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## **A Holistic Assessment of the Perceived Supportive Care Needs of Cancer Patients during Treatment**

Robert B. Gardner  
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A Holistic Assessment of the Perceived Supportive Care Needs of  
Cancer Patients during Treatment

A Dissertation

Submitted to the Graduate Faculty of the  
University of New Orleans  
in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy  
in  
Counselor Education

by

Robert B. Gardner

B.S., Auburn University, 1982  
M.Ed., University of New Orleans, 2005

August 2008

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## **DEDICATION**

I dedicate this dissertation to my wife, Kim, for her endless love and support during my doctoral journey. I will forever be grateful for the tremendous sacrifices you made so that I might pursue this academic achievement. Your unwavering belief in me, your resilience in the face of life's adversities, and your patience throughout this process inspired me to complete this journey. Your encouragement gave me the strength and confidence to overcome obstacles and kept me focused on the end result. Without you, none of what I accomplished in the counseling program would have been possible. These words cannot properly express how much I appreciate all that you have done so I simply say, thank you.

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This dissertation represents the culmination of a journey that began in 2002. As with any major accomplishment in life, it is rarely a solo endeavor. Rather, my journey has involved many people who I want to acknowledge. There have been professors to guide me and keep me on the right path; mentors to protect me on my journey; fellow doctoral students and close friends to support me during challenging times; and family to provide a secure foundation on which to travel. All of these people have contributed in a significant way to this endeavor, and to each person I am grateful. I cannot acknowledge everyone who helped me during this process; however, I have several important people I would like to recognize.

I owe my mother, Elizabeth, a great deal of credit for starting me on my journey into the counseling field. Her fight with breast cancer inspired me to do more with my life. As she said to me shortly before her death, “Do something with your life that matters.” I feel certain she would approve of the path I have chosen and agree that helping people in their fight against cancer truly matters. I will forever be in debt to my mother for the life she gave me and for providing me with the inspiration I needed to change the direction of my life. Her death indeed changed my life.

My wife, Kim, came into my life around the time my mother was making her exit. You believed in me and gave me the encouragement I needed to get through every challenge along the way. Your presence and that of our beautiful daughter Paige motivated me to complete this journey. Your love and unending support reminded me that I was not alone and served to make this accomplishment all the more rewarding. I

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I offer my gratitude to Dr. April Bedford, the methodologist of my study, for sharing your knowledge, experience, and insight into conducting qualitative research. You confirmed for me the importance of incorporating structure into the data collection and analysis process of my study. I appreciate your efforts in helping me develop a cohesive approach to research so that my study might achieve the desired results. Thank you for all your support during the dissertation process.

To the final member of my dissertation committee, Dr. Tim Pearman, thank you for all that you have done for me personally and professionally. Since we first met in 2002, you have been one of my biggest supporters. More than that, you provided me with a chance to fulfill my desire to work as a mental health counselor in a cancer center setting. Beginning as an intern in the masters program at the University of New Orleans, you created an internship site for me. Later, after Hurricane Katrina turned my world upside down, you called and offered me employment as a patient navigator/mental health counselor where I continue to work today. At a time when both my wife and I were out of work, this position enabled me to financially support my family. No words can properly describe how much I appreciate what you did. Most important of all, you have always been a friend, keeping me up during the difficult times and helping me to focus on what is possible. Thank you, my friend, for all you have done and continue to do for me and my family.

My father taught me much including an appreciation for education, the value of hard work, and the importance of the written word. Thank you for sharing your insights into how to live life to the fullest. I appreciate all you have taught me over my lifetime. Thanks for always supporting me and being there when I needed you. I hope you approve of the path I have taken with my life.

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I would like to acknowledge the impact my professors as well as my fellow students have made on me during the masters and doctoral counseling programs. I have learned much from you that furthered my development professionally and helped to shape me personally. Thank you for your contributions to changing my life in a positive way.

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## FOREWORD

My interest in the research topic of this study is based on personal experience as a caregiver for my mother who was diagnosed with breast cancer and ultimately died from the disease. This event gave me an opportunity to develop real insight into the perceived needs of a person experiencing cancer while undergoing treatment, and to comprehend the implications of these needs going unsupported by medical professionals. Recently, my wife was diagnosed with cervical cancer which provided me with another opportunity to subjectively observe how a person experiences cancer. These two life events helped to shape my view of cancer as a life-threatening illness in a real and meaningful way. With regard to this research, it was important for me to acknowledge the influence these personal experiences have on my subjectivity and to remain aware of the potential for researcher bias throughout the course of the study.

As a patient navigator and counselor at a regional cancer center, I regularly meet with patients at various stages in their cancer treatment. My observations as a counselor led me to want to learn, “How do people individually experience the diagnosis and treatment of cancer?” Also, I wanted to know, “What type of needs do cancer patients have when entering treatment?” Further, “Do the supportive care needs of patients change during cancer treatment? And lastly, “How can the wellness model used by counselors be applied to help individuals diagnosed with cancer?” I believe the answers to these questions have significant implications for the way supportive care needs of patients are assessed when entering an outpatient cancer clinic for treatment. By understanding the perceived needs of patients, it is my belief that an assessment strategy

based on the whole person can be designed to maximize the supportive care patients receive during cancer treatment and minimize the potential for needs going unmet.

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## **ABSTRACT**

The purpose of the study was to describe the personal experience of individuals undergoing cancer treatment in an outpatient clinic by examining their perceived supportive care needs. The theoretical basis of the study lies in Alfred Adler's holistic view of human beings as unique and indivisible (1927/1954). Six individuals recently diagnosed with cancer were recruited from the same regional outpatient cancer clinic located at a major university medical center. A semi-structured interview process with open-ended questions was utilized to understand how people individually and collectively experience cancer and cancer treatment. The 17 factors of the wellness model (Witmer, Sweeney, & Myers, 1998) were used to assess the perceived supportive care needs of the study's participants. Data were analyzed using Interpretative Phenomenological Analysis (Smith, 1998) to ascertain emergent themes and interpret the meanings of the perceptions patients have of their cancer experience.

The data resulted in eight major themes being present including facing mortality; uncertainty about the future; understanding cancer diagnosis and treatment; reliance on faith; maintaining control; love and support from family; physical impact of cancer; and importance of self-care. These themes provide insight into the perceived supportive care needs that patients experience during cancer treatment. With the exception of cultural and gender domains, the holistic assessment process identified patients' needs. The factors of wellness appear to capture the experience of individuals during cancer treatment. As an approach to assessing the coping skills of cancer patients, the wellness

model seems appropriate for use by clinical mental health counselors. Implications for counselor theory, training, and practice with this unique client population are discussed.

Keywords: cancer treatment, supportive care, supportive care needs, holistic, assessment, needs assessment

The natural healing force within each one of us is the greatest force in getting well.

- Hippocrates

# CHAPTER ONE

## INTRODUCTION

In the United States, one in two males and one in three females will experience cancer in his or her lifetime (Rosenbaum & Rosenbaum, 2005). These statistics translate into approximately 1.4 million Americans annually receiving a cancer diagnosis. As a major cause of mortality, one in four of all deaths in the United States results from cancer (American Cancer Society, 2007a). Despite these statistics, modern medical treatments have proven to cure cancer in some patients and to prolong life in others. While advances in cancer research have addressed the physical domain, increased attention has been given to the associated psychological, emotional, and social issues of patients (Houts, Yasko, Kahn, Schelzel, & Marconi, 1986; Schofield, Carey, Bonevski, & Sanson-Fisher, 2006). The findings of a study by Asadi-Lari, Tamburini, and Gray (2004) indicate unsupported needs of patients can adversely affect their ability to comply with cancer treatment and ultimately their chances for survival.

According to Miller, Pittman, and Strong (2003) identifying needs is important for the well-being of patients, suggesting that such supportive care may also promote survival through stress reduction and favorable influences on the immune system. Within the field of oncology, supportive care is regarded as “care that helps patients and their family to cope with cancer and treatment of it ... [Further], it helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease” (National Institute for Clinical Excellence, 2004, p. 18).

Previous studies have assessed the perceived supportive care needs of patients in several different domains, including physical, emotional, daily living, social support, financial, informational, and spiritual (Moadel, Morgan, & Dutcher, 2006). Unfortunately, the generalizability of the findings of needs-based research to the cancer patient population as a whole is limited, as previous needs assessment studies were conducted with patients having a specific cancer diagnosis (Moadel et al.), located outside the United States (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, Lo, et al., 2007; Sanson-Fisher, Girgis, Boyes, Bonevski, Burton, & Cook, 2000), diagnosed with a certain stage of disease (Rainbird, Perkins, & Sanson-Fisher, 2005), or assessed either before treatment, at diagnosis (Whelan et al., 1997), or after treatment, generally referred to in the literature as cancer survivorship (Hodgkinson et al.; Houts et al., 1986; Sanson-Fisher et al.).

Carlson and Bultz (2003) in a review of the literature concluded a growing number of oncology professionals endorse taking a whole-person approach to psychosocial needs in cancer care. By assessing needs from a holistic perspective, this study sought to understand how patients perceive the full range of their supportive care needs during cancer treatment.

### **The Problem in Perspective**

People who are diagnosed with cancer face significant challenges during treatment—not the least of which involves confronting their own mortality. Most patients undergo a combination of treatments that can be effective but traumatic including surgery, chemotherapy, and radiation therapy (Sanson-Fisher et al., 2000). Although treatments have the potential to cure some cancer patients and extend the lives of others,

these regimens come with a range of physical side-effects such as pain and fatigue (Schofield et al.), and supportive care needs that can involve emotional distress, psychological difficulty, and spiritual suffering (Whelan et al., 1997).

Given the perceived seriousness of a disease like cancer, many patients report being ill-prepared to handle the challenges associated with a cancer diagnosis and treatment (Thewes, Butow, Girgis, & Pendlebury, 2004). The all-consuming nature of illness can make patients unable to acknowledge the existence of specific needs. With the multifaceted burden of cancer in mind, it is understandable why as many as 40% of cancer patients report having at least one unmet need following the completion of their treatment regimen (Sanson-Fisher et al., 2000). Further, Sanson-Fisher et al. concluded from a review of previous research that cancer patients routinely report “high levels of unmet needs [with the] difference in the types of unmet needs depending on the cancer population studied” (p. 227).

Understanding supportive care needs is necessary to guide cancer treatment planning, in part because many patients do not communicate concerns to their physicians (Frosch & Kaplan, 1999; Maguire, 1999; Suchman, Markakis, Beckman, & Frankel, 1997). When they do share their needs, they often omit or downplay the impact of important psychosocial concerns. There are several reasons for the absence of information sharing. Many patients believe that pain, anger, fatigue, and suffering are symptomatic of cancer and therefore, inevitable. Others believe that physicians do not want to address such needs, as evidenced by a lack of questioning on the part of physicians during clinic visits (Ford, Fallowfield, & Lewis, 1996). As a result of this deficiency in understanding the needs of patients, the quality of care perceived by

patients is reduced and the unnecessary suffering patients experience is increased (Cegala, 1997). Evidence is available in the literature to substantiate the damaging effects of insufficiently addressing information and supportive care needs (Peters-Golden, 1982).

Patients express a variety of concerns during cancer treatment with supportive care needs commonly falling into specific domains related to well-being that includes physical, psychological, emotional, social, financial, occupational, informational, cultural, and spiritual/existential. Combining these domains, a holistic perspective is formed encompassing the full range of supportive care needs patients encounter during cancer treatment. In the sections that follow, previous studies are presented from research in the field of psycho-oncology that centered on a specific domain or domains of patient needs (Sanson-Fisher et al., 2000). Additionally, a perspective on how people experience cancer is offered.

### ***Cancer Experience***

In her book *The Human Side of Cancer*, Jimmie Holland (2002), the person often credited with founding the field of psycho-oncology, discussed the nature of the cancer experience:

Many people's first experience with cancer begins quite simply with the discovery of a symptom or sign known to be a possible cancer indicator ... From this moment, the uncertainty of cancer begins. But this moment, before the doctor has even been called or a single test has been done, often transforms a person's life from one of general well-being and confidence to one of enormous anxiety and uncertainty about the future. This

pervasive sense of uncertainty probably characterizes the journey with cancer more than anything else ... Learning to live with uncertainty becomes the bottom line in dealing with cancer (pp. 39-40).

In a recent article, Jonathan Alter (2007), author and political journalist, wrote about the time when he learned he had been diagnosed with cancer:

I took the call on my cell phone ... from a doctor I barely know telling me that a CT scan—ordered after three weeks of worsening stomach pain—showed a large mass in my abdomen, with what she said was “considerable lymph node involvement.” I rubbed my eyes and sensed the truth instantly: cancer, and not one that had been detected early. I was 46 years old and had not spent a night in the hospital since I was born ... I was not remotely ready for this (p. 30).

