeing through fantasy or dreamlike thinking" (Zabalegui, 1999, p. 1512). Seeking and using social support, distancing, and focusing on the positive are coping strategies associated with low psychological distress (Zabalegui, 1999), and when evaluated as such may be considered effective coping strategies.

Normalizing. Normalization is an effort to maintain normal roles and continue on with one's life as normally as possible and includes employing strategies of humor, concealing emotions, distraction, and comparing self to others worse off (Cowley, Heyman, Stanton, & Milner, 2000). While some aspects of the normalization strategy
may be ineffective, humor can be very uplifting and, thus, effective, and patients report that it provides a means of coping with fear (Cowley et al., 2000).

Humor. Johnson (2002) said, “Medical research has shown that humor has positive effects on the immune system and stress levels and also may have spiritual significance for patients with cancer” (p. 691). Humor is a universal emotion, a component of the human experience, and a coping strategy in itself that enables some patients with cancer to adapt to difficult or stressful experiences related to their disease (Johnson, 2002). Many patients feel that laughter helps them to cope with the diagnosis, treatment, and prognosis of the disease, and they report that humor creates a sense of cohesiveness and a more trustworthy relationship with their nurse (Johnson, 2002). Patients with cancer also believe that humor influences their spirituality and their perception of the meaning and purpose of life.

Faith. Spirituality, possibly more than any other human dimension, affects the meaning and purpose one has for life. Illness increases awareness of the inadequacy in relying on self and the need to rely on a greater power. Prayer and putting trust in God is a significant coping strategy used by many physically ill individuals, including persons with cancer, who use prayer to cope with distressing symptoms and procedures, and to find comfort, decrease fear, anxiety, and uncertainty, and facilitate hope and adjustment to cancer. Patients with cancer use prayer, a personal form of communication involving transcendence, to ease physical, emotional, and spiritual distress of the illness (Taylor-Johnston & Outlaw-Hopkins, 2002).

Prayer may contribute to both physical and psychological health; nurses need to provide holistic care, recognizing that prayer is a valued and frequently used coping
strategy for many patients with cancer (Taylor-Johnston & Outlaw-Hopkins, 2002). It is important that nurses assess patients' spiritual needs, as well as assess for any spiritual distress or conflict. Nurses can facilitate coping as well as help patients find meaning in their situation by recognizing and facilitating patients' use of prayer, and help by fostering a condition and environment conducive to prayer, and help the patient to relax, offer spiritual reading material, place the patient with a view of nature, and offer a notebook for journaling (Taylor-Johnston & Outlaw-Hopkins, 2002).

Finding meaning. Individual coping may be influenced by the meaning that an illness has for the patients, and by their outlook of the future. A qualitative study aimed at exploring the "emotional and interactional perspectives of the meaning of illness in patients with colorectal cancer" found a theme that can serve as a theoretical basis relevant to nursing practice and education (Ramfelt et al., 2002). The main theme was that patients with cancer were "attempting to find meaning in illness to achieve emotional coherence" or emotional stability (Ramfelt et al., 2002, p. 141). This main theme consisted of two dimensions. The first, unified embodiment, includes gratefulness, confidence in oneself and others, and looking forward to creating a new future; characteristics of this meaning were hope, faith, a strong self-value, and an anticipated future. Dichotomized embodiment, the second dimension of the theme, included altered self-value, loss of temporality, and infringement of body integrity; characteristics of this meaning were struggle, loss of temporality, non-movement, and lack of hope and faith (Ramfelt et al., 2002).
When considering Ramfelt et al.'s theory, it is important to understand that "patients' emotional and intentional thoughts about the illness shaped their thoughts about the whole system, including bodily and relational aspects" (2002, p. 147). Unified embodiment is the expression of goals for the future while dichotomized embodiment often involves a loss of temporality (Ramfelt et al., 2002). From this model it becomes obvious that the cognitive and emotional meaning an individual finds in the cancer illness will profoundly affect his or her method of coping and determines whether feelings about their future will be of expectation or despair.

It is essential to recognize the "need to extend nursing care to the family of the patient with cancer. The family as well as the patient experiences and attempts to understand the meaning of cancer" (Uitterhoeve et al., 2003, p. 26). This reinforces a fact identified by Wonghongkul et al. (2000) that "social support can prevent the perceptions of uncertainty by supplying feedback on the meaning of events, so that the precision of the event is asserted" (p. 427).

**Hope vs. Uncertainty**

Hope has been defined as a desire for something one wishes for or believes in and finds possible (Ramfelt et al., 2002). It may be influenced positively by social support, self-esteem, and spirituality; it is a resource for patients with cancer that fosters coping, increases participation in treatment regimens, and strengthens the belief that difficulties can be managed (Ramfelt et al., 2002). Ebright & Lyon (2002) point out that "hope, like some other emotions, is generated from thoughts about threatening situations" (p. 561). Following initial diagnosis and throughout cancer illness, the uncertainty
regarding the future and how the disease will progress is prominent, and “when patients lack control, i.e., feel uncertain, the uncertainty causes psychologic suffering” (Ramfelt et al., 2002, p. 142). Appraisal of uncertainty can paralyze hope and reduce the individual to merely existing (Ramfelt et al., 2002). Professional caregivers “must acknowledge that hope is a powerful concept. They need to remember to protect the ideas and images on which patients rely to preserve the capacity of hope, while providing their patients with realistic information” (Uitterhoeve et al., 2003, p. 26).

Optimism. Optimistic expression seems to be associated with an ability to maintain hope and create a future that is supported by others (Ramfelt et al., 2002). Nurses should employ interventions to strengthen patients’ beliefs about their ability to manage and cope by focusing on strengths and potentials instead of limitations, promote social support, and encourage expression of spiritual beliefs and practices to increase hope (Ebright & Lyon, 2002). Nurses should provide care to reduce individuals’ perceptions of uncertainty in their illness, thereby possibly increasing their levels of hope and decreasing their appraisal of threat and harm of events (Wonghongkul et al., 2000).

Patient education. Studies have concluded that the more thorough information patients receive from specialists, the less uncertainty they experience, and the less likely they are to experience depression and other psychologic distress (Uitterhoeve et al., 2003). Patients with cancer are able to cope better with their diagnosis and treatment when communication from doctors, nurses, and health care providers is honest and open, and they are informed of what to expect from their treatment: “A combination of medical
factors and the ability of the medical specialist and other professional caregivers to guide and support patients influence coping with cancer” (Uitterhoeve et al., 2003, p. 19).

Health care professionals caring for patients who do face uncertain prognoses need to manage a “risk communication dilemma” (Cowley et al., 2000, p. 314). Fully informing a patient with cancer about the risks he or she faces can cause anxiety and depression, and even interfere with recovery, given the evidence of psychological influences on health outcomes. However, if patients do not understand the medical thinking behind the treatment, their misconceptions and uncertainty may be equally damaging (Cowley et al., 2000).

Patient perceptions. For effective communication with patients, health care providers also need to consider patients’ perception of the reason for treatment. As discussed in the section on psychological distress, patients’ psychosocial needs often go unmet due to an emphasis by health care providers exclusively on physiologic and medical aspects. For patients, the reality lies in the present experience, and they perceive their treatment as a chance for a future; on the other hand, professional caregivers often place emphasis on the content of the treatment, neglecting patients’ emotional needs and how they are coping (Uitterhoeve et al., 2003). A nurse’s role during cancer treatment consists of far more than just providing the treatment and physical care. Nurses can be important supportive figures, promoters of effective coping, and may call upon the patients’ loved ones and support system for support of the patient.
Summary

The review of literature provides a broad overview of current research pertaining to the physiological and psychological anguish as it directly relates to cancer and its treatment. It also addresses coping and its benefits, what is considered effective coping, various methods of coping, and health care providers’ role in addressing coping in relation to the physical and emotional distress that coincides with cancer.

Strengths of this review of literature include its broadness. It does not focus on one coping mechanism, but looks at many in acknowledgement that there are many ways of coping, and what is effective relates specifically to the individual; what is effective for one person may not be for another, and what is effective one day may not be the next based on the circumstances. The tremendous physiological distress that one may experience with cancer and its treatment is addressed, but so is the psychological distress, as well as sociocultural and spiritual needs. The primary strength of the review of literature is that it addresses the person holistically, which is especially important for patients with cancer because it impacts every aspect of their being.

While there is an abundance of nursing literature related to distress and coping in patients with cancer, current literature is deficient in addressing variables that might influence coping. Thus, weaknesses of this review of literature involve lack of consideration of variables that could influence differences in coping, such as length of time since diagnosis, social support, positivism, the influence of religion or faith, stress appraisal, and physical variables such as energy level and symptom distress, to name a
few. Further research is necessary to better understand factors and variables as they relate to different ways of coping.
Chapter III
Methodology

Grounded theory, as developed by sociologists Barney Glaser and Anselm Strauss in the 1960’s, is a qualitative research method that can be defined as “the discovery of theory from data that have been systematically obtained through research” (Tatano-Beck, 2004, p. 266). Furthermore, “The grounded theory approach is a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area” (Glaser, 1992, p. 16). The goal of grounded theory is to generate a theory around a core category that accounts for a pattern of behavior that is relevant and problematic for those persons involved; ultimately themes or a theory emerges from data. Grounded theory is inductive, meaning that the research process may direct questions in a certain direction to test themes that have emerged thus far from research. This method is also deductive, as the researcher will ultimately derive a conclusion from the data collected by reasoning.

Theoretical Framework

Symbolic interaction is a psychosocial theory, which provides the theoretical foundation for grounded theory. Central to symbolic interaction are the basic principles that human beings act in relation to one another, take each other’s behavior into account as they themselves act, and provide meaning to specific symbols in their lives (Tatano-Beck, 2004). Symbolic interaction focuses on the nature of social interaction among individuals, which shapes processes and meanings of situations. The researcher must understand the nature of human behavior as influenced by social interaction, individual,
and group perspectives, focus on the interaction under study, and then translate meaning obtained from interactions (Tatano-Beck, 2004). This framework may be used to develop questions initially, however, the framework does not guide the study; as data emerges it is used to guide the study.

Data Collection

In grounded theory it is important to remember that “The problem will emerge as well as the manner by which the subjects involved continually process it” (Glaser, 1992, p. 21). Unlike other research methods with preconceived research problems or hypotheses that are tested in the study, in grounded theory the researcher must remain patient, open, and objective to the emergence of the participant’s problem and be careful not to force the data with his or her own preconception of what the problem is. It is for this reason that literature review is delayed until the theory is “grounded” in data and concepts have been generated so not to be influenced by the findings of other studies.

The process of data collection is controlled by emerging theory; grounded theory is data driven. At the beginning of a grounded theory study, the researcher asks general questions and seeks to identify the chief concern or problem for people in the area of study, and what accounts for their variance or difficulty in processing the problem (Glaser, 1992). As theory or themes begin to emerge, the researcher may ask more specific questions related to the emerging theory and may ask different participants different or additional questions to expand upon and verify this emerging theory (Tatano-Beck, 2004). The researcher simultaneously collects, codes, and analyzes data and then decides what data to collect next; this is theoretical sampling; “The problem emerges and
questions regarding the problem emerge by which to guide theoretical sampling” (Glaser, 1992, p. 25).