When a person is diagnosed with cancer, one life ends and another one begins. The very foundations of a person’s life are shaken. The normalcy of everyday life is replaced with fear and uncertainty of what the future may bring. The human need to make sense of a life experience is the driving force behind the need for coping (Carlick, & Biley, 2004). After the initial shock of a cancer diagnosis, patients must begin to piece together their lives and begin the process of building new and stronger foundations for coping with what lies ahead.

Suddenly illness arrives, uninvited, unexplained. I found myself caught between life and death, light and dark, banished to an unknown place – between night and day ... The arrival of illness interrupted my cycle of life, displacing its normal parts. (Petroni, 2001, p. 12).

The diagnosis of a serious illness, particularly cancer, forces people to experience many changes in their lives. Often the physiological, psychological, and emotional stress that is present during this time precipitates the need for patients to seek meaning of their illness in an effort to gain greater control and learn better ways to cope (Johnson, 2000).

With cancer patients living longer than ever before, the trend in the research literature is to frame the cancer experience around the notion of survivorship. Patient survival is defined from the traditional biomedical perspective as an absence of disease—also referred to as *disease-free*—for a five-year period following the end of treatment (Stanton, 2006). In contrast, the psychosocial perspective of survival considers the cancer experience to be a process which begins at diagnosis and continues until an individual's death (Dow, 1991).

Consistent with the psychosocial view, Mullan (1985) postulated that there are three stages of survival through which a cancer patient progresses. The first stage, known as the acute survival phase, begins when the patient is first diagnosed with cancer and lasts throughout the prescribed treatments that can include surgery, chemotherapy, and radiation therapy. The overwhelming challenge facing patients at this stage involves learning to accept and to cope with the knowledge that they may not survive (Thewes et al., 2004). The next stage of survival starts at the end of formal treatment when the patient's cancer goes into remission. According to Mullan, the primary focus for patients at this time is a fear of recurrence of their disease. The final stage of the cancer experience is the permanent survival phase. This stage requires sufficient time to elapse when the statistical chance of recurrence is minimal (Mullan). This study focused on Mullan's acute survival phase—the time period from diagnoses throughout active cancer

treatment—and aimed to describe and understand the personal experiences of individuals with cancer.

### *Patient Needs*

According to Schofield et al. (2006), a significant percentage of cancer patients reported a moderate-to-high level of need for assistance in coping with their illness and addressing the associated demands of treatment. However, even with the demand for help prevalent, there is no consensus on the meaning of the concept of *need* in health care literature (Asadi-Lari et al., 2004). Need encompasses a broad spectrum as the range of human experiences is extensive. Based on the literature, patient needs are often associated with treatment satisfaction (Dunn et al., 2006) and quality of life (Leikweg, Eckhardt, Taylor, Erdfelder, & Jaehde, 2005; Llewellyn, McGurk, & Weinman, 2005) outcomes. Patient satisfaction seems to correspond to the degree in which health care needs are met (Asadi-Lari et al.). Other studies provide evidence to support a direct correlation between the needs of cancer patients and health-related quality of life (Bunston, Mings, Laperriere, Malcolm, & Williams, 1998; Ferrell, Smith, Cullinane, & Melancon, 2003; Snyder et al., 2007). Findings of these studies indicate quality of life is high when most needs are fulfilled and low when only a few needs are being met (Asadi-Lari et al.). The relationship that exists in the literature between patient needs and the outcome measures of satisfaction and quality of life confirms the relevance of a needs-based approach which postulates that “life gains its quality from the ability and capacity of individuals to satisfy their needs” (Hunt & McKenna, 1992, p. 308).

From a holistic viewpoint, a shortcoming of previous research in psycho-oncology lies in the tendency to narrowly focus on specific domains of need within a

particular patient population. Past studies on the perceived needs of cancer patients have centered on a single domain involving psychological distress (Lintz et al., 2003; Zabora, Brintzenhofeszc, Curbow, Hooker, & Piantadosi, 2001), social support concerns (Ferrell et al., 2003), issues involving information and patient-physician communication (Mallinger, Griggs, & Shields, 2005), spirituality and existential meaning (Moadel et al., 1999; Taylor, 2001), and psychosocial issues (Dunn et al., 2006; McIllmurry, Thomas, Francis, Morris, Sootkill, & Al-Hamad, 2001; Miller et al., 2003; Thewes et al., 2004). Additional studies have focused attention on the unmet needs of cancer survivors from various domains including psychological distress (Bonevski, Sanson-Fisher, Hersey, Paul, & Foot, in press; Foot & Sanson-Fisher, 1995; Newell, Sanson-Fisher, Girgis, & Ackland, 1999), daily living requirements (Mor, Allen, Siegel, & Houts, 1992; Siegel, Raveis, Houts, & Mor, 1991), and physician communication and cancer information needs (Bonevski et al., in press; Harrison-Woermke, & Graydon, 1993). Each of these studies focused on a specific domain or domains of supportive care need of cancer patients instead of following a holistic approach as undertaken by this research study.

### *Needs Assessment*

Previous studies focused on examining the needs of patients in relation to quality of life and patient satisfaction (Ferrell et al., 2003; Houck, Avis, Gallant, Fuller, & Goodman, 1999; Wenzel et al., 2005). Another measure for evaluating the supportive care needs of cancer patients involves the process of assessment (Bonevski et al., 2000). An operational definition of needs assessment that served to inform this research study states “assessment is about collecting information on a person’s needs and circumstances and making sense of that information to identify needs and decide on what support or

treatment to offer” (Richardson, Medina, Brown, & Sitzia, 2007). According to Zabora et al. (2001) assessment seeks to accomplish a series of tasks in the early interactions with patients including an estimate of the patient’s level of needs, development of a dynamic understanding of the patient through the therapeutic relationship, formulation of an initial course of action, and development of the support services and interventions designed to meet specific needs. Steginga, Occhipinti, Dunn, Gardiner, Heathcote, and Yaxley (2001) reached the conclusion that “needs assessment provides an indication of the relative magnitude of need for support in different domains” (p. 67). Spiegel (1994) viewed needs assessment as a way for patients with higher levels of need to be identified and targeted with appropriate early interventions.

The use of quantitative measures to assess patients’ perceived supportive care needs is consistent with the conceptual approach followed in a majority of previous psycho-oncology research. A patient needs assessment instrument is defined for the purpose of this study as “a collection of questions, scales, and other means of obtaining information that, together, provide a consistent and comprehensive system through which patients’ range of needs for support and care can be explored” (Richardson et al., 2007). One instrument, the Supportive Care Needs Survey (SCNS), was developed by Bonevski et al. (2000) and has gained some credibility in needs assessment research. According to Sanson-Fisher et al. (2000) the aim of the SCNS instrument is “to provide a direct and comprehensive assessment of the multidimensional impact of cancer on the lives of cancer patients” (p. 228). To date, the SCNS has shown promise demonstrating good reliability and validity in studies with patients having a range of cancer diagnoses

(Bonevski et al.; Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; Sanson-Fisher et al.; Steginga, et al., 2001).

In addition to the SCNS, a number of other needs assessment instruments have been developed and are being used to assess specific domains of patient needs. In a meta-analysis of 17 patient needs assessments, Wen and Gustafson (2004) found the selected instruments meet some but not all of the criteria they used for determining validity and reliability. The researchers questioned whether any instrument can be developed that represents an ideal assessment tool. According to Wen and Gustafson, a model assessment instrument is one that facilitates the exchange of information and communication between patients and cancer care professionals. Despite the findings of their study, Wen and Gustafson concluded that needs assessment offers a rich opportunity to more fully understand the experiences of patients by providing them with a chance to express the needs they want recognized and addressed.

There is some evidence from previous research to indicate the point in time when patients have their supportive care needs assessed is significant. According to a study by Sanson-Fisher et al. (2000) time since diagnosis and the time since last admission for treatment were found to correlate with certain supportive care needs of cancer patients. Studies in psycho-oncology of supportive care needs have historically focused on cancer patients during the first two years following diagnosis (Houts et al., 1986), later in follow-up (Canadian Cancer Society, 1990), or patients in advanced or terminal stage of disease (Houts et al). While previous needs-driven studies have failed to focus on recently diagnosed patients at the point of entry into the cancer care system, a study by Whelan et al. (1997) recognized “the need to provide more comprehensive services to all

cancer patients at any stage of their illness” (p. 1518). Such an acknowledgment by Whelan et al. confirms the value of taking a holistic assessment of patient supportive care needs as an initial step toward the eventual development of a needs assessment instrument and strategy for people who are recently diagnosed with cancer as they enter treatment.

Needs-based research in psycho-oncology tends to focus on a specific cancer site. Some previous studies that are cancer site specific involve patients diagnosed with breast cancer (Ashing-Giwa et al., 2004; Thewes et al., 2004), prostate cancer (Lintz et al., 2003; Steginga et al., 2001), ovarian cancer (Ferrell et al., 2003; Houck et al., 1999), cervical cancer (Wenzel et al., 2005), gynecologic cancer (Miller et al., 2003; Pearman, 2003; Pilkington & Mitchell, 2004), colorectal cancer (Dunn et al., 2006), and lung cancer (Hill, Amir, Muers, Connolly, & Round, 2003). Studies of cancer patients with a specific diagnosis tend to limit the scope of the findings to that population. This study took a broad, holistic view of patients without regard to the primary location of the cancer as initially diagnosed.

The individualistic nature of the cancer experience makes it difficult for a traditional medical approach to address the full range of perceived needs of patients. Alfred Adler (1927/1954) stated “no two human beings react in quite the same way ... if we ask them what they have perceived they will give very diverse answers” (p. 49). Adler (1927) believed the individuality and uniqueness of people is centered in what they perceive and how they perceive it. Following this logic, the perceived needs of people undergoing cancer treatment are unique and individualistic. According to Arciniega and Newlon (1995) “the individual’s unique subjective interpretation and perception are part

of the Adlerian theory, and the client's values and views are honored and accepted" (p. 578).

### **Purpose of the Study**

The purpose of this phenomenological inquiry was to explore the essence of the personal experiences of patients receiving cancer treatment at an outpatient clinic. Specifically, this study sought to understand and describe the cancer experience by focusing on the perceived supportive care needs as reported by patients following diagnosis—a time when they are confronted with a life-threatening illness and attempting to cope with the uncertainty that is commonly associated with cancer. Utilizing a holistic approach to assessment, this study investigated the full range of supportive care needs that patients encounter during cancer treatment. Methods of inquiry adhered to Interpretative Phenomenological Analysis (IPA; Smith, 2004), an approach designed to build understanding and meaning of the human experience. IPA differs from other methods of data analysis in that it relies on an exhaustive, time-consuming examination of the transcribed word to facilitate the emergence of themes and meanings.

### **Research Questions**

The foundation for this phenomenological study began with exploring the global question, "In what ways do individuals experience cancer?" This broad question led to asking the next question, "How do people experience cancer treatment?" The focus further narrowed to a holistic examination of the primary research question of this study, "What are the perceived supportive care needs of people recently diagnosed with cancer as they undergo treatment?" Additional research questions explored in this study were:

1. How do patients perceive their supportive care needs after at least one month of cancer treatment?
2. What instrument and/or strategy can be developed for use in outpatient cancer clinics to holistically assess the perceived supportive care needs of patients entering treatment?
3. How can the wellness model used by counselors be applied to help individuals diagnosed with cancer?

In addition to answering these research questions, implications of this research involves the development of assessment instruments and intervention strategies that could be used to holistically examine and address the perceived supportive care needs of patients during cancer treatment. Further, for counselors working in the field of psycho-oncology and for counselor educators instructing students, this study has implications for the development of a theoretical approach to counseling cancer patients based on the wellness model.

### **Conceptual Framework**

According to Glesne (1999), the purpose of introducing theory into qualitative inquiry is to further the understanding of the personal experiences of the study's participants instead of relying on generalizations. A conceptual framework serves as the theoretical lens to shape the kind of research questions asked and methods used (Glesne). Miles and Huberman (1994) concluded that conceptual framework establishes a structure on which to understand what is being studied and the presumed relationship between study variables. Further, Miles and Huberman viewed a conceptual framework as an

explanation of the topic to be studied; the central ideas around the purpose of the study; and the significance of these ideas in relation to the purpose of this study.

This research study holistically assessed the perceived needs of patients undergoing treatment following a cancer diagnosis. Specifically, this study identified the self-perceived needs of patients recognizing the individual characteristics and the diagnostic status of cancer patients receiving treatment at a regional cancer center; assessed the priority patients place on their supportive care needs during treatment; identified changes in the priority patients place on their needs at different point during their cancer treatment regimen; and identified assessment strategies for addressing in a holistic manner the perceived needs of patients during cancer treatment.