Analysis

Coding is the process of conceptualizing data into patterns called concepts. The constant comparative method is used for data analysis, which involves categorizing units of meaning through a process of coding or comparing incident to incident for similarities and differences until concepts and then categories emerge (Tatano-Beck, 2004). The first stage of constant comparative analysis is substantive coding: generating conceptual meaning, which includes the initial discovery of categories and then selection of primary variables. The constant comparative method requires the use of memos to record ideas. Memo writing on the research field notes “tap[s] the initial freshness of the analyst’s theoretical notions and relieve[s] the conflict in his thoughts...and provides an immediate illustration for an idea” (Glaser & Strauss, 1967, pp. 107-108). The next stage is theoretical coding, which involves forming a model of how substantive codes may relate to each other as hypotheses to include in a theory. Theoretical codes are the conceptual models that relate substantive codes to each other theoretically (Glaser, 1992); they can be a process, a condition, a consequence, a tactic, a value, a belief, etc.

The basic goal of grounded theory and the constant comparative method of analysis is to generate a theory around a core category. This “core category represents a pattern of behavior that is relevant and/or problematic for persons involved in a study” (Tatano-Beck, 2004, p. 274), and may or may not be a basic social process. The core category will be central, recurring, well supported by and meaningful to other categories,
completely variable, a dimension of the problem, and with clear and grabbing implications for formal theory or area of inquiry (Tatano-Beck, 2004). In categorizing, however, the grounded theory analyst must continue to guard against preconception and listen carefully to each incident in order to determine what the research is truly a study of (Glaser, 1992).

Grounded theory should be judged using fit, work, relevance, and modifiability as criteria. Fit means that categories identified by the emerging theory correspond with collected data; data should not be manipulated to fit preconceived categories or discarded in order to maintain an existing theory. Work indicates that the grounded theory study explains what happens, what could happen, and interprets the theory. Relevance requires that the study and findings must be relevant and comprehensible to individuals in the setting. Lastly, the theory is modifiable, which means it can be modified to accommodate the integration on new concepts (Glaser, 1992).

Grounded Theory and Nursing

Grounded theory is recognized to be “especially suited to knowledge development in nursing because nursing is a practice discipline whose essence lies in processes” (Tatano-Beck, 2004, p. 278). There are several key reasons that grounded theory research is appropriate for and applicable to nursing research. The processes underlying social experience are discovered, and they become the basis for nursing intervention. The nurse researcher is free to discover what is happening rather than assuming what should be happening. The researcher is able to remain sensitive to how patients in a social or clinical setting give meaning to their situation. Lastly, grounded theory can be practically
applied through nursing interventions, which can be designed and implemented based on substantive or concrete theory that is grounded in data.

The purpose of using the grounded theory method for this study was to explore the experiences of patients with cancer and discover themes and a core category in the area of coping with cancer and treatment. Findings from this study will allow nurses to better comprehend the problems and experiences of patients with cancer. A theory can be developed around the core category, which was identified as a pattern of behavior that is relevant and/or problematic for the individuals with cancer involved in the study. Based on the substantive theory identified and with the basis of knowledge and recommendations attained through the participants of this study, specific nursing interventions can be designed for implementation in the clinical setting to minimize areas identified as problematic and then facilitate effective coping in patients with cancer.

Biases

It is recommended that no detailed review of literature be done prior to qualitative studies because it may bias the researcher. In the case of this study, the review of literature was completed prior to the study; however, this review of literature is broad and does not focus on a particular theme or problem, but it explores many aspects of coping with cancer. Having experience with cancer patients as a healthcare provider, and also having family members with cancer influences my beliefs and ideas in relation to cancer and coping; all information, beliefs, and ideas acquired academically, personally, and professionally were acknowledged and set aside so not to influence data collection and analysis of this study. By maintaining objectivity, applying observational and listening
techniques, and remaining sensitive to how participants give meaning to their situation, I was able to identify themes or concepts unbiased by other information.

Sample

Sample criterion for this study included any man or woman with any type of cancer who was over the age of 18, could read and write in English, and was currently undergoing or had recently completed a treatment regimen of chemotherapy and/or radiation. The method of obtaining a sample for this study was a convenience sample, which is sometimes called nonrandom sampling: “Sample subjects are not selected from a larger group of subjects (population). Instead, the researcher collects data from whomever is available and meets the study criteria” (Fain, 2004, p. 112).

Some participants were obtained with the assistance of a cancer care coordinator at a larger regional hospital. She used the above sample criterion and approached patients with cancer she knew from her interactions to be open to discussion about their disease and able to provide valuable information about the process of achieving more effective coping based on her knowledge of their struggles and reactions to them. Some participants were obtained through a cancer support group. Attending a support group is a variable among patients with cancer that influences coping. Patients with cancer who have sought to enhance their coping through a support group have no doubt had struggles but recognized their need for more effective coping; thus, they may also be able to provide valuable information about the process of achieving more effective coping. Volunteers were given a copy of the informed consent, which included a summary of the
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purpose, procedures, potential risks and benefits, and a guarantee of confidentiality (see Appendix A).

The sample consisted of only three individuals with cancer. Two were women and one was a man. All participants had different types: one participant had breast cancer, another had ovarian cancer, and the other had esophageal cancer. All were in different phases of the disease. One participant had a terminal prognosis, one was uncertain of his or her prognosis, and one had a very positive prognosis. All participants were receiving chemotherapy and one was receiving radiation as well at the time of the interview. One participant was married and two were single. All participants had children. One participant attended church and the others did not. Two attended cancer support groups and one did not. All participants are from rural geographical settings.

Procedure

A time was established with each participant individually to meet for an audio taped interview in private, either at the participant’s home or at the treatment facility during the time of chemotherapy infusion or in between appointments. Participants were asked open-ended questions and the interview was conducted using standards of therapeutic communication, which include genuine interaction necessary for clients to build trust, being non-judgmental and providing positive regard, respect, and acceptance, providing empathetic understanding, and communicating clearly as well as clarifying meaning (Fortinash & Holoday-Worret, 2000). Response techniques that enhance therapeutic communication that were used in the interview session included using silence as a listening tool, providing support and reassurance in a genuine and honest manner,
sharing observations, acknowledging feelings, allowing the client to assume control of topics by making broad, open-ended statements, encouraging clients to describe, comparing past and present experiences, and restating, reflecting, clarifying, and summarizing key points (Fortinash & Holoday-Worret, 2000).

Initial interview questions were modified in order to expand upon and verify emerging data; thus, each participant’s interview questions were slightly different, which is in accord with theoretical sampling or simultaneously collecting, coding, and analyzing data and then deciding what data to collect next (see Appendix B). Interviews were transcribed for coding and analysis. The constant comparative method was used for data analysis; thus, responses and incidents were compared with those of other participants for similarities and differences until concepts and then categories emerged (Tatano-Beck, 2004). Categories were identified from the data of shared experiences, feelings, concepts, difficulties, or stages from the individual cancer experiences, until a theory could be generated around a core category or pattern of behavior that was relevant and/or problematic for the patients with cancer involved in this study using theoretical coding. The findings of this study were mailed to participants with a self-addressed stamped envelope allowing them to validate the reported findings that represented their experience and then return responses to the researcher to affirm the relevance of this study.
Chapter IV

Findings

The purpose of this qualitative study was to explore and better understand patients’ experiences, problems, and ways of coping with cancer and treatment and then to identify interventions for nurses to implement to minimize these areas identified as problematic and assist patients to cope more effectively with cancer. Taking Action was the core category that described the experiences and problems of the participants of this study. The following seven supporting categories describe participants’ ability to take action, cope, and achieve personal control: (a) seeking information, (b) enduring physical symptoms, (c) maintaining hope, (d) finding meaning, (e) establishing social support systems, (f) accepting change and loss, and (g) acknowledging fear and emotions.

While it is expected that individuals will interpret and react to a similar situation in different ways, there are common feelings, responses, and reactions that are expected to exist. The three individuals with cancer who took part in this research project shared numerous feelings, reactions, and struggles in relation to their disease and ability to cope in spite of differences in their specific cancer type, prognosis, gender, age, and life experience, as discussed in the sample section in Chapter III.

Taking Action to Adapt to the Reality of Cancer and Treatment

The core category that was central, problematic, and relevant in each participant’s cancer experience was the ability to take action in adapting to the reality and effects of cancer and treatment. This pattern was well supported by and meaningful to each of the sub-categories that will follow, which include seeking information, enduring physical
symptoms and discomforts, finding meaning, maintaining hope, establishing social support systems, accepting change, and acknowledging emotions.

A common experience. For each of these individuals, receiving the initial diagnosis was a frightening and devastating experience. One participant who had always been very active began to experience increasing breathlessness with even minimal activity; these symptoms were ‘brushed off’ at first by her healthcare provider: “I got so I couldn’t even walk a whole block . . . so I went right over to the ER and found out [while on vacation] that I had the cancer. So that cut the trip pretty short. . . . It’s difficult for me to talk about it, even after all this time. It’s a real blow to know that, well that your life is just never going to be the same.” Another participant found a lump in her breast, immediately called her doctor, and went in for an exam. They did the tests and she received the news the following day at work: “I just started crying and dropped to the floor. It was such a shock, I just felt like a robot going through the motions. I thought it meant I was going to die.”

The participants received different information specific to their individual diagnoses and treatment options; however, each chose aggressive treatment out of a desire and a will to survive and endured the sickening, appearance altering, and even life-threatening effects of such treatment. One participant said, “As soon as we knew what the options were, we made decisions. I wanted to begin the process as soon as possible. Two weeks after the diagnosis I was in having a radical mastectomy. I just wanted to live, it didn’t matter if they had to take my breast or that my hair would fall out—take it; life is what is most important.” Exploring the options was the first step for another participant:
"I just had to find out what the alternatives were, and there weren’t too many. It was to take the treatments or to let [the cancer] take its course, and that was it."

Each participant held a different outlook, however, as each participant’s prognosis was different. One participant’s cancer was discovered early, surgery was curative, and at the time of the interview she was receiving chemotherapy for the purpose of ensuring the cure. For this participant, “when you couldn’t do anything and you just had to wait, those were the toughest times,” but her “positive prognosis and high chance of surviving has really been a cushion.” Another participant who would soon undergo tests to evaluate the effectiveness of his treatments, but with no guarantees understood cancer to be:

a particular type of illness that you’ll never get over. It might arrest to a point that you can try to live and go on living, but that don’t mean you’re cured. . . . It’s always there; it could come back at any time. So you just don’t know. Just to get to the point where I can eat has been like that. Just go on doing what they tell you to do, hope it turns out for the best because it’s the only option you got.

One participant whose prognosis had not been reassuring said, “It’s just hard to know that you’re never going to get well. Some do, but I think with [this type] you don’t really expect to. It’s just a hard cancer to treat, but you never give up.” In spite of uncertain prognoses, participants did try to remain positive.

*Achieving a sense of control.* Following their initial diagnoses, in spite of their fears, the participants wanted to know what their options were so they could make decisions and begin treatment. “Taking action and doing everything I can as soon as I
can” had been an important coping strategy for one participant. Not only did this strategy give her a sense of control over the cancer, but it helped her realize her strength:

I started seeing how much stuff I was really going through and that, overall, I was dealing with it all pretty well. . . . You start feeling good about how you’ve dealt with this or that . . . and you just go into the next thing with a more positive ‘I can do this’ attitude. . . . The only way to win is to be stronger and positive. . . . You can just curl up and really feel sorry for yourself, or you can go out there and try to kick it in the ass.

After learning his treatment options, one participant began treatment right away. When asked some of the feelings he experienced he said, “I’m not a very emotional person . . . you just gotta do it, you know? It’s like having a cold or the flu, or anything else, if you’re sick, you’re sick, but do what you can to get over it and just go on. . . . Right now you’re just trying hard to keep you’re medicines going to see if it’s going to correct the problem.” To cope with his cancer he said, “[I] just handle living my life the way I always have. Course there’s always changes due to the fact you have the different treatments and seeing there’s things you can’t do no more. . . . Just go on and do what you can do.”

One participant attended the cancer support group regularly and belonged to a cancer newsletter; “You get other gals’ opinions, and how they’re doing, and how they’re coping. That’s been helpful.” This participant had not let cancer prevent her from doing the things she enjoyed, which had, in fact, been a way for her to cope: “We do have a cabin up in Flathead, and we get away during the summer up there, and that’s been
helpful too. You can get away, and you can forget about it. We try to take trips once in a while.” For this participant, getting away was something she could look forward to and focus on rather than allowing the reality of the cancer to bring her down.

_Taking action to oppose defeat._ The participants sought to survive by taking action, by making treatment and lifestyle choices to promote positive health outcomes, and they tried to stay busy with things they enjoy to cope with some of the emotional difficulties related to their cancer. According to the participants of this study, however, there were very real issues one struggles with in order to maintain control by taking action, which made it more difficult to adapt to and cope with cancer. Participants mentioned struggles, situations, and setbacks that interfered with their “take action” attitudes, such as severe fatigue (a side effect of the treatment), depression, fear, or bad news regarding their cancer, such as cancer marker values being up.

One participant commented on her feelings about and struggle with the first chemo treatment:

*It was so hard, and I was so upset. I remember just watching and feeling this poison going into me. Not only had I had the cancer in me but now this poison too. I knew it was important and would kill any possible stray cancer cells floating around, but I knew it would also kill my cells. It was strange, scary, and I sort of resented having to go through all this. The first treatment made me real sick, the nausea and vomiting, and I was so tired I could barely move for a couple days.*
One participant really struggled with depression in association with some of the symptoms and side effects: “Lots of times you get very depressed. But now with this [treatment], usually I feel pretty well and strong. But it’s just hard when you don’t feel well from taking all this stuff.” Another participant who enjoyed his work, had a hard time not being able to work; “[the treatment] makes you so weak sometimes you can’t do nothing. . . . I been so used to getting up and being able to go and do things.” This participant said that a major blow to his morale would be “finding out the results whether you’ve accomplished anything . . . [after] months of radiation, chemo, and all of this that I’ve gone through and it comes up negative.” For another, “the worst parts were the waiting periods . . . when you couldn’t do anything and you had to wait, those were the toughest times. Once we knew, we just took the next step as soon as possible.”

Supporting Category: Seeking Information

To be able to understand what was happening, what could be done, and what to expect was very important to each of the participants; the primary source of this information was from the doctors and nurses. While it was usually the doctors who discussed treatment options, coordinate and explain treatment plans, deliver test results, and address concerns, nurses were also involved in information provision and clarification, answering questions, and they were responsible for patient education. One participant agreed that the nurses were a knowledge source: “They always know what’s going on. They know the chemos that I’ve been taking and how they affect you. . . . Sometimes you kind of forget when you’re talking to the doctor about certain things [you
want to tell him or ask], so you’re sitting there getting your chemo and things pop into
your mind that you forgot; they can pick up on that pretty fast.”

_Treatment options._ It was important for all the participants to know and
understand what their treatment options are so that they could make decisions and act, as
previously discussed. For one participant who believed “the key to this is just to follow
doctors, do what they recommend and what they suggest,” the information that was
important to him related more to the physical issues, test results, and progress. He felt
that he had been adequately prepared for the sickness and negative effects of treatment:
“Before it ever starts, they pretty much go through it, you know, the brochures and all of
this and let you know basically what this particular treatment will cause or could
cause. . . . You know something is coming up, so it just don’t hit you, like ‘wow, what’s
going on.’ You’re pretty well prepared for it.” He also felt that the doctors had been
really good about keeping him informed of what’s going on and why, as well as, of his
progress. His experiences with the nurses were positive as well: “They go out of their
way to help you if you need something or finding something out for you. . . . They kind
of explain to you what they’re doing, why they’re doing it, which helps a lot, especially
when you don’t understand a lot of what’s going on, and so that’s comforting, you know,
it’s kind of nice.”

_Side effects._ Another participant acknowledged the importance of being prepared
for the negative effects of treatment as well; however, she felt that she wasn’t prepared as
well as she should have been, and “not getting good information caused a tremendous
amount of fear. These things were happening to me on top of everything else, and I didn’t
know why.” When she showed her doctor what was happening in a visit following surgery, “He was like, ‘oh yeah, you have some cording going on,’ but it was kind of like I should have known even though no one ever warned me.”

Inconsistencies. In the hospital following her mastectomy, this same participant remembered being told several times that she could never have blood pressures taken or IVs in her right arm again: “They didn’t say why though. We looked it up and found out it could cause lymphedema on our own. We asked the doctor about the lymphedema and he said it was very rare and nothing to be concerned about. It felt like no one taking care of me was on the same page—and I was lost. I had to figure things out on my own.” It would have been very beneficial for a nurse or someone to address her feelings and concerns as well as provide her with information regarding symptoms, complications, and emotions that might be expected. The day following her mastectomy this participant “left the hospital thinking ‘what do we do now?’ I realize everyone is really busy, but this is a common enough thing that they could maybe make up a packet with information. It made us feel like our questions and problems weren’t valid.” This participant reported that information was much more accessible to her by the nurses in the cancer center: “I think they try to stay one step ahead of you; they offer you the information before you actually have to ask the question. They are very knowledgeable.”

Sense of control. There was a definite need for information by all the participants in order for them to understand what was going on and feel some control. There is evidence of some unnecessary fear related to a lack of information. For these participants, information and knowledge of the process and being prepared for the negative effects
was an essential component for effective coping with the emotional and physical distress of cancer and treatment.

Supporting Category: Enduring Physical Symptoms and Discomforts

Expecting symptoms. The participants of this study said that knowing what symptoms to expect with the treatment was helpful. One participant who suffered from severe nausea, vomiting, fatigue, and constipation with the first chemotherapy treatment said she did not get sick at all after the second treatment: “It was strange, I was expecting these symptoms, but never had them. But it was after the second one that I lost my hair. The third made me tired and a little sick to the stomach. I’ve just been so busy, which I think is another thing that’s helped me to cope.”

Caring for oneself. For the participant with esophageal cancer, not being able to eat had been the worst effect of his cancer and treatment, beginning with blockage in his esophagus and then related to nausea and vomiting from the treatments. He said, “This weekend I just came off of a chemo treatment and it really made me sick not being able to keep stuff down, and, um, I had a problem two or three weeks ago with constipation; in fact, I ended up in the hospital. It started up again this weekend, but now I know what to do and I got stuff to correct it and know what the feelings are, so I just pretty much take care of myself now.” Each participant expected to feel sick for a few days after a chemotherapy treatment. This participant said that it took him about two days of not feeling well until he gets back to normal; however, the fatigue often lasts longer. He tried to remain positive: “I’m not used to sitting around, and then the weakness just makes you so weak you can’t do too much. Your mind says ‘do it,’ but your body won’t allow you
to. So you sit there saying, ‘What are you going to do?’ Just kick back and relax, I guess, that’s all you can do.”

**Being prepared.** For all of the participants, dealing with the fatigue was difficult because they all would naturally try to keep themselves busy to cope with the disease. One participant said she would get “achy around my shoulders, and some days right after I have chemo I get really tired so I just don’t plan to do much those three or four days. . . . But usually I have to take a rest in the afternoons, or I just do because I get too tired if I don’t.” She said she also did a lot of reading, which was a good activity to keep her busy when she didn’t have a lot of energy: “When I first started out I think it was an emotional thing, because I got sick to my stomach and just had lots of problems. You have no idea how to cope, but over the years you learn how to cope, and what to expect is coming. So you can prepare yourself and take it easy.” She said that after dealing with the treatments for a while, “you can kind of figure out how the treatment is going to affect you, what you can take, and what will make you feel better.” She also said that having her treatments only once a month helped: “It’s nice that it’s spread out and you have a little while to recover in between treatment.”

Several of the participants acknowledged a mental or emotional factor as an influence on physical symptoms. One participant talked about a woman he knows from the treatment center: “When she comes in she’s just as spry and everything as you and I right now. As soon as she sits in that chair all of the sudden she’s the sickest person. . . . I’ve seen where she hasn’t even had nothing started on her yet and she’s sick already.”
This participant said he thinks that a lot of it is mental: “People expect it and then it happens.”

Supporting Category: Maintaining Hope

Staying positive. One participant with an uncertain prognosis put his hope into the medicine and the doctors and did “what they recommend and what they suggest,” and what kept him going was doing what he had to do and all that he could: “I just get up and go, see, just try to keep going anyway . . . but I gotta get it done early in the morning before I get too tired [laugh].” One participant with a non-reassuring prognosis said she never gave up hope, although she said,

the doctor sometimes isn’t as optimistic sounding to me as I wish he would be. . . . When my [protein cancer marker] count was always up, it was up for a whole year, and he would always say, ‘I’m very sorry, I’m very sorry.’ That kind of got me down because it was like he was giving me a death sentence. He could say, ‘Well, your count is up, but maybe next time it will be down’ . . . just maybe to keep me thinking positive.

This participant did not dwell on her disease: “I ignore it . . . I don’t focus on it. Oh no, you’d be down all the time if you thought about it too much.” When asked her feelings about the future, she said that they were hopeful, “not necessarily through medicine, but I try to take vitamins, I try to eat right, and things. The doctors really say those things are good and they help you cope with your chemo, but they probably won’t cure you, but I hope they will help.”
Looking to the future. One participant, whose treatment has been curative, said, “I really excited about the future because I feel like in a lot of ways I’m healthier than I have been in literally years and years, mentally and physically. You start looking at your dreams a little bit more seriously. . . . There are definitely things that I am determined to at least attempt to accomplish and not put them off anymore.” She said she had stopped taking things for granted and had held “the assumption that we’re all going to live to be 100 years old; suddenly you realize that is not necessarily the case.”