The conceptual framework for this study is rooted in the work of Adler (1927/1954) who promoted the notion that to fully understand human beings they must be viewed in a holistic manner. In his book, *The Practice and Theory of Individual Psychology*, Adler (1927) emphasized the importance of holism as a perspective from which to understand the individual. Further, Adler believed that the body, mind, and spirit are indivisible (Adler), theorizing that individuals are comprised of various parts that function together. Within the context of this research study, a cancer diagnosis means that one part of the individual is diseased or damaged, and when the cancer is removed, the person becomes whole or healthy again (Myers & Sweeney, 2005b). Such an Adlerian-based approach to the phenomenological experiences of individuals receiving cancer treatment served as the context for developing the study's research questions, reviewing available literature, designing data collection instruments, and creating the questions used in the interviews with subjects in this study.

As a writer and researcher of the unique experiences of human beings, Adler considered the subjective more significant than the objective, meaning the inner reality of a person, or the way that person perceives the world, is most relevant (Ansbacher & Ansbacher, 1956). The principle focus of this study was on the perceptions that patients have of their needs during cancer treatment. Applying Adler's view to this study's primary research question, what is important is how people diagnosed with cancer perceive reality, not the perceptions of others, or what actually takes place (Ansbacher & Ansbacher).

*The Indivisible Self: An Evidence-Based Model of Wellness (IS-Wel)*, developed by Witmer, Sweeney, and Myers (1998), is foundationally rooted in the work of Adler. An assessment instrument based on this wellness model was used to contextually understand the perceived needs of cancer patients at specific intervals during their treatment regimen. The *IS-Wel* (Witmer et al.) offered a holistic approach to assess patients' perceived issues across a single higher order wellness factor and five second-order factors including the creative self, coping self, social self, essential self, and physical self. From the second-order factors, Witmer et al. developed 17 third-order factors that include thinking, emotions, control, work, positive humor, leisure, stress management, self-worth, realistic beliefs, friendship, love, spirituality, gender identity, cultural identity, self-care, nutrition, and exercise (Witmer et al.). This research study used the third-order factors of the *IS-Wel* (Witmer et al.) as the foundation for undertaking a holistic assessment of the supportive care needs of patients experiencing cancer treatment.

## **Overview of Methodology**

This research study utilized an IPA approach to explore in detail the personal experiences of participants and how they make sense of their experiences (Smith, 2004). In an IPA study, the researcher takes an active role in a two-stage interpretative process whereby the participants try to understand their world while the researcher tries to understand the participants trying to understand their world (Smith & Osborn, 2003). This qualitative methodology is phenomenological (Giorgi & Giorgi, 2003) in its concern with how people perceive events in their world. Phenomenology was appropriate for this research because it allows the researcher to gain an understanding of events from the perspective of those who live it. IPA is grounded in hermeneutic philosophy which informs qualitative inquiry by focusing on the problem of interpretation (Smith, 2004). On this basis, IPA was well suited to serve as the methodological foundation for this research study.

## **Overview of Procedures**

The setting for this research study was an outpatient cancer center clinic located in downtown New Orleans that is one part of a comprehensive healthcare and medical teaching facility. A full range of services related to cancer care are offered at the research setting including surgery, chemotherapy, radiation therapy, hormonal therapy, stem cell transplantation, and psychosocial support. The primary diagnoses treated at this site include cancer of the breast, prostate, lung, colon, and blood. This academic institution was selected because I had access to all the patients and resources needed to conduct this study.

Prior approval to conduct this study was granted by the Institutional Review Board (IRB) at the research setting (see Appendix A). In addition, I received approval from the IRB of the University of New Orleans (see Appendix B) before proceeding with this study. As an employee at the research site, I had full access to all recently diagnosed cancer patients undergoing treatment. Members of the medical staff at the research site assisted in the recruitment of subjects for this study. A recruitment letter (see Appendix C) outlining the nature of the research study was given to each person considered for inclusion in this study. Potential participants received a screening interview with selection based on specific criteria including their willingness to participate, availability, level of psychosocial distress, and stage of disease. A fairly homogeneous sample of six participants was selected for this study. Written informed consent (see Appendix D) was obtained from each participant prior to beginning the research.

Data were collected from the participants at two specific times through the use of questionnaires, self-assessments, and semi-structured interviews. Information on the participants' personal characteristics and their cancer diagnosis and treatment plan was obtained through a written questionnaire (see Appendix E). A self-assessment (see Appendix F) was administered to gather data on how participants assess themselves on psychosocial distress and coping skills.

The phenomenological experiences of participants during treatment were collected through the administration of a self-reported assessment (see Appendix G)—and a second, revised version of the self-assessment instrument (see Appendix H)—based on the 17 third-order factors of wellness of the *IS-Wel* (Witmer et al., 1998). The assessment instrument was administered to each participant shortly before the first

interview was conducted. Responses to the self-assessment instrument served as information that was explored in greater detail during the semi-structured interview. An initial interview protocol (see Appendix I) was used to provide some structure to the interview process. After interviewing the study's first participant, I revised the initial interview protocol (see Appendix J) to make the questions more relative to a person experiencing cancer diagnosis and treatment.

A second assessment instrument (see Appendix K) was developed from the information gathered during the first assessment process that focused on the participants' supportive care needs. The initial interview process served to inform the second interview. An interview protocol (see Appendix L) was developed and utilized to conduct the follow-up interview with the study's participants.

### **Definitions of Terms**

The following terms are relevant to this research study. The definitions are presented to assist the reader in fully understanding the meaning of the terms within the context of this study.

#### ***Assessment***

The working definition of assessment that informed this research study states "assessment is about collecting information on a person's needs and circumstances and making sense of that information to identify needs and decide on what support or treatment to offer" (Richardson et al., 2007).

#### ***Brief Symptom Inventory 18 (BSI 18)***

The *Brief Symptom Inventory 18 (BSI 18)* is a self-report symptom inventory used to screen for psychological distress in medical populations (Derogatis, 2000). Derived

from the original *Brief Symptom Inventory*, a 53-item inventory, the *BSI 18* has 18 items with equal numbers from each of the symptom dimensions of somatization, depression, and anxiety. The administration time for the *BSI 18* is four to five minutes, and scoring the completed test is equally brief. Despite being a self-report inventory, the *BSI 18* has been shown to be a valid measure of psychological distress (Derogatis). According to Derogatis, “self-report techniques have the singular advantage of deriving their data from the ‘experiential self’—the individual centrally involved in the phenomena” (p. 2).

### ***Chemotherapy***

Chemotherapy is a treatment for cancer using drugs designed to kill cancer cells or stop them from multiplying (Rosenbaum & Rosenbaum, 2005). Statistics show that most people who are treated for cancer receive chemotherapy at some point during their treatment regimen (Eyre, Lange, & Morris, 2002).

### ***Distress***

Distress is a term used to describe unpleasant feelings or emotions that may interfere with a person’s ability to cope with cancer, and the treatment for cancer (National Comprehensive Cancer Network, 2005). Distress encompasses a wide range of emotions from normal fear and sadness about receiving a diagnosis of cancer to severe levels of anxiety and depression that constitutes a psychiatric disorder. Distress may be reflective of psychological, social, or spiritual concerns.

### ***Hermeneutics***

Hermeneutics is synonymous for the principles of interpretation. Hermeneutic philosophy argues that individuals can only interpret the meaning of something from some perspective, whether they are reporting on their own findings or reporting on the

perspectives of people being studied (Smith, 2004). Hermeneutics challenges the assertion that an interpretation can ever be absolutely correct or true—it must remain only an interpretation. Hermeneutic inquiry is part of a movement away from empirical knowledge (Patton, 2002), and is becoming more pervasive in qualitative research. Within the context of this study, hermeneutics is “intellectually connected” to IPA (Smith & Osborn, 2003) as patients attempted to understand the meaning of their cancer experience just as the researcher made an effort to understand patients trying to understand the meaning of their cancer experience. This two-stage interpretative process, or double hermeneutic, is an important aspect of IPA.

### *Holism*

Sweeney (1998) defined holism as “a point of view from which to understand human behavior as dynamic, self-directed, interrelated mind and body moving through life with a unique goal-oriented plan for having significance in relation to others” (p. 23). In his *Individual Psychology*, Adler (1927) emphasized the value of holism in understanding human behavior. Holism served as the theoretical basis for this research study.

### *Holistic*

The term *holistic* refers to Adler’s *Individual Psychology* which places the focus on the *whole* person, indivisible and unique (Adler, 1927/1954). According to Sweeney (1998) the term *holistic* denotes a philosophy, an attitude, or a mindset that consists of a person’s “physical, mental, and emotional states, social relationships, spiritual orientations, and life habits” (p. 44). In the context of this study, patients are comprised of indivisible parts—mind, body, and spirit—that ideally work together; however, an

illness of the body can negatively affect the mind and spirit interrupting their holistic nature. This operational definition of holism was used as a foundational basis for framing the research questions, the written questionnaires, and the prepared questions that were used in the semi-structured interviews.

### ***Holistic Medicine***

Holistic medicine promotes wellness i.e., holistic health, by focusing on the manner in which physical, mental, emotional, and spiritual elements of the body are interconnected (American Cancer Society, 2002). Based on this definition, when one part of the body is not working properly, the whole person is affected. Treatment in holistic medicine concentrates on the whole body rather than focusing narrowly on the disease or the part of the body that is not healthy.

### ***Idiographic***

Smith (2004) characterized IPA as being strongly idiographic, which refers to the process of conducting an in-depth analysis of a single case before moving to a detailed examination of the next case, and so on until all cases have received an exhaustive review. Only when that has occurred is a cross-case analysis attempted.

### ***Indivisible Self***

Indivisible self is both a theoretical concept and an assessment instrument. Theoretically, Adler (1927/1954) believed that a human being could only be understood by considering the whole person—body, mind, and spirit—indivisible and unique. Based on the theoretical beliefs of Adler, *The Indivisible Self: An Evidence-Based Model of Wellness* was developed by Witmer et al. (1998). This wellness model offers a holistic assessment across five “second-order factors” including the creative self, coping self,

social self, essential self, and physical self. The second-order factors are comprised of 17 corresponding “third-order factors” including thinking, emotions, control, work, positive humor, leisure, stress management, self-worth, realistic beliefs, friendship, spirituality, love, gender identity, cultural identity, self-care, nutrition, and exercise (Witmer et al.).

### ***Interpretative Phenomenological Analysis (IPA)***

Interpretative Phenomenological Analysis (IPA) was first introduced by Smith (1998) in the mid-1990s as a phenomenological approach to qualitative research in health psychology. Theoretically, IPA seeks to “explore in detail participants’ personal lived experience and how participants make sense of that personal experience” (Smith, 2004, p. 40). IPA recognizes the central role of the researcher in the analytical and interpretive process. IPA as a methodology is connected to theories of interpretation, especially hermeneutics (Smith & Osborn, 2003).

### ***Oncology***

The American Cancer Society (2007b) web site defines oncology as “the branch of medicine concerned with the diagnosis and treatment of cancer” and an oncologist as “a doctor with special training in the diagnosis and treatment of cancer”.

### ***Perception***

Edmund Husserl (1913/1983), the person who is credited with creating phenomenology believed that “the natural experience that is presentive of something original is perception” (p. 5). In phenomenology, perception is considered as “the primary source of knowledge, the source that cannot be doubted” (Moustakas, 1994, p. 52). Adler (1927/1954) believed that “no two human beings react in quite the same way”

... “the individuality and uniqueness of a human being consists of what he perceives and how he perceives” (p. 49-50).

### ***Phenomenology***

Phenomenology refers to “knowledge as it appears to consciousness, the science of describing what one perceives, senses, and knows in one’s immediate awareness and experience” (Moustakas, 1994, p. 26). Adler’s emphasis on subjectivity, or the way a person perceives the world, is considered to be phenomenological (Sweeney, 1998).

### ***Psycho-oncology***

The medical subspecialty psycho-oncology focuses on the psychosocial problems of cancer patients by researching, clinically assessing, and responding to the psychosocial needs of patients. According to Holland (2002) psycho-oncology involves two psychological dimensions: 1) the responses of cancer patients and their families at all stages of disease; and 2) the psychological, social, and behavioral factors that play a part in the cancer experience. The contributions of psycho-oncology to cancer care include a focus on emotional and psychological responses of patients to their disease and its treatment; the measurement of emotional distress (e.g., depression, anxiety, somatization) and its treatment through psychotherapeutic interventions; the assessment of quality of life in terms of physical and emotional functioning; and a focus on the quality of communication between clinicians and patients (McIllmurray et al., 2001).

### ***Psychosocial***

The American Cancer Society (2007a) defines psychosocial as “the psychological and/or social aspects of health, disease, treatment, and/or rehabilitation”. Psychosocial concerns for individuals diagnosed with cancer often include physical, psychological,

emotional, and interpersonal challenges that can extend from diagnosis into survivorship (Stanton, 2006). Psycho-oncology tends to focus attention on the emotional and psychological effects of cancer and its treatment (McIllmurray, 2001).

### ***Protocol/Regimen***

A protocol, or regimen, is “a carefully designed and written description of a cancer treatment program” (Rosenbaum & Rosenbaum, 2005, p. 558). The treatment protocol for cancer patients is based on empirical data that support the program for treatment that is proposed by an oncologist.

### ***Radiation Therapy***

At least half of all people who undergo treatment for cancer receive radiation therapy (Eyre et al., 2002). Also known as radiotherapy, x-ray therapy, and irradiation, radiation therapy involves the use of x-ray waves or a stream of energy particles to destroy cancer cells or damage them in such a way they can no longer multiply.

### ***Spirituality***

Because of the universal and highly personal nature of the concept of spirituality, it is difficult to define (Cashwell, 2005). Spirituality has been defined as a search for the divine through any life experience (National Institute for Healthcare Research, 1997). Another definition of spirituality stated that it is a belief in God or a higher power that has authority over life and the universe (Ashing-Giwa et al., 2004). A broader view of spirituality includes feelings of connectedness with self and others, a community, nature, and the meaning or purpose of life (Bellingham, Cohen, Jones, & Spaniol, 1989). Within the context of the cancer experience, the term “spirituality” can be understood by how the beliefs, practices, and experiences of patients help them make meaning of their illness

(Myers & Sweeney, 2005b). According to Myers and Sweeney, studies “suggest that there is a significant, positive relationship between spirituality ... and holistic well-being or wellness” (p. 20).

### ***Staging***

Staging describes the extent to which cancer has spread at the time of diagnosis. It is essential in assessing a patient’s prognosis and designing the course of treatment to achieve the best results. According to the *2007 Cancer Facts & Figures* published annually by the American Cancer Society (2007a), “a cancer’s stage is based on the primary tumor’s size and location and whether it has spread to other areas of the body” (p. 3). Staging is based on three factors: 1) the size of the primary tumor; 2) absence or presence of regional lymph node involvement; and 3) absence or presence of disease in other organs of the body (American Cancer Society). Once these factors are determined, a disease stage of I, II, III, or IV is assigned for diagnostic purposes, with Stage I representing early stage of disease and Stage IV signifying advanced disease. This staging system represents a linear scale that signifies an advancement in disease as the number increases.

### ***Supportive Care***

The term supportive care has traditionally been used in oncology to describe the care provided patients with advanced disease (Levy, 1994). Recognizing the applicability to all cancer patients at any stage of their illness, Whelan et al. (1997) defined supportive cancer care as those health services and related activities designed to help patients and their families with their cancer experience during diagnosis, treatment, recovery, and palliation. The broad areas of need addressed by supportive care include

physical, emotional, psychological, social, informational, financial, sexual, existential, spiritual, and cultural (Richardson et al., 2007). From the patient's perspective, "the quality of supportive care can be considered to be the extent to which needs are addressed and met" (Richardson et al.).

### *Wellness*

The global concept of wellness is a way of living that can be seen as both a process and an outcome (Myers & Sweeney, 2005). Based on a review of the literature, Myers, Sweeney, and Witmer (2000) proposed that wellness is "a way of life oriented toward optimal health and well-being, in which the mind, body, and spirit are integrated by the individual to live life more fully within the human and natural community" (p. 252).

### **Organization of Remaining Chapters**

In this chapter, I introduced the research problem and created a context for this study by providing a conceptual framework. A review of existing literature on cancer and the cancer experience, supportive care needs of patients, and needs assessment is offered in chapter two. Additionally, literature on the theoretical and methodological underpinnings of the study is examined. The research methodology that was used in this study including the research questions, descriptions of participants and sampling procedures, researcher's role and responsibilities, methods of data collection, and a general overview of how data was analyzed is presented in chapter three. The fourth chapter is a detailed description of the cancer experience through the perceptions of the study's participants. The results of this study as reported in chapter four were achieved through the use of an interpretative phenomenological analysis process. The fifth chapter

includes a summary of the study's results, implications for counselor education, theoretical and practical implications, limitations of the study, and suggestions for future research. Additionally, I offer my personal reflection on my experience as a researcher within the context of this study.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

The purpose of this chapter is to examine the previous research and existing literature related to how individuals experience cancer in general, and specifically cancer treatment. Further, this chapter explores the literature regarding the supportive care needs of cancer patients during treatment. This literature review is organized into five sections that develop the context from which to examine the perceived needs of cancer patients and frame the case for using a holistic needs assessment approach to address the problem of unmet patient needs. The first section provides an overview of the process used to conduct this literature review. The second section describes the cancer experience from the perspective of how patients experience treatment. A discussion of patient needs is presented in Section Three supported by a review of the major research literature on needs assessment instruments and unmet supportive care needs. A discussion of Adler's (1927/1954, 1929) theory of holism and the indivisible self is presented in the fourth section. Section Five summarizes the information presented in this literature review.

#### **Overview of the Literature Review**

According to Moustakas (1994) preparation for a phenomenological study involves reviewing existing literature connected to the research topic and question. A review of the literature establishes “a framework for establishing the importance of the study [as well as] a useful backdrop for the problem or issue that has led to the need for the study” (Creswell, 2003, p. 30). This research study strived to understand the cancer

experience by reviewing the research that has been done before examining the strengths and weaknesses of existing studies, what these studies might mean in relation to this research, how existing research informs this study, and what still needs to be learned. According to Boote and Beile (2005) a literature review enables the researcher “not only to summarize the existing literature but also to synthesize it in a way that permits a new perspective” (p. 4).

To ascertain which studies are relevant to the research topic, searches were performed using available databases including PubMed, MedLine, PsycINFO, CANCERLIT, OVID, and Dissertation Abstract. The search engine Google Scholar was also utilized to locate relevant materials. All studies available in these databases in April 2007 were considered. The following search terms were used in a variety of combinations with the exact wordings varying between databases: cancer, oncology, psycho-oncology, cancer patients, cancer treatment, perceived needs, patient needs, supportive care, cancer care, supportive care needs, psychosocial needs, quality of life, patient satisfaction, needs assessment, psychosocial, psychological distress, holistic, global, qualitative, phenomenology, interpretative phenomenological analysis, hermeneutics, and qualitative research. Additionally, the names of authors commonly published in journal articles were entered in PubMed to locate other literature on topics related to this research study.

Searches were limited to literature written in English and published in recognized peer-reviewed print or online journals. All available literature germane to the topic under study was considered without preference to publication date. The abstract of each article was initially reviewed to determine the relevance of the literature to the research

questions. The reference lists of selected literature were used to locate additional journal articles, books and book chapters.

## **Cancer**

A diagnosis of cancer in any form has a profound effect on the patient, as many people equate this disease to mean an early death (Roing, Hirsch, & Holmstrom, 2006). Statistics indicate the threat is real given that cancer is responsible for 25% of all deaths in the United States (American Cancer Society, 2007a) which makes cancer the number two cause of death after heart disease. According to the American Cancer Society, cancer is projected to exceed heart disease as the leading cause of death in the United States by the year 2020. This year an estimated 1,444,920 Americans will be diagnosed with some form of cancer with 559,650 people expected to die from this disease (American Cancer Society).

In spite of these statistics, over the past 75 years significant advancements have been made in the early detection, diagnosis, and treatment of cancer as evidenced by the increase in the five-year survival rate from 20% in 1930 to more than 60% in 2005 (Rosenbaum et al., 2005). The annual report *Cancer Facts and Figures 2007* from the American Cancer Society (2007a) stated “the five-year relative survival rate for all cancers diagnosed between 1996 and 2002 is 66%, up from 51% in 1975-1977” (p. 2). While advances in cancer treatments have addressed the physical needs of patients, greater attention of late is being placed on the psychosocial concerns of patients (Schofield et al., 2006). The literature suggests that psychosocial needs of patients when unmet can adversely affect their ability to comply with cancer treatment and ultimately their chances for survival (Asadi-Lari et al., 2004).

## Cancer Treatment

Most cancer patients traditionally undergo a combination of treatments that are often times effective, but nonetheless, traumatic. Following a medical protocol—a carefully designed cancer treatment program based on empirical data (Rosenbaum & Rosenbaum, 2005)—cancer patients may be required to endure surgical removal of the cancer, chemotherapy, radiation therapy, and hormonal therapy (Braunwald, Fauci, Kasper, Hauser, Longo, & Jameson, 2001). Surgery, radiation therapy, and chemotherapy are the three primary forms of cancer treatment. Statistics indicate most cancer patients receive chemotherapy at some point during their treatment regimen (Eyre et al., 2002). Further, nearly half of all people who undergo cancer treatment receive radiation therapy (Eyre et al.). Using a combination of treatments, physicians are able to affect a definitive cure—five to ten years free of cancer—in about 50% to 58% of all cancers (Rosenbaum, Rosenbaum, Margolis, Meyler, Hass-Kogan, & Hawn, 2001). Whatever the combination of cancer treatments used, the ultimate goal for any treatment plan is to give patients the best chance for survival.

While treatments have been shown to be curative in some cancer patients and to prolong the lives of others (Newell et al., 1999), cancer treatments often have side effects that cause patients to experience multiple physical and psychosocial challenges. For example, chemotherapy is associated with physical symptoms that include pain, fatigue, nausea, vomiting, hair loss, appetite loss, diarrhea, constipation, and changes in eating and sleeping patterns (Ignoffo, Festa, Rosenbaum, & Rosenbaum, 2001). Additionally, many aspects of the quality of life of patients are diminished: their physical and work activities are reduced, their social activities are disrupted, their relationships with family

and friends frequently deteriorate, their level of sexual activity decreases, and they often find themselves under increasing financial burdens. The types of needs cancer patients possess during treatment largely depend on their personal history and their individual reactions to cancer treatment.

### **Patient Needs**

Providing the appropriate level of supportive care is not likely to happen without a good understanding of patient needs (Richardson et al., 2007). This view of supportive care emphasizes the importance of examining the needs of patients when entering the treatment process. The challenge for health care professionals is to define the meaning of *need*—a concept that is not clearly delineated in the literature (Asadi-Lari et al., 2004)—and then put into practice strategies for meeting the supportive care needs of patients. In a study of the unmet needs of cancer patients, Sanson-Fisher et al. (2000) concluded that need can be defined as “the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being” (p. 227). This definition of need appeared to be most appropriate for the research question under consideration and was selected for this study.

### ***Domains of Patient Needs***

Given the wide variety of definitions of need, it is not surprising that needs assessment is conducted in very different ways (Jordan & Wright, 1997). A meta-analysis was undertaken by Richardson et al. (2007) to identify the existing instruments for assessing patient needs in cancer care. The results of the search concluded that a wide variety of supportive care needs are commonly reported by patients including physical, psychosocial (encompassing a combination of psychological, emotional, and social

needs), social support, communication and information, occupational/work-related, financial resource, sexual and intimacy, cultural, and spiritual/existential. A shortcoming of previous research in psycho-oncology lies in the tendency to narrowly focus on specific needs of a particular patient population. This research study examined the perceived supportive care needs of cancer patients holistically, which stands in contrast to past studies which had a narrow scope and focused on either a single domain of need or a limited number of domains of patient need.

### ***Physical Need***

Physical side effects of cancer treatment are commonly reported by patients undergoing chemotherapy and radiation therapy. Newell et al. (1999) found that pain, fatigue, nausea, and hair loss were the most commonly reported symptoms; hair loss, skin rash, and hot flashes were the most enduring physical symptoms; and fatigue, nausea, and vomiting were the most debilitating symptoms of cancer treatment. The physical needs of patients are directly associated with the side effects of cancer treatment. In a study of 271 patients actively receiving treatment at an outpatient cancer clinic, 30% reported experiencing some need related to the physical domain (Newell et al.). A recent report by the Institute of Medicine (IOM; 2007) indicated fatigue is the most commonly reported symptom of cancer, although estimates of rates of fatigue among individuals with cancer vary greatly. With regard to pain—another commonly reported symptom—the Institute of Medicine estimated one-third to one-half of patient undergoing treatment for cancer experience pain resulting from the illness, its treatment, or co-morbidity. The prevalence of physical symptoms underscores the importance of assessing the physical needs of patients during cancer treatment.

### ***Psychosocial Need***

In a review of the literature, Carlson and Bultz (2004) concluded that “a significant proportion of cancer patients at all stages of the disease trajectory will suffer social, emotional, and psychological morbidity as a result of their diagnosis and treatment” (p. 837). Psychosocial needs are associated with degrees of emotional and psychological distress or poor emotional functioning (McIllmurray et al., 2001). From a psycho-oncology perspective, patients have a psychosocial need when they develop a “clinically defined problematic psychological response to cancer” (McIllmurray et al., p. 262).

*Psychological need.* Several recent studies illustrate the point that psychological distress is prevalent in cancer patients. The frequency of psychological morbidity in cancer patients is high, with estimates ranging from 35% to 50% of patients experiencing a clinically significant level of psychological distress (Carlson & Bultz, 2003). The prevalence of depression among cancer patients is reported to be in the 20-25% range, increasing with higher levels present of physical disability, pain, and advanced stage of illness (Sellick & Crooks, 1999). A large study of 4496 cancer patients conducted by Zabora et al. (2001) found significant levels of psychosocial distress in 35.1% with the greatest distress in lung cancer patients.