This participant struggled with the same fears and uncertainty as the other two during her treatment process: “Sometimes I just break down and cry. . . . I’ve had all the emotions of ‘why me?’ . . . But it happened to me, it changed me, and I’m a stronger person now.” In order to maintain hope through her treatment process, she needed to know that she was taking action and doing everything she could. Within two weeks of her diagnosis her radical mastectomy was complete: “I didn’t care that they had to take my breast or that my hair would fall out. . . . This is what I needed to do to live and I did it.”

In spite of uncertainty for what the future would hold, participants struggled, but managed to maintain hope in knowing that they were doing everything they could. They found meaning in their cancer and a deeper meaning or purpose in life.

Supporting Category: Finding Meaning

For each participant, the diagnosis of cancer and hardships and discomforts they had endured as well as feelings of uncertainty had changed their priorities and brought those things and people that they value most into perspective. One participant’s family, her husband and her children, were definitely of the highest value to her. The cancer had
affected her family: “My husband is very concerned, and my children. . . . They know I have cancer of course, but I think they know I get along okay.” It was difficult for her to think about being taken away from her loved ones, and she was not ready to accept that it could happen anytime soon. For her life and the time she had with her family, she remained optimistic that there might be a cure or development and was determined to continue her battle, and her feelings about the future remained “positive and hopeful.”

*Changing priorities.* The diagnosis of cancer totally changed her priorities and her perspective on life, according to one participant: “I look at life so differently now; my priorities are very different. I have a whole new life ahead of me now. Things that used to be important aren’t anymore. It is all about surviving and those I love most.” She also came to realize and appreciate the strength of her character: “It’s definitely made me a lot stronger. It’s brought out a lot of qualities in me that I didn’t realize were there that you don’t until you have to tap into them. I think it’s brought out a lot of good. I look at life a lot differently now.” Without having had to deal with all that she had, this participant couldn’t imagine coping with all the changes to her appearance and how they would affect her relationships:

When a person is actually being faced with it, when you’re actually going through it, yeah, you go through an emotional process of the loss and changes that are taking place in your body. But it’s not the priority because the priority literally becomes life. If it’s a matter of losing one or both breasts and or hair versus life, it’s just not a priority like it is if you’re just hypothetically thinking about going through it. I think I dealt with those things better than I actually thought I would.
One participant, a self-proclaimed “loner,” said, “I’m not in with any groups, or I don’t mingle with a lot of people. It’s just pretty much myself, take care of myself, do what I gotta do, and just get by. . . . I just try to survive.” However, this participant had formed relationships with his nurses and care providers that were very meaningful to him: “I’ve had a lot of good nurses through the infusion center here . . . even the receptionists have all been really good to me, been good. Even the nurses the couple of times I’ve had to go over to the hospital have been really good, you know, helpful, really nice. I’ve liked them [smiling with tears].” He felt that they went out of their way to help him and he said they explained things and helped him understand what was going on, which he said “helps a lot . . . that’s comforting and kind of nice.”

Supporting Category: Establishing Social Support Systems

Nurses. For the above participant, his nurses had truly become a support system for him. He had always been very independent, taken care of himself, and gotten by. But since his diagnosis of cancer and having begun his treatment regimen, his relationships with his doctors and nurses were very important. He relied on them to provide him with information, address his questions and concerns, keep him updated on his progress, and inform him of what he could do to fight the cancer. This participant felt that his nurses had taken “the time to make you feel like you’re welcome” and “explain to you what they’re doing . . . why they’re doing it,” which helped him understand what was going on and were a comfort to him. He felt that the nurses really met his needs. He did not have a lot of people he was close to that he could talk to if he needed to. This participant recognized that if he were to find out from his upcoming tests that his treatments were not
doing any good and there was nothing else they could do that he would need some help emotionally, and he knew that “if I needed more help they [nurses] would be there or there would be something here for me.”

_Support systems._ When asked how she copes with the difficulties and emotions related to cancer, one participant said, “I come to the support group and everyone is in the same boat so that really helps, they understand. And lots of friends ask about me. So I think keeping in touch with your friends and family; that’s about the only way you can really cope.” She felt that she drew strength from her faith and from people: “Church is important, and my husband, and my friends through the support group. People will say, ‘oh, I’ll keep you in my prayers,’ and I feel that’s good.”

_Significant others._ For one participant, her significant other was her primary support system: “He has been there for me through everything. He has gone to every appointment with me, and it really has been like ‘our cancer.’” This participant expected her hair to fall out and waited for it: “One night when I wasn’t thinking about it, I ran my hand through my hair and a big clump of hair fell out. I just started screaming and crying. Jim was in the bathroom or something and ran out and just held me and told me that it had to mean the chemo was working, which made me feel better. He has been such a support for me.” She also said, “the [women’s cancer] support group has also been very helpful, although I haven’t been able to go as often as I would like to.” This participant had had problems with “certain people that I thought were pretty connected in my life. . . . I felt like I had to say, ‘Excuse me, I’m trying to deal with breast cancer, can we hold off on that, can you give me some space or time.’ . . . It brought out people’s true
colors and showed you who was in your corner and who wasn’t. Then once you know, then you just deal with it and accept it, again, you don’t have time to dwell on it.”

Supporting Category: Accepting Change and Loss

For the participants of this study, finding acceptance in change and loss has been an important but difficult part of adapting to the reality of cancer. Learning that she had cancer “was very hard for me,” according to one participant who said through tears: “It’s difficult for me to talk about it, even after all this time. It’s a real blow to know that your life is just never going to be the same.” While she said she got depressed sometimes, especially when she was not feeling well, her husband, family, and friends in the support group have helped her get through the hard times: “I have a whole new set of friends now.” She knew that she did not have a lot of energy in the afternoons, so she took afternoon naps: “I just do it because I get too tired if I don’t.”

Lifestyle changes. One participant has been able to accept the lifestyle changes he had to make because of the treatments: “There’s a lot of things you just can’t do no more, but you just have to accept that. I used to love to drink, I worked in a bar, but because of some of the medications, you just can’t do that, so you accept it and go on. I know a lot of people probably fight that stuff, but it seems stupid to me. . . . Just stop, and go on, and do what you can do.” He had also not been able to work, and it was hard for him not to be able to get up and do things. He said, “You get so weak you can’t do too much. Your mind says ‘do it,’ but your body won’t allow you to do it. What are you going to do? Just kick back and relax, I guess.”
Body image. One participant had pushed herself to come to terms with and accept the changes that were taking place with her body: “I made myself look in the mirror at my body without my breast when the Band-Aids came off. I just wasn’t going to let myself be in denial of all this.” She acknowledged the emotional process involved in coming to accept the loss and changes, and was able to grieve as well: “I remember the day we shaved my head. It was probably a good thing I was alone because I just needed to cry and accept this. Again, I got out of the shower and stood in front of the mirror. I was bald and my breast was gone. This was me now and I had to accept that.”

Supporting Category: Acknowledging Fear and Emotions

Life will never be the same. For one participant, as previously discussed, it was hard for her to know that her life would never be the same, and it scared her to think that she could be taken away from her family. The key to overcoming these fears for her was not to dwell on the cancer, “keeping in touch with your family and friends,” getting away and taking trips once in a while, and truly enjoying her family and her time. With some of her first chemo treatments, she was sick with nausea and vomiting and had a lot of other problems: “I think it was kind of an emotional thing . . . but you kind of learn how to cope and know what to expect is coming.”

Recognizing emotional needs. When asked about some of the emotions that he had in his cancer experience, one participant said, “I’m not a very emotional person. . . . There ain’t a whole heck of a lot you’re going to do about it getting all upset. . . . Do what you can to get over it and just go on.” This participant was concerned, however, about whether his treatments had done any good: “Finding out the results whether you’ve
accomplished anything, if it’s doing any good, all this stuff. That’s when you’re going to have a lot of the emotional problems. When you go through three months or better of radiation, chemo, and all this and it comes up negative . . . that changes everything.” He said that “right now you’re just trying hard to keep your medicines going to see if it’s going to correct the problem, and if you go through all that and it don’t correct the problem, what are you going to do then? When you get to that point is when you’re really going to need help.” Because the nurses had been so good to him and available to him throughout the process, he knew they would be there if he received bad news, “to more or less comfort you in what ways they can. . . . I probably will have somebody talk to me or some different help if it goes the wrong way, but right now it’s just too soon to tell.”

Releasing emotions. One of the participants who had recently lost her hair said, “My wigs are a way I can bring some humor into this. I got a brown one first and then this red one. It depends on how I feel for the day which one I wear. People will say, ‘Oh, you’re a redhead today, you must be feeling feisty.’ I’ve just gotten to the point where I’m comfortable taking them off for bed. Now we’re both bald at night; it’s really been something we can laugh about.”

This participant also discussed how she handled some of the difficult emotions she had experienced as well: “I’ve definitely done my share of letting the emotions go. . . . I feel like you need to more than you want to, sit down and cry uncontrollably for a half hour, and that’s what I’ll do.” Breaking down and releasing her pent up emotions was “like a cleansing, because you get through that and whatever fears and negative feelings . . . and we [she and significant other] talk about everything. So we get through
that and you can breathe again, and you feel cleansed and ready to tackle the next thing."

_Nurses' Role_

For each participant, the nurses played an integral role in information and knowledge provision. Not only were the nurses able to provide information to prepare each person for the symptoms and side effects that they might expect to experience, but they were open and available to address concerns and serve as an information source during treatments. All participants acknowledged the helpfulness, knowledge, understanding, sensitivity, availability, and openness of the nurses in the cancer centers where their chemotherapy was administered. They each described these nurses as just doing their jobs, and doing them very well: "They just seem very capable, and you ask them something and they always give you an answer for it. So I think they are very knowledgeable about what we should and shouldn’t do. I think I get as much from them as I do from the doctors. All of the nurses, they are very understanding and great help."

Because they spend hours at a time at the cancer center, not only did participants get to know their nurses very well, but they also had the opportunity to get more information: "If I was sitting through a treatment and had a question I forgot to ask the doctors, they would either give me an answer or find out the answer."

_Angels in disguise._ Of the nurses in the cancer center, one participant said, "They try to kind of buoy you up; a couple of them are pretty funny, they all try to lift your spirits. They are awfully nice." Another participant said: "They are so good; they’ve been the best experience. . . . They continuously explain what they’re doing before they do it and what it is. Even though you’ve been through it a few times, they still go through the
process. They are constantly checking on you and [trying to] make you comfortable. They are absolutely wonderful. They’re there. There just like angels.”

*Meeting individual needs.* One participant said, “The nurses in the cancer center are much different than the nurses [on the surgical floor]. I think I may have been treated the same way had I just had my appendix removed. There wasn’t a lot of addressing your particular situation. . . . I was in the hospital 24 hours. . . . Maybe if I had that extra day in the hospital, maybe they would have spent more time talking to me.” She said she was excited to go home, “but as we were walking out the door we really didn’t know what was next. We didn’t know what we were supposed to do. . . . My surgeon came in there that morning; he said keep the area clean and showed me how to drain the drain tube.” She remembered feeling scared and confused following her surgery; “The cancer and losing my breast was hard, but while I was in the hospital after the surgery no one asked how I was doing with it all; I just thought someone should have. The day of the surgery I was pretty woozy all day, you know, I would have been out of it . . . but I think the following morning would have been probably a really good time.”