*Emotional need.* The emotional aspects of gynecological cancer have been a focus of several studies including one by Fitch, Gray, DePetrillo, Franssen, and Howell (1999) in which 315 Canadian women with ovarian cancer were surveyed during their cancer treatment. Fitch et al. (1999) found that 63% of participants reported they had a need to address psychological and emotional concerns regarding their cancer. A survey

by Steginga and Dunn (1997) of 82 Australian women with gynecological cancer who were disease-free following treatment resulted in 81% of respondents reporting psychosocial challenges as being their primary need. Within this category, 49% of the study's participants reported having a problem with depression, and 37% stated experiencing a heightened level of anxiety (Steginga & Dunn). Another study conducted by Miller et al. (2003) of 95 women being seen in follow-up for gynecological cancer found that 57% of the participants reported they had needed help during treatment dealing with emotions. The emotions for which help was needed most frequently, and the percentage of participants stating a need, are as follows: feeling nervous (40%); being worried (34%); feeling afraid (25%); and needing to talk with someone about feelings (24%) (Miller et al.). The conclusions from the findings of studies on psychosocial need indicate that psychological and emotional concerns are common and prevalent, and need to be addressed early in patients' cancer experience.

*Social support need.* Social well-being is often associated with a person's quality of life in that it encompasses activities related to roles and relationships that exist at home and at work (Ferrell, Smith, Ervin, Itano, & Melancon, 2003). A study conducted by Ferrell et al. concluded that support provided by family and friends to patients throughout the cancer experience is an essential component of quality of life for women with ovarian cancer. In a study of breast cancer patients, Kornblith et al. (2001) found the women who were most vulnerable to serious psychological distress had minimal social support. The findings of the Kornblith et al. study point to the importance of support from family and friends for women as they learn to cope with life following a diagnosis of breast cancer. While social well-being is recognized as an important factor in the life of a cancer

patient, according to Broadhead and Kaplan (1991) there remains a fundamental need to adequately conceptualize and measure social support. Such a view supports the approach of this study followed to assess the social support needs of patients during cancer treatment.

### ***Communication and Information Need***

In a study of 182 survivors of breast cancer, Mallinger et al. (2005) concluded the need for information is an important component of quality of life as patients who are more satisfied with information experience better psychosocial outcomes, fewer symptoms of distress, and are more likely to comply with medical treatments. The researchers recognize the implications their findings have for clinical practice, particularly the development of interventions targeted towards increasing *whole person* communication which could lead to more productive physician-patient interaction (Mallinger et al.).

Another study of 236 breast cancer survivors in New South Wales, Australia conducted by Girgis et al. (2000) found that of the 15 reported moderate to high unmet needs, two-thirds of the reported unmet needs related to health information. The findings of these studies confirm the importance of information in meeting the needs of people throughout their cancer experience.

The type and amount of information and the manner in which that information is conveyed by physicians to patients has received a significant amount of attention by researchers. The findings of a study by Jenkins, Fallowfield, and Saul (2001) suggest that assumptions regarding the communication of disease information are incorrect. Jenkins et al. found that while 87% of patients want to receive as much information as

possible, not every patient desires full and complete information. According to Hack, Degner, and Parker (2005) the problem to which many oncologists want to find a solution is “how to determine the appropriate type and amount of information to impart to patients” (p. 833). Based on previous research, this challenge can be addressed by assessing the information and communication needs of patients at strategic moments in their cancer experience.

### ***Financial Resource Need***

It is commonly known that cancer has an affect at some level on all aspects of a patient’s life. The impact of cancer is certainly felt in a person’s ability to continue to earn income through work. Such a situation can cause cancer patients and their families to experience a financial crisis in which a resource need develops. A review of the literature on studies of cancer and financial resource need indicated this subject has not been well researched across all types of cancer. Nevertheless, studies with specific populations have consistently shown that up to 70 percent (Spelten, Sprangers, & Verbeek, 2002) stop working or experience a change in employment (e.g., reduction in work hours, interruption of work, change in place of employment) after being diagnosed or treated for cancer that have significant implications on their financial situation. Therefore, to holistically examine the full range of needs patients experience during cancer treatment, financial need must be considered. To that end, financial resource needs were assessed in this research study.

### ***Occupational/Work-related Need***

The importance of employment for people with cancer goes beyond satisfying financial need. Ferrell Grant, Funk, Otis-Green, and Garcia (1997) conducted a

qualitative, descriptive study evaluating the quality of life of 21 breast cancer survivors and found the ability to return to work following cancer treatment was seen as a sign of triumph and validation. Of the women who participated in the study, 54% reported they were employed at the time of the survey and cited returning to work as validation of their survival (Ferrell et al.). For most people, work represents an important part of their life and can be significantly impacted by cancer diagnosis and treatment.

### ***Sexuality and Intimacy Need***

According to Penson et al. (2000) human sexuality “integrates the somatic, intellectual, emotional, and social aspects of being sexual” (p. 341). Cancer treatments often cause physical and psychological changes that impact a person’s sexual health. The threat that cancer poses to one’s sexuality ranges from disfigurement, infertility, and impotence to fatigue, discomfort and hair loss (Penson et al., 2000). Bergmark, Avall-Lundqvist, Dickman, Henningsohn, and Steineck (1999) surveyed women with early-stage cervical cancer about their sexual health following treatment, and found 26% of the women reported moderate to severe distress due to physical changes that affected sexual performance and pleasure. Another study of 279 men with early prostate cancer indicated that sexual impotence was almost universally reported three months following surgery (Talcott et al., 1998).

The personal and sensitive nature of sexuality and intimacy often makes patients uncomfortable voicing concerns to medical professional which can have a profound influence on how they cope with these issues following treatment (Penson et al., 2000). Patients often do not volunteer information on sexual problems and health care professionals frequently do not ask about sexual function (Penson et al.). This lack of

information sharing on sexual health can lead to unmet needs that make recovery from cancer treatment more difficult. In a study of 542 women undergoing treatment for a gynecological malignancy, Stead et al. (1999) found that a questionnaire is an acceptable tool for assessing sexual needs. Further, Stead et al. reported that women did not consider a questionnaire on the topic of sexual activity intrusive. This finding confirms the appropriateness of including sexuality as a domain of need in this study.

### ***Cultural Need***

Culture consists of a variety of elements including shared communication; similar physical and social environments; common beliefs, values, traditions, and world views; and similar lifestyles, attitudes, and behaviors (Healthcare Association of New York State, 2005). A search of the literature revealed no study that specifically addressed the domain of cultural need as related to cancer care. A number of studies have focused on investigating a particular ethnic or racial population (Ashing-Giwa et al., 2004; Foley et al., 2006; Moadel et al., 2006). Many of these studies have concentrated on the disparities in cancer care among ethnic patient populations. However, no study has specifically emphasized the assessment of cultural need.

### ***Spiritual and Existential Need***

Assessment of the spiritual and existential needs of cancer patients is considered at least as important as the physical, psychological, and social support domains in determining quality of life (Cohen, Mount, Tomas, & Mount, 1996). Fitchett and Handzo (1998) “points to the importance of including an assessment of religious and spiritual needs ... in a holistic assessment of cancer patients and their families” (p. 790). Assessing the spiritual and existential needs of cancer patients not only involves

identifying what needs are important, but which patients are most in need (Moadel et al., 1999).

Recently, there has been an increase in research on the spiritual and existential needs of cancer patients with advanced stage of disease. Specifically, Balboni et al. (2007) studied spiritual support found that 72% of patients with advanced cancer reported unmet spiritual needs, and 88% of patients reported that spirituality is somewhat important to extremely important. In a study by Miller et al. (2003) of women following treatment for gynecological cancer, 32% stated that, as a cancer patient, they felt a need to discuss questions of spirituality with someone.

Existential need is grounded in the belief that people strive to find value, meaning, and purpose in their lives (Seligman, 2001). A life-threatening illness such as cancer is an experience that can often facilitate an existential search for meaning and purpose. Recently, more attention has been given to investigating the existential needs of cancer patients. A study of the existential concerns of colorectal cancer patients conducted by O'Conner, Wicker, and Germino (1990) explored concepts such as finding meaning from a cancer diagnosis, enhanced appreciation for life, and what is learned from the cancer experience. Taylor (2001) interviewed newly diagnosed colorectal cancer patients to elicit their perspectives of the cancer experience and one major theme that emerged from the interview data involved making sense of the diagnosis. Ramfelt, Severinsson, and Lutzen (2002) examined the perspectives of colorectal patients and found that patients reported existential meaning of the cancer experience to be of moderate to high importance.

## **Needs Assessment**

Needs assessment is a commonly used approach to evaluate the supportive care needs of cancer patients (Bonevski et al., 2000). They can produce a direct listing of those concerns with which patients have a need for help as well as the perceived level of help required (Rainbird et al., 2005). Needs assessments represent a direct method of identifying the specific services and assistance desired by patients. Assessment instruments have been used frequently in the design of needs-based intervention strategies (Bonevski et al., 2000; Sanson-Fisher et al., 2000; Thewes et al., 2004; Whelen et al., 1997). The importance of assessing patient needs is highlighted by the findings of previous research on this topic: (a) unmet needs have been associated with reduced quality of life (Sanson-Fisher, 2000); (b) attention given to psychosocial needs has been linked with increased patient satisfaction (Walker, Ristvedt, & Haughey, 2003); and (c) provision of unwanted interventions that do not fit with the personal needs of patients may actually cause harm (Gray et al., 1998).

### ***Needs Assessment Instruments***

A search of the literature revealed two meta-analyses (Richardson et al., 2007; Wen & Gustafson, 2004) both of which reviewed the needs assessment instruments that have been developed and are being used to assess specific domains of patient needs. In a meta-analysis of 17 patient needs assessments, Wen and Gustafson found the selected instruments met some but not all of the criteria they used for determining validity and reliability. The researchers questioned whether the development of a model assessment instrument—one that promotes the sharing of information and facilitates communication between patients and cancer care professionals (Wen & Gustafson)—is possible. From

their study, Wen and Gustafson concluded that needs assessment offers a viable approach to more fully comprehend the experiences of patients by giving them the opportunity to have their needs recognized and addressed.

Another meta-analysis conducted by Richardson et al. (2007) reviewed 15 different needs assessment tools and found that there is widespread recognition of the value in assessing the needs of cancer patients, as evidenced by the number of assessment tools that have been developed. Richardson et al. concluded “assessment of patients’ needs is fundamental to understanding their experiences and developing an effective care response.”

Reviews of the literature by Wen and Gustafson (2004) and by Richardson et al. (2007) revealed a number of needs assessment instruments that seemingly take a more comprehensive approach to measuring the supportive care needs of cancer patients. Of the instruments that showed up in the literature, The Cancer Needs Questionnaire (CNQ), Psychosocial Needs Assessment Survey (PNAS), Breast Cancer Patients' Needs Questionnaire (BR-CPNQ), Supportive Care Needs Survey (SCNS), Needs Assessment for Advanced Cancer Patients (NA-ACP), and Cancer Survivors’ Unmet Needs (CaSUN) were recognized as being most relevant to the topic of this study and deserve additional investigation.

### ***Cancer Needs Questionnaire (CNQ)***

The Cancer Needs Questionnaire (CNQ) contains 52 items to measure participants’ perceived needs within five domains: psychological, health information, provider care and support, physical and daily living, and interpersonal communication needs (Newell et al., 1999). For each item, participants indicate on a five-point response

scale to consider their level of need for help with the item by choosing one of the following response options: no need—not applicable; no need—already satisfied; low need; moderate need; or high need (Bonevski et al., 2000). Based on the premise of this study that patients are better served to be assessed holistically, the CNQ falls short of the goal to examine the full range of supportive care needs.

### ***Psychosocial Needs Assessment Survey (PNAS)***

The Psychosocial Needs Assessment Survey (PNAS) was designed to assess the patterns and predictors of psychosocial needs among the underserved, ethnically-diverse cancer patient population (Moadel et al., 2006). Four categories of needs are identified as significant to assess within this cancer patient population: informational, practical, supportive, and spiritual. Given that the PNAS only assesses four domains of need, it fails in its capacity to holistically assess the full range of supportive care needs of cancer patients.

### ***Breast Cancer Patients' Needs Questionnaire (BR-CPNQ)***

The Breast Cancer Patients' Needs Questionnaire (BR-CPNQ) is a 52-item needs assessment that examines the perceived needs of breast cancer patients across five domains: psychological, health information, physical/daily living, patient care/support, and interpersonal communication (Girgis et al., 2000). Items assessing breast cancer specific needs as well as access to services and resources are included in this questionnaire. While the BR-CPNQ does assess five important domains of patient need, it lacks a holistic approach to examining supportive care needs.

### ***Supportive Care Needs Survey (SCNS)***

The Supportive Care Needs Survey (SCNS) was adapted from the CNQ with the aim of comprehensively assessing multiple needs of cancer patients (Sanson-Fisher et al., 2000). The SCNS is comprised of 71 items divided into three main sections: needs items, disease and treatment, and patient background. The five areas of need assessed by the SCNS include psychological, health information, physical and daily living, patient care and support, and sexuality. In initial psychometric testing, the SCNS showed promising results by demonstrating good reliability and validity in studies with patients having a range of cancer diagnoses (Bonevski et al., 2000; Girgis et al., 2000; Sanson-Fisher et al.; Steginga, et al., 2001). While the SCNS represents a viable measure of some patient needs, it falls short of providing a comprehensive assessment because it does not address areas of need such as spiritual/existential, occupational/work, or cultural.

### ***Needs Assessment for Advanced Cancer Patients (NA-ACP)***

The Needs Assessment for Advanced Cancer Patients (NA-ACP) was developed to assess the perceived needs of cancer patients with advanced, incurable disease (Rainbird et al., 2005). The NA-ACP specifically measures seven domains of need—medical communication/information, psychological/emotional, daily living, financial, symptom, spiritual, and social—derived from a review of existing literature related to perceived needs and quality of life of patients with cancer. Despite the fact the NA-ACP is designed for patients with advanced, incurable cancer, the wide-ranging needs assessment offered by this instrument supports the holistic focus of this research study.

### *Cancer Survivors' Unmet Needs (CaSUN)*

The Cancer Survivors' Unmet Needs (CaSUN) is a self-report measure of cancer survivors' supportive care needs (Hodgkinson et al., in press). Individual unmet need items were developed and constructed into a 46-item questionnaire that involves seven domains of need: physical functioning, emotional concerns, information and medical care, socio-economic issues, relationship issues, expectations of self and others, and life perspective. The findings indicate evidence for the internal consistency and validity of the CaSUN to assess supportive care needs of cancer survivors. (Hodgkinson et al.). However, the CaSUN measure fails as an assessment instrument to comprehensively assess the full range of survivors' needs.

### *Unmet Needs*

Based on a review of the literature, Sanson-Fisher et al. (2000) found that “research on the [perceived supportive care] needs of patients with cancer has identified high levels of unmet need and a difference in the types of unmet needs depending on the cancer population studied” (p. 227). Sanson-Fisher et al. surveyed 1492 cancer patients at nine major public cancer treatment centers in New South Wales, Australia. The aim of the study was to measure the prevalence of unmet needs among people receiving active treatment and to examine variables that are predictive of different types of needs (Sanson-Fisher et al.). The results of the study “suggest that cancer patients continue to experience high levels of unmet needs across a range of domains” (p. 234)

Another study by Girgis et al. (2000) focused on assessing the prevalence and predictors of perceived unmet needs among women diagnosed with breast cancer, with a particular emphasis on the impact of location. Findings of this study seem to suggest that

both rural and urban women with breast cancer have unmet needs, particularly in the information and psychosocial domains. In reviewing the literature on patient-physician communication, Hack et al. (2005) found that cancer patients continue to have unmet communication and information needs; however, when physicians attend to the emotional needs of patients, communication outcomes are improved.

The significant research on unmet needs conducted by Sanson-Fisher et al. (2000) led to their conclusion:

The needs of some cancer patients will never be fully met and some levels of perceived unmet need will always be detected. Hence, it is important to monitor routinely the unmet needs of cancer patients so that health services and health care professionals can implement and streamline those components of oncology care that best meet the needs of their patients (p. 236).

### **Holism**

The first documented use of the term *holism* appeared in the 1926 work *Holism and Evolution* by noted South African scholar Jan Christiaan Smuts to define “the tendency in nature to produce wholes (i.e., bodies and organisms) from the ordered grouping of unit structures ... The whole-making holistic tendency, or Holism, operating in and through particular wholes, is seen in all stages of existence” (Smuts, 1926/1999, p. 109). The idea of *the whole is more than the sum of its parts* goes back to the time of Aristotle. Smuts shaped this notion into a philosophical concept that maintains the whole is primary. This idea was diametrically opposed to atomism that postulates any whole can be broken down or analyzed into its separate parts in an effort to better understand

the relationships that exist between them. Holism takes the view that by examining something in totality, it is possible to learn more about it and better understand its nature and purpose (Smuts).

### ***Adler's Individual Psychology***

Adler used wholeness as a foundational basis for Individual Psychology which he introduced in 1927 in his groundbreaking work entitled *The Practice and Theory of Individual Psychology*. Adler followed Smuts' concept of the *holistic tendency* with his theory of the indivisibility of the individual (Way, 1950). Adler (1927) believed in the importance of having "... an intimate knowledge of the whole individual, so that an understanding of one part becomes possible only after we have understood the whole" (p. 5). Adler believed that by studying the parts—provided the parts are considered in relation to the whole—a better sense of the whole develops.

Adler referred to his theory as Individual Psychology because the name emphasized the manner in which he studied individuals; namely, by relating each unique person to his or her environment (Way, 1950). In writing about Individual Psychology, Adler (1927/1954) realized the significance of holism in understanding the individual when he noted "it is always necessary to look for ... reciprocal actions on the mind on the body, and of the body on the mind, for both of them are parts of the whole with which we should be concerned" (Ansbacher & Ansbacher, 1956, p. 225).

Adler believed in the inherent unity of the personality in every human being. This is evident when Adler (1927/1954) stated that "every individual represents in equal measure the unity and wholeness of the personality and the individual shaping of this unity" (p. 30). His views on personality and the wholeness of the individual had a

significant influence on early humanistic theorists Abraham Maslow, Rollo May, and Carl Rogers. Indeed, Adler's Individual Psychology paved the way for the humanistic movement of the 1950s that helped shape the fields of psychology and counseling as they are practiced today.

### ***Humanistic Psychology***

Humanistic psychology evolved out of a reaction to both behaviorism and psychoanalysis, and was concerned with the human dimension of psychology; particularly, that humans beings cannot be reduced to components (Bugental, 1965). As two of the theorists considered to have laid the foundation for humanistic psychology, Maslow and Rogers agreed that it was important to assess individuals as wholes, and not merely as the sum of parts. The aim of much of the humanistic approaches to therapy is to give a holistic description of the client. The humanistic counselor seeks to gain insight into the whole person and not just learn about fragmented parts of the personality (Schneider, Bugental, & Pearson, 2001).

Adler's holistic view of the individual can be clearly seen in Maslow's (1954) renowned work, *Motivation and Psychology*, in which he stated "the individual is an integrated, organized whole" (p. 3). Further, Adler's influence can be seen in Rogers (1980) who believed that one of the qualities "the person of tomorrow [will possess a] desire for wholeness ... wholeness of life, with thought, feeling, physical energy, psychic energy, healing energy, all being integrated in experience" (p. 350-351). Rogers (1980) observed in his research and clinical practice how individuals struggle to become whole persons, with body, mind, feelings, spirit, and psychic powers fully integrated.

According to the holistic doctrine espoused by Fritz Perls (1973) and other Gestalt psychologists, “man is a unified organism” (p. 8), a fact that was largely ignored by the traditional schools of psychiatry and psychotherapy which adhered to the notion of a separate mind and body. Adler (1927) realized the connection between Individual Psychology and Gestalt psychology when he wrote “the obvious similarity ... lies in the emphasis on the whole rather than on elements and on the interaction between the whole and its parts” (Ansbacher & Ansbacher, 1956, p. 11).

### *Holism and Medicine*

Maslow (1954) took note of the impact of holism on the practice of medicine when he wrote:

[Reductionism] is one of the basic premises that underlie the prevailing medical practice. Although it has its utility, it is profoundly limited view of the human being. The shift toward holism is really irreversible, not because it is being forced upon medicine ... but rather because the shift is part of a much larger change in perspective about who and what the human being is. (p. 259).

According to reductionism, individuals are comprised of parts that work together. When a part is diseased or unhealthy it is removed or repaired, and the person is whole or healthy again (Myers & Sweeney, 2005b). This portrayal of human beings as parts in conflict with one another is consistent with Freud’s conceptualization of personality development (Maslow, 1966). Holistic medicine is based on theory directly opposed to reductionism that suggests “individuals are mind, body, and spirit, indivisible, unique, creative, and purposeful” (Myers & Sweeney, p. 17). Maslow (1954) supported a holistic

position when he stated “the whole is something else than the additive sum of the parts ... the main quality that characterizes the whole can be seen in any of its parts if these parts are understood not reductively, but holistically” (p. 220).

### ***Wellness***

Myers et al. (2000) incorporated holistic theory when they defined wellness from a counseling perspective as:

A way of life oriented toward optimal health and well-being, in which body, mind, and spirit are integrated by the individual to live life more fully within the human and natural community. Ideally, it is the optimum state of health and well-being that each individual is capable of achieving (p. 252).

Adhering to an Adlerian holistic perspective, Myers and Sweeney (2005a) operationalized wellness to “incorporate the entire scope of human functioning and provide guidance for understanding the holistic needs and strengths of diverse individuals across the life span” (p. 8). This research study holistically assessed the perceptions patients have of their experiences during cancer treatment.

### ***The Indivisible Self***

*The Indivisible Self: An Evidence-Based Model of Wellness (IS-Wel)*, developed by Witmer et al. (1998) is foundationally rooted in the work of Adler. The *IS-Wel* offers a holistic approach to assess the perceived issues of patients across a single higher order wellness factor and five second-order factors that includes the creative self, coping self, social self, essential self, and physical self. The second-order factors are comprised of 17 corresponding third-order factors including thinking, emotions, control, work, positive

humor, leisure, stress management, self-worth, realistic beliefs, friendship, love, spirituality, gender identity, cultural identity, self-care, nutrition, and exercise. While the *IS-Wel* has not been previously applied to a research population of cancer patients, the following subsections make the connection between many of the 17 factors of wellness to previous research studies involving cancer patients.

### ***Thinking***

Common psychological challenges for cancer patients include anxiety from diagnosis, effects of adjuvant therapies, and fear of recurrence (Antoni et al., 2006). In a study of 199 women recently treated for breast cancer, Antoni et al. found that “thought intrusion about these adversities are commonly experienced symptoms ... that can compromise quality of life beyond the physical demands of these medical treatments” (p. 1795). In a study of 246 women newly diagnosed with breast cancer, Arora, Rutten, Gustafson, Moser, and Hawkins (2007) found that individuals diagnosed with cancer who seek to adapt to their illness generally engage in a cognitive and behavioral process that serves to promote problem-focused coping and emotional control.

### ***Emotions***

A study conducted by Lauver, Connolly-Nelson, and Vang (2007) of 51 female breast and gynecologic cancer survivors within four months of completing treatment found “a significant majority used emotional support over time” (p. 109), indicating it was helpful in coping with the challenges associated with cancer diagnosis and treatment. In research with 93 individuals treated for cancer, Quartana, Laubmeier and Zakowski (2006) concluded that the positive expression of emotions appears to reduce the frequency of intrusive thoughts and lower psychological distress. A study by Classen,

Koopman, Angell, and Spiegel (1996) of 101 women with a diagnosis of metastatic or recurrent breast cancer found emotional expressiveness to be associated with better psychological adjustment. The findings of these studies underscore the importance of emotions in the adjustment process for individuals diagnosed with cancer.

### ***Control***

A survey of 1000 adult cancer patients conducted by McIllmurray et al. (2001) at four hospitals in England found that 52% of the respondents expressed a need for “help in maintaining a sense of control in my life” (p. 265). McIllmurray et al. concluded from this finding that “maintaining a sense of control ... was a significantly higher level of need for patients at both first recurrence and palliative care than for patients at other critical moments” (p. 267). The uncertainty that comes with a cancer diagnosis (Holland, 2002) challenges the ability of people to maintain a sense of control in their life.

### ***Work***

Recent improvements in cancer treatment regimens have increased survival and individuals’ ability to work during and following treatment. The impact of cancer on survivors’ ability to fully engage in paid work has not been thoroughly researched. A recent study by Pryce, Munir, and Haslam (2007) explored the association between treatment symptoms and work adjustments for patients who worked during cancer treatment and survivors who returned to work after their primary treatment was completed. The study concluded that symptom management is important and necessary to facilitate work-related adjustment for patients in active treatment as well as for survivors following the completion of cancer treatment (Pryce et al.).

### ***Positive Humor***

Humor is an important part of life. Laughter eases the mind, defuses tension, and has positive physiologic effects on cancer patients (Erdman, 1991). Christie and Moore (2005) conducted an in-depth review of the literature and found a positive correlation between humor and comfort levels in patients with cancer. Additionally, the literature indicated that humor frequently was used in cancer care to promote relaxation, by reducing anxiety and discomfort, which enabled patients' fears and concerns to be discussed openly (Christie & Moore). Christie and Moore concluded from several quantitative research studies that humor has a positive effect on the immune system, improved physical stress responses, and promoted feelings of well-being. A qualitative study of 45 men with testicular cancer conducted by Chapple and Ziebland (2004) found the use of humor beneficial in work and social settings as a way to challenge assumptions about the disease, and in health care settings to manage feelings, reduce stress, and share a sense of solidarity with others. The study's participants described having positive reaction to the humor of others which helped to relieve tension and reassure them that they were being treated as normal (Chapple & Ziebland).