One participant who had received care through a different hospital said that he had a lot of good nurses, both in the infusion center and the hospital: “I love the staff, everybody so far right down the line has been very, very nice to me, and I got no complaints, I couldn’t ask for better nurses or doctors or any of them.” Of the nurses he said, “If you have a problem they go out of their way to help you, as far as if you need something or finding something out for you.” He also said, “They make you feel like you’re welcome, they don’t just do it and go, which helps a lot, especially when you
don’t understand a lot of what’s going on, and so that’s comforting, you know, it’s kind of nice.” As discussed above, this participant had established good relationships with his nurses, and because there were not a lot of people in his life that he was close to, his nurses served as a support system for him with whom he felt comfortable and knew he could talk to if he needed to or if he had a problem: “They meet my needs ... and I’m sure if I needed more help they would be there.”

**Participant Validation**

Two of the three participants returned the participant response questionnaire (see Appendix C) that had been mailed to allow participants to validate the findings of this study and affirm personal relevance. On taking action and gaining control to adjust to cancer one respondent said, “It keeps me taking forward steps! Taking action increases positive thinking and energy levels.” On taking action another respondent said, “I think it’s important to feel like I’m shaping my own treatment by making decisions regarding the type of chemo, when I take chemo, in conjunction with my doctor.”

In response to the question about whether or not the seven supporting categories were ways that he or she took action and helped with coping, a respondent said, “Definitely. I discuss information with the doctor and he is willing to explain this so it makes it more understandable. The support group is a source of information and comfort.” The other respondent said that the seven supporting categories are “crucial actions necessary to feel I have as much control of my cancer as I can have. Rather than fight against this illness, I am involved with it.” One respondent went to a national
convention for individuals living with cancer, and noted “working on my nutrition” as other ways of coping.

In regards to the question on how the findings of this study relate to participants now, one respondent simply said, “Just the same as when I talked to you.” The other respondent said, “I am applying all of these [tasks of taking action] strongly in my life; on a stronger, healthier level than when I interviewed with you. They have become my way of being. I embrace all that is good. I’m really happy.”
Chapter V

Discussion

Taking Action in the Face of Adversity

Taking action was the core category and basic social process found to be central, problematic, and relevant in each participant’s cancer experience. Similar results were found in a study by Merluzzi, Nairin, Hedge, Martinez Sanchez, and Dunn (2001), which explored a self-regulation model of coping using and revising the Cancer Behavior Inventory (CBI), which measures self-efficacy for behaviors related to coping or adjusting to cancer. Major tasks facing patients with cancer during the course of their illness that made up the revised CBI included the following: (a) maintenance of activity and independence, (a) seeking and understanding medical information, (c) stress management, (d) coping with treatment related side-effects, (e) accepting cancer/maintaining a positive attitude, (f) affective regulation, and (g) seeking support (Merluzzi et al., 2001). Merluzzi’s research team reported that patients with cancer who feel more efficacious or effective in their capacity to cope are better adjusted. Coping is related to the confidence people have in their ability to execute courses of action, such as coping behaviors, as well as to a higher probability of attaining a goal, such as maintaining a desired state of quality of life. Also “more efficacious patients have fewer episodes of negative psychological states (e.g. depression) and persist longer at goal attainment than those who are inefficacious” (Merluzzi et al., 2001, p. 206).

Patient control through activity. In a study comparing the difference in patients with cancer who perceive control over their disease compared to those who do not, Link,
Robbins, Mancuso, and Charlson noted that for patients with cancer, "Better psychological adjustment and decreased anxiety and depression have been associated with actively engaging with the stressor. . . . Given the loss of control that people experience when diagnosed with cancer, perceived control over this stressor may moderate their ability to adjust" (2004, p. 220).

Link et al. introduced a new dimension of coping: proactive strategies, which are intended to optimize one’s well being and are used by those who consider them methods of control, and reactive strategies, which are used to maintain well-being and are used by those who do not consider them methods of control. It was found that "cancer patients who considered their coping strategies to be methods of control cited more proactive coping strategies, and had less depression and greater fighting spirit—positive orientation to the illness (Link et al., 2004, p. 224). Link et al. concluded that effective psychological adjustment to cancer is related to both the type of coping strategies used along with beliefs about control.

In support of these findings, Kershaw, Northouse, Kritpracha, Schafenacker, and Mood (2004) found that cancer patients with good psychosocial adaptation and higher quality of life tended to use active coping strategies, whereas patients with poor psychosocial adaptation and lower quality of life tended to use avoidant coping strategies, such as denial. This finding correlates with the findings of the current study, as the participants had good psychosocial adjustment to the realities of cancer through the use of active coping strategies; however, avoidant strategies used by participants, such as not
focusing on the cancer and uncertain prognoses, allowed them to maintain hope and quality of life.

**More positive outcomes.** In a study to explore personal control for people with advanced cancer, “participants desires reflected personal values and beliefs about how they want control over their care” (Volkner, Kahn & Penticuff, 2004, p. 954). Participants described “active engagement with treatment decisions and the desire to control the disease and its sequelae for as long as possible to be able to live as fully as possible” (Volkner, Kahn & Penticuff, 2004, p. 957). Promotion of a sense of control was found to be a helpful strategy for some people who face terminal illness, as it was for the participants of the current study. Volker, Kahn, and Penticuff noted that “control is a core element of psychological functioning. . . . Individual differences in perceived control are linked to numerous positive outcomes, including health and physiologic outcomes, optimism, persistence, motivation, coping, self-esteem, and personal adjustment” (2004, pp. 959-960).

**Activity vs. defeat.** The participants of my study fight to survive by taking action, trying to stay in control by making treatment and lifestyle choices that promote positive outcomes for their health, and they try to stay busy with activities they enjoy to cope with some of the difficulties related to their cancer. A factor that remains critical in the lives of patients with cancer is maintenance of activity and independence; however, “the loss of activity and independence represents a transition that would cause major readjustments in the lives of those with cancer” (Merluzzi et al., 2001, p. 206). Participants of the current study talked about struggles, situations, and setbacks that have interfered with their ‘take
action' attitude, such as severe fatigue, depression, fear, or bad news regarding their cancer, such as cancer marker values being up, that have made it hard to adapt to and cope with the cancer. These issues produce a force, feeling, or even a pattern of behavior reflecting hopelessness or defeat that can make it especially challenging to take action against the cancer. The conflict between these two forces or behaviors is ongoing, as negative side effects, negative emotions, and bad news cannot always be prevented and controlled.

*Seeking*information

*Making sense of a new reality.* To be able to understand what is happening, what can be done, and what to expect has been very important to each of the participants as understanding symptoms and prognoses decreased uncertainty and provided control; the main source of this information is from the doctors and nurses. Xuereb and Dunlop (2003) described a concept called “cognitive confrontation under stress,” which is characterized by actively looking for information, going deeply into a situation by reading about it, and getting information from other doctors, patients, or organizations. This concept demonstrates a pro-active way for patients with cancer to stay engaged and take on and deal with a new reality.

*Delivering medical information.* Merluzzi et al. recognized seeking and understanding medical information to be a major task that patients with cancer must face during the course of their illness that requires assessment of “the confidence patients have that they can pose questions to medical personnel and understand the information given” (2001, p. 214). Providing accurate information and correcting misconceptions may help
eliminate fears and reduce anxiety as well (Carpenito, 2002). Nurses and other health care providers should remember: “providing information in an honest, respectful, and compassionate manner can increase the levels of hope. Conversely, providing information in a disrespectful or cold manner, trivializing the situation, or giving discouraging medical facts without offering something to hold on to decreases levels of hope” (Felder, 2004, p. 324).

Information to empower not burden. Patients with cancer will have different views on what they want to know, how much they want to know, and when they want to know it; health care professionals must strive to meet these individual information needs (Beever, 2004). Timing is important as well; information tends to be given primarily at the stressful time of diagnosis when recall and retention of information is low. Information provision should be a dynamic and ongoing process responsive to patients’ needs (Beever, 2004). Furthermore, not all patients want to learn as much as possible about their condition and would rather not be inundated with information. According to Xuereb and Dunlop (2003), “when patients asked for details it was often an attempt to gains some agency [control] in an apparently helpless situation, to gain some hope that would enable them to plan or prepare for the next step, rather than accumulate medical facts” (p. 407). Nurses and other health care providers must be sensitive to patient needs and the fact that information should be provided to empower patients to make decisions and maintain a sense of control over their life and illness.

Enduring physical symptoms and discomforts

Merluzzi et al. reinforced the fact that “coping with treatment related side-effects
represents some of the most dreaded aspects of cancer treatment such as dealing with physical changes (e.g. hair loss) and limitations (e.g. lack of energy)” (2001, p. 214). Fatigue is one of the most frequent, bothersome, and consistent complaints of patients with cancer during the treatment and recovery periods, and it can impair daily functioning and have negative effects on quality of life (Mohammad El-Banna, Berger, Farr, Foxall, Friesth & Schreiner, 2004). For all participants of the current study, dealing with the fatigue has been difficult because all would naturally try to keep themselves busy to cope with the disease. Patients’ quality of life is a significant concern as decreased quality of life is often associated with symptoms such as fatigue (Ahlberg et al., 2004).

Coping with fatigue. The nurse can help the client and family accept and prepare for fatigue as an expected and reversible side effect of treatment (Ignatavicius & Workman, 2002). It is important to encourage patients to verbalize feelings about their limitations. The nurse can also help patients develop strategies to reduce effort and energy expenditure. If one has higher energy levels in the morning, energy-intensive activities can be carried out in the morning, rather than later in the day (Ignatavicius & Workman, 2002). Spacing activities and allowing for rest in between is also helpful for conserving energy (Ignatavicius & Workman, 2002). These are strategies that several participants of my study report to cope with their fatigue.

Emotional influence on symptoms. All participants recognized a mental or emotional aspect as an influence on physical symptoms. Ahlberg, Ekman, Wallgren, and Gaston-Johansson (2004) found a positive correlation between general fatigue, anxiety, depression, or other psychological distress. Difficulty coping in connection with the
many side effects that may occur with cancer treatment could contribute to the development of fatigue. According to Ahlberg et al., one’s "disposition may be related to fatigue by influencing coping reactions. For example, optimists may be more likely to engage in active attempts to cope with a problem" (2004, p. 207). Research shows "a relationship between psychological distress and fatigue. Distress can result in fatigue, but fatigue may also act as a stressor" (Ahlberg et al., 2004, pp. 206-207).

*Being prepared for symptoms.* The participants of my study said that knowing what symptoms to expect with the treatment is helpful. Ahlberg et al. emphasized the importance of keeping patients informed of the expected adverse physical symptoms that will impact their lives during their treatments, which sometimes last for months at a time, "thereby giving them a chance to cope more effectively with these changes" (Ahlberg et al., 2004, p. 211). Nurses need to assess for these symptoms before, during, and after treatment to plan and implement appropriate interventions, remembering that fatigue may be lessened and the complications and discomfort of constipation can be prevented, for example, if these side effects are detected early and interventions are initiated. Patient awareness and continuous management of treatment-related symptoms can limit undue physiological and psychological distress.

*Nursing care.* Because symptoms and impaired comfort can increase psychological distress, in which the combination can decrease a patient’s ability to cope with cancer, it is important to promote physical comfort as much as possible. Not only should nurses prepare patients for the symptoms and discomfort they may experience, but encourage them to verbalize their feelings about their symptom distress, discomfort, and
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limitations as well. The nurse can proceed with health teaching to increase knowledge and lessen fear of the unknown, by explaining the causes of the symptoms and the interventions that can relieve the symptoms (Carpenito, 2002). The nurse can provide comfort during episodes of discomfort; for example, during nausea and vomiting the nurse can help clean up, providing oral care after each episode, and applying a cool damp cloth to the patient’s forehead, neck, and wrist (Carpenito, 2002). Drug therapy can be used to manage symptom distress and impaired comfort with analgesics to control pain and anti-emetics to control nausea. Complementary and alternative therapies can also be used to manage pain and discomfort, such as massage, distraction, therapeautic touch, acupuncture, cognitive and behavioral strategies, and relaxation techniques (Ignatavicus & Workman, 2002).

When severe symptom distress is anticipated, the nurse can be prepared as well as prepare the patient to manage physical symptom distress and help the patient establish coping strategies that will be effective. The nurse can also enable sharing of experiences and provide emotional support for patients. Because a high correlation was noted between anxiety, depression, and nausea, preparatory information to increase control and understanding will reduce anxiety as well as symptoms (Gatson-Johansson et al., 2000). Cognitive restructuring, or cognitive-behavioral training, helps develop coping skills and lessen anxiety and depression, which may exacerbate physical symptoms. Gatson-Johansson et al. noted that “Progressive muscle relaxation and imagery have been found to help patients either to escape the problem or to think of the problem in alternative ways...relaxation techniques may allow for further emotional relief in alleviating a patient’s
fatigue” (2000, p. 279). The above interventions not only reduce the physical and psychological symptom distress of cancer and treatment, they also empower the patient to take control of these issues, both of which improve patient quality of life.

Maintaining Hope

Activity and optimism. Kershaw et al. noted that people with advanced cancer report “considerable uncertainty about their future, many troubling symptoms, and difficulty maintaining hope” (2004, p. 139). In spite of uncertainty for what the future holds, participants of my study struggle, but do manage to maintain hope. Another study on hope and coping in 183 patients with cancer has found that even with advanced-stage cancer the level of hope remains high and is associated with better psychological well-being and the will to live (Felder, 2004). Regardless of gender, age, marital status, education, or site of malignancy, Felder found a “positive correlation between level of hope and coping style use and effectiveness among all patients, indicating that participants had relatively high levels of hope and were able to identify effective coping styles” (2004, p. 323). Participants of Felder’s study “used optimistic, confrontive, and evasive coping styles most frequently and found them to be most effective” (Felder, 2004, p. 323). Optimistic coping styles include those that demonstrate a positive outlook, confrontive styles demonstrate constructive problem solving, and evasive styles involve avoidance behaviors (Felder, 2004). These coping styles Felder identified correlate with the active coping used by the participants of my study: participants remained optimistic and hopeful for their futures, used aggressive means to fight the cancer, and made
positive lifestyle changes to promote well-being, and sometimes found means to escape the overwhelming reality of the cancer for a while.

**Hope preservation.** Beadle et al. (2004) found that some patients with advanced cancer express and maintain “optimistic views in the face of declining health and a limited lifespan” (p. 26) and that illusory attitudes towards their illness and beliefs about the outcome of treatments influence their perception of quality of life. Will to survive, use of alternative therapies, and belief in the curability of the cancer were found to contribute to this optimism as well. Beadle et al. recognized the benefits to one’s quality of life that could result from a strong will to live along with illusory beliefs as hope is preserved.

While the importance of maintaining hope and a positive attitude has been established, maintaining hope and accepting the reality of the disease can be a paradoxical task. According to Merluzzi et al., “There is a delicate balance struck between an optimistic and a realistic perspective in the mindset of cancer patients…maintaining that perspective may be possible for optimists but not for pessimists” (2001, p. 214). Furthermore, pessimists tend to hold a wide range of goals that can be easily abandoned, while optimists commit to a few focused goals that may be challenging but are not out of the realm of possibility (Merluzzi et al., 2001).

**Realistic hope.** Nurses should be careful not to instill unrealistic hope and determine if hope is unrealistic, as well as recognize that “uncontrolled symptoms, especially pain, abandonment and isolation, devaluation of personhood, and negative hospital experiences” (Felder, 2004, p. 324) can destroy hope and must be avoided.
Nursing interventions should promote hope that is reality based by “developing an awareness of life, identifying a reason for living, establishing a support system, incorporating religion and humor into their practice, and helping patients set realistic goals” (Felder, 2004, p. 324). Nurses are in a unique position that can foster hope by incorporating presence, touch, active listening, values clarification, and reality surveillance into their practice (Felder, 2004), which can also bring meaning to the experiences of patients with cancer. Each participant in my study was optimistic and hopeful in spite of the challenges they have faced and that more lie ahead. They have found meaning in their cancer and a deeper meaning or purpose in life.

Finding Meaning

Appreciating life. For each participant, the diagnosis of cancer, the hardships and discomforts they have to endure, and the feelings of uncertainty have changed their priorities and brought those things and people that they value most into perspective. Xuereb and Dunlop (2003) also found that for participants of their study on meaning and control for patients with hematological cancers undergoing bone marrow transplants, material goals became secondary as they stepped back from the “competitive world” and “experienced a greater appreciation for other people and their needs . . . and of life itself” (p. 407). It is important to understand the meaning patients ascribe to their overall cancer experience.

Meaning in the experience. Patients with cures or at least reassuring prognoses may find the occurrence of cancer meaningful and expect something positive out of the experience, while patients with poor prognoses may question why the disease struck and
attempt to find a meaningful answer (Winterling, Wasteson, Glimelius, Sjoden & Nordin, 2004). Nonetheless, “the search for meaning is a way to endure discomforts for patients . . . and finding meaning is accompanied by lower levels of distress” (Winterling et al., 2004, p. 386). In a study to evaluate how women with breast cancer gave meaning to their experience, it was found that the majority attached positive meaning to their experience of having cancer. This positive stance did not come without a struggle: “loss of a person’s previous, more stable life situation can stimulate a psychological quest to make sense of a new existence marked by uncertainty and the possibility of premature death” (Degner, Hack, O’neil, Kristjanson, 2003, p. 169). This positive meaning is said to be achieved “from the process of reviewing their lives and the way they were living with the conclusion that they were stronger as a result of the cancer experience” (Degner et al., 2003, p. 175). Such findings are consistent with those from the participants of my study, several of whom also reported feeling stronger and having discovered inner strength.

*Previous life experiences and values.* It is important to realize the role that previous life experiences play as patients seek to find meaning in their cancer experience. It was found that “people brought both the present values in their life, as well as a life-long pattern of dealing with adversity into their confrontation of a life-threatening illness. Issues of personal meaning and agency (the capacity to act and control valued aspects of one’s life) were found to be paramount” (Xuereb & Dunlop, 2003, p. 397). Finding meaning and purpose in life and disease is an important part of the cancer experience that influences decision-making, goal formation, and discovering new sources of meaning (Xuereb & Dunlop, 2003). These findings are significant as they point to the importance
of identifying patients’ values and previous coping patterns to promote hope, meaning, and appropriate adjustment.

Establishing Social Support Systems

A broad base of support. Whether a spouse or significant other, family, close friends, friends from a support group, or even one’s cancer nurses, knowing they did not have to go through the hardships alone and having someone there to talk to for encouragement and support were important for the participants as well. In a qualitative study on the perceptions of women with ovarian cancer, they described support from various sources: “Extended family members provided emotional and practical support. Some women found that friends in the community, personal relationships, and the church community were especially helpful during the treatment phase” (Sodergren, 2003, p. 127).

For younger patients with cancer, important resources for adjustment and effective coping with cancer include emotional, material, and informational support, although this support is not exclusive of family and friends. The confidence and reassurance, as well as the security of a therapeutic relationship with health care providers and the emotional and informational support they provide was an important component of social support, according to Kyngas, Mikkonen, Nousianen, Rytilahti, Seppanen, Vaattovaara, et al. (2000). Nurses’ provision of emotional support can reduce patients’ feelings of isolation and prevent them from feeling alone in managing their symptoms or dealing with their problems (Ream & Alexander-Dann, 2002). Similar to the participants of the current study, participants of Ream and Alexander-Dann’s study
on fatigue during chemotherapy praised the nurse’s supportive qualities, which included sense of humor, listening skills, empathy, and sensitivity, which were similar to those supportive qualities recognized by participants of this study.

*Adaptive support.* Consistent with the self-regulation model, seeking support “represents the notion that in order to adjust to cancer a patient seeks out people who foster adaptation. . . . This theory assumes that there is some optimal match between the patient’s needs and the social support provided” (Merluzzi et al., 2001, p. 215). When the patient is a “passive recipient of social support, or does not actively seek out the adaptive support one needs for adjustment, that optimal matching of need and provision may not be attained” (Merluzzi et al., 2001, p. 215). Furthermore, Trask, Paterson, Fardig, and Smith (2003) found that in patients with testicular cancer receiving chemotherapy increasing distress was associated with lower levels of social support or well being. In such cases it seems appropriate for the nurse to intervene to facilitate patient identification of support needs and assist the patient attain such social support to improve adjustment to cancer.

*Psychosocial functioning.* According to Winterling et al. (2004), “Social Support and a good family function, including communication about the experience in the family, are associated with better adjustment and a lower level of psychological distress” (p. 388). Because coping strategies influence both patients and their families/support groups, adjustment to the effects of cancer influences overall quality of life for both illustrating the need for nurses to help families learn active and effective coping strategies as well (Kershaw et al., 2004).
Accepting Change and Loss

Kershaw et al. (2004) defined acceptance as “an active attempt to learn to live with the illness and reality of one’s situation” (p. 152) and found this to be the most frequently used coping strategy by patients with advanced cancer. Finding acceptance in change and loss has been an important but difficult part of adapting to the realities of cancer for participants of my study. Some of these changes included making lifestyle changes, accepting changes to one’s body and appearance, or that life is just never going to be the same because of the cancer.

Accepting a new reality. In Sodregen’s study on the perceptions of women with ovarian cancer, “women struggled to integrate changes and experienced emotional distress as they realized that life was changed forever” (2003, p. 126). For a woman following a mastectomy, looking at the change in her body is the beginning step in acceptance. Her ability to look at, touch, and care for her incision reflects the beginning of adjustment to change in her body image. A participant in the current study discussed her struggle to achieve this first step of acceptance following her mastectomy as well.