### ***Leisure***

According to a review of previous research, many observational studies have concluded participation in physically-oriented leisure activity reduces the risk of developing many types of cancer, particularly breast cancer (Abrahamson et al. 2006). However, little is known about the effects of recreational activity on prognosis following cancer diagnosis. A follow-up study by Abrahamson et al. of 1264 women diagnosed with invasive breast cancer investigated the relationship between pre-diagnosis leisure

activity and survival. The findings of the study suggested evidence to support the beneficial effect of physical leisure activity undertaken in the year before diagnosis on breast cancer survival especially among young women. The result of this study supports the view that leisure activity can have a positive effect on individuals experiencing cancer diagnosis and treatment.

### ***Stress Management***

Diagnosis and treatment of cancer are clearly stressful events (Antoni et al., 2006) with numerous factors contributing to the level of stress present in individual patients. According to research conducted by Lauver et al. (2007) of female cancer survivors, the primary stressors that are present at the end of treatment included feelings of uncertainty, lingering physical symptoms of treatment, difficulty concentrating, body image concerns, and coping with mortality. Stress management intervention strategies tend to be cognitive-behavioral and are used with cancer patients to facilitate adjustment during and after treatment (Antoni et al.).

### ***Self-worth***

One area that has not been widely studied involves the impact of cancer on the self-worth of survivors (Seitzman et al., 2004). Self-worth or self-concept, has been defined as “a set of self-attitudes that reflect ... a description and an evaluation of ones own behavior and attributes” (Piers, 1984). A study by Seitzman et al. compared overall self-worth among 578 young adult survivors of childhood acute lymphoblastic leukemia (ALL) with a control group comprised of siblings. The study found that despite global self-worth being significantly lower in ALL survivors than the sibling control group, 81% of survivors still reported having positive self-concept (Seitzman et al.). Based on their

research, Seitzman et al. concluded that negative changes in self-worth due to cancer diagnosis and treatment may be predictive of future psychological adjustment problems for survivors.

### ***Realistic Beliefs***

A diagnosis of cancer challenges patients' beliefs about all aspects of their life. A study by Beadle et al. (2004) of 149 patients with advanced cancer investigated their beliefs about the curability of their disease. The responses of the patients varied greatly with 27% believing their cancer was curable, 31% believing their cancer was incurable, and 42% were uncertain. These findings demonstrate the diverse beliefs patients have regarding cancer, some realistic and others illusory, which is consistent with a variety of psychological adaptations patients commonly report when confronted with a life-threatening illness. (Beadle et al.).

### ***Friendship***

A study by McIllmurray et al. (2001) of 1000 cancer patients found that 85% report "support from friends" as important or very important. A study of 234 women with breast cancer conducted by Arora et al. (2007) found that friends played a predominant role in providing emotional support during diagnosis and treatment. As women moved further from active treatment, friends continued to play a significant role in promoting emotional well-being (Arora et al.). The findings of these studies provide evidence of the value of friendship in supporting people throughout their cancer experience.

### ***Love***

Love is a concept that for most people is closely associated with family. The love of family members is significant support for people experiencing cancer diagnosis and treatment. While the literature does not specifically name love as a variable that has been studied within the context of the cancer experience, the importance of family has been researched. McIllmurray et al. (2001) surveyed 1000 cancer patients and found 89% report “support from family” as important or very important to them throughout their cancer experience.

### ***Spirituality***

The results of a study by Lauver et al. (2007) found that cancer survivors reported experiencing meaningful changes in their perceptions of life following cancer treatment. Lauver et al. concluded from their study that spirituality has particular relevance for patients ending treatment—a time when they often are “challenged to make sense of their experience in light of their spiritual beliefs” (p. 109). A growing amount of research has explored the impact of spirituality on health. A number of studies concluded that religious and spiritual beliefs are integral to coping for some patients when confronted with a serious illness such as cancer (Koenig, 1997; Koenig, Pargament, & Kielsen, 1998; Ott, Ehman, Short, Ciampa, & Hansen-Flaschen, 1999).

### ***Gender Identity and Cultural Identity***

In examining the literature, no study specifically addressed the concept of gender identity. Instead, one study conducted by McIllmurray et al. (2001) surveyed adult cancer patients on a more global construct of *identity* and found that needs related to identity are less commonly expressed but still remain strongly felt. Based on a 48-item

psychosocial needs inventory, 47% of the study's respondents indicated needing support in dealing with issues such as "changes in my sense of who I am" and "changes in the way others see me" (McIllmurray et al., p. 265). This study suggests that identity plays a role in how people adapt to their experience with cancer.

### ***Self-care***

Alleviating symptoms of cancer treatment (e.g., pain, fatigue, and nausea) is the focus of patient self-care. A descriptive study conducted by Williams et al. (2006) on self-reported symptoms and self-care of 37 adults receiving chemotherapy and radiation therapy found that maintaining self-care can help patients complete their treatment regimen that may eventually lead to a cure of their illness. Further, the study found the self-care strategies that patients used to effectively manage symptoms complemented the medical care they received (Williams et al.). Findings from this study seem to suggest that self-care is important in helping individuals undergoing cancer treatment and recovery to feel more in control over their cancer experience.

### ***Nutrition***

Diet-related factors are thought to account for up to 30% of all cancers in developed countries (Blackburn, Copeland, Khaodhiar, & Buckley, 2003). According to Blackburn et al. numerous studies have been conducted on nutrition and diet as related to cancer with the majority of the research centered on the role of nutrients, foods, and food groups in disease prevention. Some nutrition-associated research has focused on lifestyle behavior adjustments of individuals following a diagnosis of cancer. In one such study of 352 adults, Blanchard et al. (2003) found 47% of patients reported improvement in their nutritional habits indicating that a cancer diagnosis may have a positive influence on diet.

The result of this study supports the notion that proper nutrition is important for people to consider during and after cancer treatment.

### ***Exercise***

Three recent studies have examined the connection between physical exercise, cancer recurrence, and overall survival in individuals diagnosed with breast (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005) and colon cancer (Meyerhardt, Giovannucci, et al., 2006; Meyerhardt, Heseltine, et al., 2006). The findings of these studies suggest that survivors who regularly participate in physical activity have significantly lower risk of developing a recurrence of cancer or dying from the disease compared to those who do not exercise. These results confirm the importance of regular exercise for cancer survivors following the completion of primary treatment.

### ***Holism and this Research Study***

A comprehensive review of previous research indicated that no study to date has taken a holistic view, based on a wellness model, of the perceived supportive care needs of patients during cancer treatment. This study incorporated an Adlerian holistic approach to address the lack of research by investigating the question, “In what ways do people who are recently diagnosed with cancer experience treatment?” More specifically, this study answered the question, “What is the full range of perceived supportive care needs that patients report during cancer treatment?” The researcher believed these questions were best answered from a holistic perspective that adhered to Adler’s concept of the indivisible self; namely, that an individual cannot be divided into parts but rather must be viewed as a whole person.

## Summary

Building an assessment strategy on a solid conceptual theory is vital to understanding the relationships that exist among patient needs (Wen & Gustafson, 2004). Based on the findings of a meta-analysis of 17 needs assessment instruments, Wen and Gustafson concluded that no conceptual theory adequately addressed the relationships between needs. If the goal of cancer care is to help patients achieve optimal health, the key indicator of success should be to determine individual needs of patients (Asadi-Lari et al., 2003). According to Richardson et al. (2007), taken from the perspective of patients, “the quality of supportive care can be considered to be the extent to which needs are addressed and met, and if they are to be addressed adequately, must first be identified”.

## **CHAPTER THREE**

### **METHODOLOGY**

This chapter outlines the methodology that was followed in this research study. Specifically, the chapter is organized in subsections that state the research questions, the nature of the inquiry, conceptual framework, and procedures with information on the research setting, sampling procedures, descriptions of the participants, and the researcher's role and responsibilities. Additionally, data collection methods and the process for analyzing data are addressed in detail. Last, discussion of the validity of the findings is presented for consideration.

#### **Research Questions**

A review of previous research indicated a tendency to focus on one specific type of need—for example, psychosocial, communication, informational, or spiritual—of a particular patient population—newly diagnosed breast cancer patients, young women with cervical cancer, or female cancer survivors. An exhaustive search of available literature resulted in a finding that no study had taken a holistic view, based on a wellness model, of the perceived supportive care needs of cancer patients during treatment. This lack of research supported investigating the research questions of this study.

This research study began with the broad question, “In what ways do individuals experience cancer?” Further examination of this expansive topic led to a narrowing of the focus that resulted in another question, “How do people experience cancer treatment?” The focus of the research was narrowed again to arrive at the primary question of this study which was to comprehensively examine and answer, “What are the

perceived supportive care needs of patients during cancer treatment?” Additional research questions investigated in this study included:

1. How do patients perceive their supportive care needs after at least one month of cancer treatment?
2. What instrument and/or strategy can be developed for use in outpatient cancer clinics to holistically assess the perceived supportive care needs of patients entering treatment?
3. How can the wellness model used by counselors be applied to help individuals diagnosed with cancer?

In addition to answering the research questions, an ancillary purpose of this study centered on the development of assessment instruments and strategies that can be used to holistically examine the perceived supportive care needs of cancer patients entering treatment.

### **The Nature of Inquiry**

The dearth of information on the perceived supportive care needs of cancer patients during treatment confirmed the suitability of a qualitative approach to guide the investigation and explore the research question. According to Creswell (2003), a descriptive research design promotes a more meaningful and informative examination of an individual’s experience. Qualitative methods can enhance research into psychosocial issues and existential concerns through the use of multiple data collection methods that are interactive and humanistic, and the themes and meanings that emerge from the unique experiences of the participants in the research study (Creswell).

Over the past decade, there has been an increase in commitment to research using qualitative methodology in the area of health psychology (Lyons, 1999). One of the primary reasons for conducting a qualitative study is the exploratory nature of this type of inquiry (Glesne, 1999). Because little is known about the topic of this study, a qualitative research design was appropriate. According to Creswell (2003), qualitative inquiry enables researchers to capture the participants' stories and then using their perceptions construct a better understanding. The essence of this study was to use the experiences of the participants to promote greater understanding of the research topic.

With regard to the supportive care needs of cancer patients, no study had undertaken a holistic assessment. This research study utilized a qualitative paradigm to expand the knowledge base through the collection and analysis of the experiences of people undergoing cancer treatment. The primary goal of this study was to build greater understanding of the perceived supportive care needs of patients by examining from a holistic perspective the themes and meanings that emerge from the data, ultimately leading to the creation of assessment strategies that can assist counselors working in the field of psycho-oncology to comprehensively address the needs of patients entering cancer treatment.

A comprehensive report recently released by the Institute of Medicine (IOM) entitled *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* identified critical components of an effective strategy for addressing the supportive care needs of cancer patients. The IOM report cited five components of an effective strategy that are common to many of the existing, empirically validated models: (a) identify patients with supportive care needs that are likely to affect their ability to receive cancer

care and manage their illness; (b) link patients to appropriate psychosocial health care services; (c) support patients in managing their illness; (d) coordinate psychosocial services with biomedical health care; and (e) follow up on psychosocial care provided to monitor the effectiveness of services and determine whether any changes are necessary (IOM, 2007). This study supports the inclusion of these components in an assessment strategy designed to holistically identify and then address the perceived supportive care needs of patients during cancer treatment.

### **Procedures**

Methodology offers a system for conducting a research inquiry in an organized and disciplined manner. The procedures that comprise the methodology provide a study with the direction and steps to be followed, and move a study forward by facilitating the flow of the investigation and the collection of data (Moustakas, 1994). Interpretative Phenomenological Analysis (IPA; Smith, 2004) served as the methodology for this study by providing a structure for gathering detailed descriptions on how people experience cancer and how they perceive this experience. According to Smith and Osborn (2003), “IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing” (p. 53).

The primary aim of IPA is to examine in detail how people make sense out of their world (Smith & Osborn, 2003). This approach is phenomenological in that it focuses on individuals’ perception of an experience, event, or object (Smith, Jarman, & Osborn, 1999). Over the last ten years, IPA has become well established as a viable method for conducting qualitative research in health psychology (Smith, 2004). Since 2000, in excess of 120 journal articles have been published on studies that used IPA to

analyze and report the findings of research in a variety of areas including mental health, physical illness, bereavement and loss, disability, genetic counseling, and psychotherapy. Within the field of health psychology, a number of IPA studies have been recently published on such topics as chronic pain (Jordon, Eccleston, & Osborn, 2006), dementia (Langdon, Eagle, & Warner, 2007), Parkinson's disease (Bramley & Eatough, 2005), workplace stress (Gyllensten & Palmer, 2006), and eating disorders (Marsden, Karagianni, & Morgan, 2007).

One IPA study by Wallace et al. (2007) had procedural relevance to this research study as it involved interviewing six adolescent females who had undergone cancer treatment. This study exemplified how IPA can be applied to investigate and understand the individual and collective experiences of people diagnosed with cancer.

#### ***Approval to Conduct Research***

Prior to conducting this research, I submitted an application to conduct research to the Institutional Review Board (IRB) of the research site. I received an approval from the IRB committee on September 10, 2007. Subsequently, I submitted an application for review to the IRB of the University of New Orleans (UNO), and received an approval on October 2, 2007 to conduct this research study.

#### ***Research Setting***

The site for this research study was a regional cancer center outpatient clinic located in the New Orleans metropolitan area. The cancer center is one part of a comprehensive healthcare network that includes a medical school. The oncologists at the setting specialize in the treatment of breast cancer, gynecological cancers, blood-related cancers, head and neck cancers, and lung cancer. Cancer patients at this facility are

offered a variety of treatment services including clinical examination, diagnostic testing, radiation therapy, chemotherapy, and stem cell transplantation. The research setting is a small volume cancer center as compared to other outpatient cancer clinics around the country with an average of 550 new patients and 2600 patient visits per year. The annual operating budget for this facility is \$3.2 million.

Because the researcher was employed at the research site and had full access to all recently-diagnosed cancer patients entering treatment, this institution served as an ideal setting for this study. An important consideration for conducting *backyard research* (Glesne, 1999) at this site is the rapport the researcher had established with oncologists, nurses, and staff members at the regional cancer center. These relationships enabled the researcher to conduct research free from any interference and with the full support of the administration and the medical staff at the research site. One potential problem in conducting backyard research is the possibility of the staff and patients becoming confused over the role of the researcher when interacting with individuals participating in a research study (Glesne). This potential problem was addressed in the initial meeting with participants so that they were fully aware of the two distinct roles the researcher played at the research setting.

### ***Sampling and Screening Procedures***

Because the purpose of this study was to describe in detail the perceptions of the experience of the particular sample group rather than make more general claims about a larger population, a small number of participants were studied. For an IPA study, a sample size of five to six subjects is considered reasonable and appropriate (Smith & Osborn, 2003). The reason for using a small number of individuals lies in the manner in

which IPA research is conducted—a commitment to an in-depth, case-study level of analysis and reporting (Smith & Osborn). In an IPA study, Smith and Osborn prefer using as homogeneous a sample group as possible so that the research question under study has significance for all participants. This preference emphasizes the commonality that should exist between the participants. In the case of this study, the common thread is the diagnosis and treatment of cancer.

Given the exhaustive nature of the analytical process characteristic of IPA studies, this research study recruited a small sample of six participants. The participants were recruited with the assistance of members of the medical staff at the research site. A letter explaining the nature of this research study was provided to each person recruited to participate. Twelve recently diagnosed cancer patients received a screening interview with selection based on the following criteria: (a) willingness to participate; (b) availability as determined by the participants' treatment schedule; (c) level of psychosocial distress; and (d) stage of their cancer diagnosis. The potential participants were administered the *Brief Symptom Inventory 18* (BSI 18; Derogatis, 2000) to assess their current level of psychosocial distress—namely, the presence of depression, anxiety, and somatization. Patients who reported a high level of overall psychosocial distress were excluded from consideration, and immediately referred for supportive counseling to the clinical psychologist on staff at the research site.

Patients diagnosed with Stage III or Stage IV cancer or those patients believed to have a terminal illness were also excluded from participation in the study. Exceptions were made for people diagnosed with an advanced stage of cancer who scored in the low to moderately low range for psychosocial distress as determined by the *BSI 18*. These

patients were allowed to participate only after undergoing a psychological assessment interview conducted by the researcher to ascertain whether they met the criteria for a significant mental health diagnosis as indicated by the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000). Three of the six participants selected for this study were diagnosed with advanced disease; however, each individual passed the psychological screening process and subsequently was allowed to participate.

Regarding the number of participants, it is only possible to do the detailed, in-depth analysis associated with IPA on a small sample with five to six people representing an appropriate sample (Smith, 2004). This study followed other IPA studies (Smith et al., 2006; Wallace et al., 2007) by recruiting a sample of six participants. All of the cancer patients recruited for this study were referred by oncologists and nurses at the research site. Each of the participants received a recruitment letter that highlighted important information pertinent to the study. Additionally, individuals who agree to participate in the study were provided written information through informed consent that explained to the nature and conditions of the research. Participants were required to read and sign the informed consent form prior to entering the research study. I answered all questions and addressed any concerns participants had with regard to the study. Confidentiality was maintained in the reporting of the findings of this study as I took the appropriate measure of assigning participants with a pseudonym to disguise their identity.

### ***Researcher's Role and Responsibilities***

According to Miles and Huberman (1994) the researcher's role is to gain a 'holistic' overview of the phenomena under study. Adhering to a phenomenological

inquiry, the researcher assumed the position of active participant/observer to capture and understand the essence of the cancer experience as reported by the participants. Due to this interactive role, the potential for researcher bias was considered and noted during the evaluation of the findings of this study.

During the time when this study was conducted, I was employed at the research setting as a patient navigator and counselor. This position afforded me full access to patients receiving their cancer treatment at the research site. Throughout the research study, I adhered to all policies and procedures of this medical facility. Further, I took appropriate steps to maintain the confidentiality of the participants including: (a) all written information was secured in a locked filing cabinet in a locked office at the research site; (b) tape recordings were kept on a digital recorder that was secured in the same locked office; (c) the computer that was used to transcribe the interviews was password protected and kept in a locked office at the research site; and (d) the true identity of the individuals that participated in the study was known only to me. In addition, I followed the federal guidelines as established through the Health Insurance Portability and Accountability Act (HIPAA) that protects the privacy of medical records. As a member of the American Counseling Association (ACA), I adhered to ACA ethical guidelines and made every effort to act in a legal, moral, and ethical manner at all times during this research study.

Given the sensitive and potentially emotional nature of the subject matter that was addressed in this study, I took the appropriate measures to protect and support all participants. I arranged for supportive counseling for any research participant who requested assistance with psychosocial and emotional issues. Counseling was conducted

by a licensed clinical psychologist employed at the research site and was made available at no cost to the participants. This offer of free supportive counseling was disclosed in the informed consent document that was reviewed and signed by each participant.

According to Smith and Osborn (2003), IPA research is a dynamic process that requires the researcher to take an active role in the process. IPA recognizes the central role for the researcher in making sense of the personal experience of participants and thus, has a strong connection to the interpretative or hermeneutic tradition of investigation (Palmer, 1969). This research study followed an IPA model as I was actively engaged in the collection of data through interaction with participants throughout the entire interview process. Further, I adhered to one of the primary tenets of an IPA approach by playing a central role in the interpretation of data. By taking an active role in the collection and analysis of data, I recognized the potential for bias and tried to maintain self-awareness so as to monitor my subjectivity throughout the research process.

### **Participant Profiles**

To recruit participants for this study, I contacted three medical oncologists and two nurses at the research site to introduce them to the research topic and to obtain their support. Without exception, each of the oncologists and nurses contacted agreed to provide full access to their patients. Over the course of the recruitment process, I conducted screening interviews with 12 recently-diagnosed cancer patients to arrive at the six participants selected for this study. A profile of each participant follows.

#### ***John***

John is a 48 years old, African-American male. He reported being single but has one child age 21 from a previous relationship that did not involve marriage. He was

employed as a bartender and waiter prior to being diagnosed with lung cancer. Because he cannot work, John depends on government assistance programs to meet living expenses. John lived with his mother who provided him with housing rent free. He was raised as a Baptist and reported maintaining a strong religious faith. John attended three years of college studying electrical engineering; however, he did not complete the requirements needed to earn a degree.

It is important to note that when John was screened for this study he reported not knowing the stage of his disease. His disease stage was later confirmed by his medical oncologist as Stage IV lung cancer—a disease that often times is referred to another medical facility for treatment. In the case of John, he was diagnosed with a blood-related illness for which he received treatment at the research site. In an effort to treat all his medical conditions, his medical oncologist agreed to allow John to be treated at the research setting.

As a condition of inclusion in this study, potential participants are excluded if they have a high level of psychosocial distress, a condition commonly reported by people with advanced stage of disease. Despite having Stage IV cancer, John scored in the moderate level for psychosocial distress as measured by the *Brief Symptom Inventory 18 (BSI 18)* and demonstrated a willingness to participate in this study. During the screening interview he reported having no emotional or psychological condition that would preclude him from participating in this research. Based on the results of the screening process, I felt comfortable including John in this study.

Given the advanced stage of his disease, I was sensitive to John's emotional and psychological condition and periodically assessed his psychosocial needs throughout the

interview process. I agreed to stop the interview at any point if the subject became upset. There were two times when John became emotional and I asked him if he wanted to take a break or end the interview. On both occasions, I allowed John the necessary time to collect himself after which he agreed to continue the interview. Following the completion of one month of cancer treatment, John agreed to meet with me again for a short follow up interview as specified in the protocol of this research study.

### *Cheryl*

Cheryl is a 41 year old, Caucasian female married with one nine-year old child. She was employed as a marketing executive prior to being diagnosed with ovarian cancer but had to quit her job. Her family's annual income is between \$45,000 and \$50,000. Cheryl attended college where she earned a bachelor's degree. She was raised Catholic and throughout her adult life has continued to the connection to her religious beliefs. Cheryl reported having a strong spiritual faith that she has relied upon during difficult times.

Cheryl was initially diagnosed with Stage II thyroid cancer that was successfully treated with surgery. Recently, she was diagnosed with Stage IV ovarian cancer which was surgically removed. She is currently undergoing chemotherapy to treat her advanced disease. Cheryl was referred to this study by her medical oncologist at the research site.

As a condition of her participation in this study, Cheryl was screened for psychosocial distress using the *BSI 18* instrument. Despite being diagnosed with Stage IV disease, she scored in the moderate range for distress. Cheryl acknowledged the presence of anxiety and depression but reported no emotional or psychological condition that would preclude her from participating in this research. I met Cheryl prior to

recruiting her for this study and based on the results of the screening process felt comfortable including her in this study.

I scheduled an interview with Cheryl and met with her at the research site for approximately one and one half hours. Prior to beginning the interview, I presented Cheryl with the informed consent form and explained the contents of the form to her. Cheryl read the informed consent and signed it without asking me any questions. She appeared comfortable throughout the interview and was receptive and open to answering all questions. Cheryl described in detail her experience being diagnosed with cancer. Given her advanced stage of disease, I was sensitive to the potential for emotional and psychological distress and continuously monitored Cheryl's reaction to questions asked during the interview. I agreed to stop the interview at any point should she become upset. There were three times during the interview when Cheryl was overcome with emotions at which point I asked her if she wanted to take a break or end the interview. Cheryl was allowed the necessary time to collect herself after which she agreed to continue the interview. Cheryl agreed to meet again after completion of another month of chemotherapy treatment for a short follow up interview.

### ***Karen***

Karen is a 40-year old, Caucasian female married with one child age two. She was employed in communications prior to Hurricane Katrina but lost her job and had not worked since that event. Her family's annual income is between \$40,000 and \$45,000. Karen attended graduate school and earned a master's degree. She was raised as a Catholic and has practiced within that religious faith her entire life.

Karen was recently diagnosed with Stage I cervical cancer and underwent surgery to treat her disease. No further treatment was recommended; however, according to her oncologist that situation could change depending on the results of diagnostic tests conducted three months after the date of her initial cancer diagnosis. Karen was referred to this study by the nurse of her medical oncologist.

I interviewed Karen at the research site in the patient resource library for approximately 70 minutes. Prior to beginning the interview, I presented Karen with the informed consent form and explained the contents of the form to her. Karen read the informed consent and signed it without asking any questions. She appeared comfortable throughout the interview and was open to answering all questions. Karen provided a detailed description of her experience being diagnosed and treated for cervical cancer. She agreed to be interviewed again in one month to offer her perspective on the supportive care needs of a cancer patient during treatment.

### *Rachel*

Rachel is a 48 year old Caucasian woman married with one child age 15. She attended medical school and has worked as an obstetrician/gynecologist for the past 18 years. Rachel decided not to return to her career until after she fully recovers from her cancer treatment. The annual income for her household exceeds \$100,000. Rachel was raised in the Jewish faith but has attended the Catholic Church with her husband since they were married. She reported having a strong faith in God. Rachel was referred to this study by her medical oncologist.

Diagnosed with Stage I breast cancer, Rachel had surgery to remove the disease and recently began a chemotherapy regimen. I interviewed