Expressing control. Not giving in to the cancer but upholding values, finding meaning, and redefining and reconstructing “normal life” may help patients to accept their disease and the associated changes and losses; acceptance may be a way for patients with cancer to express some control over their situation (Ekman, Bergborn, Ekma, Berthold, & Mahsneh, 2004). Patients with cancer, especially those with advanced cancer, and their families perceive considerable changes in life, and it was found that patients seem to accept their situation to a higher degree, whereas more spouses felt
despair and used hope and avoidance more (Winterling et al., 2004). Winterling et al. noted that spouses who use active coping strategies during the final phase of their partner’s disease may be ineffective as they can do little to influence the disease and attempts to do so may increase frustration. Assistance to accept the situation would be beneficial to these family members.

*Helping families.* Because families often struggle more with acceptance and use more avoidant and ineffective coping strategies, it is important that nurses create an atmosphere where both patients and family can express feelings about changes and loss, despair, hope and meaning, as well as provide support to promote acceptance and adjustment to life with cancer and the possibility/reality of death. Reflecting on one’s life and its meaningfulness and fulfillment is associated with accepting death for patients with cancer and their families (Winterling et al., 2004). As discussed in the section on social support, family support and communication is related to better adjustment and a lower level of psychological distress for both patient and family, which is important throughout the cancer process.

*Alleviate distressing feelings.* It is also important for nurses to help patients understand and alleviate distressing feelings that interfere with acceptance. In a study by Ekman et al. (2004) on the perspectives of patients with ovarian cancer, “women reported feeling that their control was threatened and wondered if they would achieve normality again. Caregivers could therefore have an important role in providing additional support for patients who need acceptance when experiencing feelings of weakness and anxiety” (p. 181).
Acknowledging fear and emotions

Anxiety. Cancer prognosis and treatments are sources of anxiety for patients with cancer, as they pose a threat to biologic integrity and survival. Anxiety is a form of psychological distress manifested by physical, emotional, and cognitive symptoms. It may include negative coping mechanisms such as denial, anger, and depression (Ignatavicius, 2002). Helping a patient with cancer manage anxiety can decrease both physical and psychological distress and allow him or her to cope effectively and feel more control. First and foremost, the nurse can provide comfort by listening attentively and using a calm, reassuring approach: “Providing emotional support and encouraging sharing may help a patient clarify and verbalize his fears, allowing the nurse to give realistic feedback, reassurance, and correct misconceptions” (Carpenito, 2002, p. 123). In addition to a therapeutic approach, helping patients understand their anxiety and its sources provides an opportunity to work through it (Carpenito, 2002). The nurse can reinforce positive coping mechanisms and patient strengths, as well as encourage patient decision making to provide a sense of control, which enhances coping ability (Carpenito, 2002).

Anticipatory distress. As previously discussed in the section on enduring the physical symptoms and discomorts, all of the participants of my study recognized an emotional or psychological factor as affecting symptom distress. Findings of the study by Trask et al. about emotional health and quality of life and the degree of distress in 16 patients with testicular cancer undergoing chemotherapy affirm that “pre-treatment anxiety and distress that appears to be primarily anticipatory, decreases over the course of
chemotherapy, and occur in the context of improved quality of life and reduced symptom severity” (2003, p. 814). It is likely that such anticipatory distress is the result of fear for what they may experience as a result of chemotherapy. Two of the participants of the current study mentioned symptom distress with initial treatments that they believed to be psychologically based that declined as treatments proceeded. These results suggest that “additional education efforts conducted prior to chemotherapy on the likely course of treatment and side effects may reduce anxiety” (Trask et al., 2003, p. 819), as well as related physiological and psychological distress.

_Fear and uncertainty._ Recognizing and dealing with their emotions has been another area that has been important to their adjustment to cancer for the participants of the current study. They have been faced with fear and uncertainty but have found ways to cope and release emotions, sometimes laughing or crying. They have had to anticipate challenges and be prepared for the difficulty, and come to realize their strength. Dealing with the uncertainty can be ongoing, however, and poses a major challenge that can invoke many emotions, such as feeling a lack of control over events in one’s life, which can lead to a sense of sadness and fear that can be difficult to share with others, fear of the unknown and of death, anger, and concern for and worrying about one’s family (Sodergren, 2003).

_Affective regulation._ The ability to express negative feelings as well as contain them adaptively may promote better adjustment to cancer. The Merluzzi et al. theory on self-efficacy for coping with cancer includes the task of affective regulation; “this factor contains items that reflect, on one hand, the ability to express strong negative feelings
and, on the other hand, the ability to withdraw from situations by using denial, escape, and avoiding” (2001, p. 215). For one participant who maintains hope and optimism in spite of her non-reassuring prognosis with regards to her cancer she said, “I ignore it. I can’t focus on it, oh no. You’d be down all the time if you thought about it too much.”

Nurses must be able to differentiate whether or not the containment of fears and emotions is adaptive and promoting patient adjustment or if it is, in fact, maladaptive.

_Nurses’ Role_

_Promoting patient control._ For the participants of the current study and as shown by the studies discussed above, nurses can and do influence patients’ ability to adjust to and cope throughout the process of cancer by reinforcing their need to take action and maintain control. Nurses are able to provide information, prepare patients for the symptoms and side effects they might experience and help them manage these. Nurses are able to promote hope and help patients with cancer find meaning by helping them develop an awareness of life, their values, a reason for living, as well as by helping patients set realistic goals and establish support systems. Nurses provide additional support and can assist patients recognize the need for and process of accepting change and loss as well as to help patients effectively cope with some of the fears and emotions that influence both psychological and physiological well-being. All participants acknowledged the helpfulness, knowledge, understanding, sensitivity, availability, and openness of the nurses in the cancer centers where they receive chemo. They each describe these nurses as just doing their jobs, and doing them very well.
Empowering the individual. Nurses must be sensitive to the individual preferences of their patients with cancer and ensure that they are engaged in decisions regarding treatment, care management, and activities of daily living (Volker, Kahn & Penticuff, 2004). Furthermore, by promoting patient empowerment and encouraging and helping patients with cancer to achieve control, nurses can facilitate adjustment, effective coping, decreased psychosocial distress, and improved quality of life. Link et al. reinforce that “by delineating how beliefs of control relate to coping strategies and other factors, researcher and clinicians are better equipped to understand the process of coping with, and adjusting to cancer from the patient’s perspective” (2004, p. 223).

Coping is an issue necessary for a nurse to address when caring for a patient with cancer. Successful coping reduces stress to manageable limits, maintains feelings of personal worth, promotes significant social relationships, and facilitates personal feelings of mastery (Carpenito, 2002). The nurses caring for patients with cancer must also be sensitive to their needs and provide empathy, calmness, and emotional equilibrium (Uitterhoeve et al., 2003). By addressing emotional and spiritual needs and encouraging the expression of feelings, the nurse can facilitate coping and adaptation to cancer: “The nurse-patient relationship and interaction should include a high degree of skilled communication that takes a holistic approach” (Ramfelt et al., 2002, p. 148).

Holistic care. In order to attend to the holistic needs of patients with cancer, it is important to first form a therapeutic relationship, one that is trusting, empathetic, genuine, and non-judgmental so that the nurse may act as a support person with whom the patient is comfortable communicating physical as well as psychosocial issues. Easing
physical discomforts and giving patients the means to do so themselves can make coping with the disease a bit easier. This relationship will also ensure patients are comfortable opening up to discuss their fears and emotional struggles as well. The nurse in this supportive role is able to answer questions, raise patients’ mood and morale, encourage a positive outlook, and bring about feelings of control (Ream & Alexander-Dann, 2002). Knowledge decreases fear of the unknown, and guidance through the management of the physical symptoms decreases physical distress. These interventions enable patients with cancer to cope better than they otherwise would have done, not only with physical and emotional issues but also with their illness.

*Nursing Implications*

From the theme that encompasses issues of the participants of my study, taking action to adapt to the realities of cancer and treatment, we learn of the need to empower patients with cancer in order to help them achieve a sense of control over factors affected by and affecting the cancer. The importance of nursing support to help patients with cancer fulfill the seven tasks identified by the patients of this study has been established; however, a model of patient empowerment needs to be established as the means to meeting the needs of patients for effective adjustment to and coping with cancer.

*Empowerment model.* Grace Adamson, nurse and co-founder of an Australian cancer support foundation that focuses on teaching patients with cancer how to empower themselves and to help them find meaning and purpose in their lives, emphasizes a need for a holistic approach for empowering patients with cancer: “We need to acknowledge the four aspects of healing and pay attention to [physical, psychological, sociocultural,
Coping with Cancer

and spiritual] as separate yet integrated aspects of the whole; this will take us to a place of true restorative healing” (Adamson, 2003, p. 109). She emphasizes that healthcare providers must take a holistic approach to restore personal empowerment for patients allowing them to make decisions using psychological, emotional, and spiritual intelligence. Because they are empowered, patients with cancer can make conscious, informed, considered choices regarding treatment, for example (Adamson, 2003). Adamson proposed that such empowerment promotes holistic healing by improving of quality of life.

Adamson explained that “complementary supportive care with the active intervention of empowerment methods can do much to alleviate human suffering: Pain and suffering go far beyond the physical. . . . Emotional pain is debilitating and disempowering and worsens any physical pain being experienced” (2003, p. 111). While medical care can reduce the impact of an illness, inattentive care and focusing on medical needs alone can increase the disruption caused by illness, which reiterates the need to empathize with and seek to understand the holistic needs of those affected by cancer. Adamson reiterates the need for nurses and healthcare providers to “acknowledge and encompass the whole experience of the cancer patient as a person who has body, mind, emotion, and spirit” (2003, p. 111). Jean Watson’s Theory of Human Caring may provide the framework to empower patients with cancer by caring for holistic needs and facilitating holistic healing.

Clinical caritas process. Watson’s Theory of Human Caring was established to uphold nursing values, knowledge, and practices of human caring directed at subjective
inner healing processes for patients (Watson, 2000). Transpersonal caring relationships are central to this theory, which can be described as a human-to-human transaction involving concern for the inner world of another and seeking to connect with and embrace the spirit through the processes of caring, healing, and being in authentic relation in that moment. A caring moment is transpersonal when “each feels a connection with the other at the spirit level, thus it transcends time and space opening up new possibilities for healing and human connection at a deeper level than physical interaction” (Watson, 2000, ¶ 27).

The Theory of Human caring involves unique caring and healing arts with a framework of “carative factors,” which complement conventional medicine, yet do not depend on “curative factors” (Watson, 2000). Watson describes transpersonal caring as being reflective on the part of the nurse, who “has the ability to center consciousness and intentionality on caring, healing, and wholeness, rather than on disease, illness, and pathology” (Watson, 2000, ¶ 19), which makes it a very appropriate model to meet the holistic needs of patients with cancer. To potentiate therapeutic healing processes and relationships, Watson’s theory is applied through an emerging model of transpersonal caring called the “Clinical Caritas Processes,” which follows:

1. Practice of loving-kindness and equanimity within the context of caring consciousness;
2. Being authentically present, and enabling and sustaining the deep belief system and subjective life world of self and one-being-cared-for;
3. Cultivation of one’s own spiritual practices and the transpersonal self, going
beyond ego self;

4. Developing and sustaining a helping-trusting, authentic caring relationship;

5. Being present to, and supportive of the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for;

6. Creative use of self and all ways of knowing as part of the caring process; to engage in artistry of caring-healing practices;

7. Engaging in genuine teaching-learning experience that attends to unity of being and meaning attempting to stay within other’s frame of reference;

8. Creating healing environment at all levels, (physical as well as non-physical subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.

9. Assisting with basic needs, with an intentional caring consciousness, administering “human care essentials”, which potentiate alignment of mind, body, spirit, wholeness, and unity of being in all aspects of care; tending to both embodied spirit and evolving spiritual emergence;

10. Opening and attending to spiritual-mysterious, and existential dimensions of one’s own life-death; soul care for self and the one-being-care-for. (Watson, 2000, ¶ 12)

The Clinical Caritas Process is a tool that can guide nurses’ relationships and interactions with patients to care for the whole person and understand the effects of the cancer on one’s inner being. With this tool nurses can promote self-understanding, inner and holistic healing, patient empowerment to take action and maintain control, and
effective adjustment and coping. Caring for the psychological and physiological needs, as well as spiritual and sociocultural needs simultaneously can decrease the distress experienced by patients with cancer that the disease is notorious for causing. By acknowledging and caring for all areas of need for patients with cancer, as well as recognizing the significance of empowering patients and encouraging them to take action, nurses can directly act to promote effective coping, positive outcomes, and holistic healing, even if a cure is not in sight.

Conclusion

By taking action and feeling empowered to exercise some control over factors affecting and affected by cancer, the individuals involved in this study were able to adapt to the realities of cancer and treatment to cope more effectively. There were several essential tasks these individuals needed to attend to, which influenced their ability to take action and achieve personal control including (a) seeking information, (b) enduring physical symptoms, (c) maintaining hope, (d) finding meaning, (e) establishing social support systems, (f) accepting change and loss, and (g) acknowledging fear and emotions. Being informed to make treatment decisions, managing physical symptoms, staying optimistic and finding meaning in the experience, building support systems, accepting change and loss as well as one’s fear and emotions all demonstrate components of a process in the cancer experience, taking action in spite of the challenges that cancer presents, which makes coping and adjustment possible for these individuals.

The nurse’s role in supporting this process and alleviating the physical and psychological symptom distress in patients with cancer is significant. Even as patients
face a life or death battle with cancer, when nursing care is directed at physiological, psychological, spiritual, and sociocultural aspects of their being and empowering them to take action and control, the nurse serves as a facilitator of well-being and holistic healing. The nurse’s support, guidance, and care can improve the patients’ quality of life, which is perceived as “the net physical, psychologic, social, and spiritual well-being” (Ream & Alexander-Dann, 2002, p. 300).

*Judging the Grounded Theory*

Fit means that categories identified by the emerging theory correspond with collected data; data should not be manipulated to fit preconceived categories or discarded in order to maintain an existing theory (Glaser, 1992). All participants of this study sought to be active and maintain control in relation to the cancer and their lives. In spite of different diagnoses, prognoses, and individual variables, the seven tasks to achieve control through action are present for each participant. Although each participant faced different issues and achieved the tasks differently, the core category and seven tasks were evident and correspond with collected data for each participant nonetheless.

Work indicates that the grounded theory study explains what happens, what could happen, and interprets the theory (Glaser, 1992). The theory on taking action to adapt to the realities of cancer and treatment in spite of challenges and the seven tasks that influence this is a process, which is part of the cancer experience for the participants of this study. This process, its significance, and the implications it has for the nurses caring for patients with cancer are discussed in great detail in Chapter IV on the findings of this
study, and in Chapter V, which compares findings of this study to other studies and discusses nursing interventions and implications throughout.

Relevance requires that the study and findings must be relevant and comprehensible to individuals in the setting (Glaser, 1992). To ensure the validity and accuracy of the findings of this study, participants were sent a summary of the findings to review and were asked to briefly comment on the relevance of these findings to them, how they do and do not apply and on changes as well, since coping is a dynamic process. The responses of the participants, regarding the relevance of the study and findings, are covered in the section on Participant Validation in Chapter IV. Lastly, the theory is modifiable, which means it can be modified to accommodate the integration of new concepts (Glaser, 1992). Chapter V, or the Discussion, compares and integrates the findings of other research into the theory at hand. The findings of this study can and should be further explored by modifying participant variables and further exploring the various tasks or themes found to be significant to taking action and maintaining control for the participants of this study.

*Future Research*

Receiving the diagnosis of cancer frequently leaves people feeling helpless, fearful, anxious, and depressed. As an appropriate result, there is a large body of research that addresses how individuals cope with cancer. There is a rich source of nursing literature and research available related to coping with cancer and various related stressors, holistic care, as well as the need for and benefits of patient control and empowerment, which suggests the profound impact that nurses have on coping and
adjustment and the important implications for clinical practice. The development of an accessible and easy to use clinical tool to assess coping would serve to enhance nursing care of the patient with cancer.

The findings of this study, as well as those of the Merluzzi et al. study support the use of the revised Cancer Behavior Inventory (CBI), which is a “comprehensive approach to the measurement self-efficacy for behaviors related to coping with cancer” (2001, p. 207). Similar to those of the participants of the current study, the CBI covers seven prominent issues patients with cancer face, including maintenance of activity and independence, seeking and understanding medical information, stress management, coping with treatment related side-effects, accepting cancer/maintaining a positive attitude, affective regulation, and seeking support (Merluzzi et al., 2001). Future research studies could adapt this tool to be used by oncology nurses in a clinical setting, test its accuracy in measuring patient self-efficacy, and ultimately promote self-regulation and more effective adjustment and coping to cancer by nurses, as “cancer patients who feel more efficacious about their coping capacity are better adjusted. . . . The greater the confidence people have in their ability to execute courses of action, such as coping behaviors, the higher the probability of attaining some goal such as maintaining a desired state of quality of life” (Merluzzi et al., 2001, p. 206).
Appendix A

Informed Consent

Carroll College-Department of Nursing, Helena, MT
Consent to Participate in a Research Project

Title: *Coping with the Physical and Psychological Effects of Cancer*
Researcher: Jessi Yates, Senior Nursing Student
    Thesis Director: Jocie Waldron, RN, MN
    Thesis Advisor: Kim Garrison, RN, MN
    Thesis Advisor: Lois Fitzpatrick

**Purpose**
You are invited to volunteer for a research study. You have been chosen to take part in this study because you have cancer and are currently undergoing treatment. The main objectives include 1.) exploring your personal experiences with cancer and ways of coping and 2.) discussing ways for nurses to minimize areas identified as problematic and assist patients to cope more effectively with cancer.
It is important for you to know that your participation is entirely voluntary. You may decide not to take part in or quit the study at any time. You will be told about any new information or changes in the study that might affect your participation.
To take part in this study you must consent to participate in an audio-taped interview that would take place in a mutually agreeable location.

**Procedure**
If you agree to participate in this study, a time will be set with you individually to meet for the audio-taped interview in a neutral and private setting. You will be asked open ended questions and your responses will be compared with those of other participants to establish themes that may arise from the data of shared experiences, concepts, difficulties, or stages from the individual cancer experiences. The findings of this study will be mailed to you allowing you validate the reported findings that represent your experience and return them to the researcher in a self addressed stamped envelope.

**Risks**
We can foresee few risks that might occur if you decide to participate in this study. A minor risk is the possibility that questions regarding emotions toward cancer may arouse unpleasant or distressing feelings or memories.

**Benefits**
There is no promise or guarantee of medical benefits to you resulting from your participation in this study. Telling your story, however, may be therapeutic and empowering. You might have better insight into your own values, goals, needs, strengths, and the progress you have made as they relate to living and coping with cancer. In addition, your participation may help others with cancer in the future as a result of knowledge gained from this study.

**Confidentiality**

Your research records will be confidential. In all records of study you will be identified with a code number and your name will be known only to the researcher. Your name will not be used in any reports or publications of this study. Once again, your participation in this study is entirely voluntary and you may withdraw from the study at any time. Please feel free to ask any questions you may have about the study or about your rights as a research participant. If other questions occur to you later, you may contact Jessi Yates at (406) 491-1600. If at any time before, during, or after the study, you would like to discuss the study or your research rights with someone who is not associated with the study you may contact Cynthia Gustafson, PhD, RN, Chair of the Carroll College Department of Nursing, at 406-447-5494.

Consent to participate in the research project entitled “Coping with the Physical and Psychological Effects of Cancer.”

Participant’s Name__________________________________________________________

Researcher’s Name__________________________________________________________

The purpose and procedure of this research project have been explained to me and I understand them. I have been told about all the predictable risks and benefits that might result and I understand them. I agree to take part as a participant in this research project. I understand that I may end my participation at any time.

_________________________________________________________ Date:_____________
Appendix B

Initial Interview Questions

1. Tell me about your cancer: when were you diagnosed, what type of cancer is it, and what treatment you have undergone. How has this impacted your life.

2. When you were first diagnosed what was your initial reaction? Has that changed?

3. Please attempt to describe some of the emotions you have experienced up to this point.

4. What have you done to cope with the negative emotions (emotional distress or suffering)?

5. Can you describe some of the symptoms and physical distress you have experienced due to the cancer and treatment?

6. What have you done to cope with the physical distress? Were you prepared for the negative effects of treatment?

7. Tell me about your biggest struggles and most difficult moments you have experienced since you were diagnosed with cancer?

8. What coping strategies have you used (both positive and negative) through your cancer experience from your initial diagnosis up to this point? How has your coping changed from then until now?

9. What coping strategies have you found to be most effective?

10. From what sources do feel that you draw your strength?

11. What are your feelings about the future?

12. What role have your nurses played in your cancer experience?

13. Have nurses helped you with coping and, if so, in what ways?

14. How do you think nurses could promote or facilitate more effective coping for patients with cancer?
(I will conduct the interview using standards of therapeutic communication. In accord with grounded theory, I may modify the ongoing interview based on data obtained, such as by asking the participant to expand on a certain issue he or she has expressed. Subsequent interviews may also be adapted to expand on data obtained from preceding interviews, as research is data driven in grounded theory.)

Appendix C

Participant Response Questionnaire

Your Responses: Please answer the following questions as you are able. You may write on the back or use another sheet if you need more space.

1.) Do you think that taking action has given you some control and been an important part of your adjustment to cancer?

2.) Do you think that finding information to understand your disease and treatments, being able to manage your physical symptoms, staying positive and optimistic, finding meaning in this experience, having others available to support you, learning to accept changes, and understanding and not denying your feelings have been ways that you have taken action that have helped you cope with cancer?

3.) Are there other things you have done to cope that are not listed above?

4.) How do you think the findings of this study relate to you now?
Additional Comments:

References


autologous peripheral blood stem cell transplantation. *Oncology Nursing Forum*, 31(5), 937-944.


Sodergren, K. (2003). Women living with ovarian cancer described changes in day to day living, major challenges, and sources of support. *Evidence-Based Nursing*, 6(4), 126-127.


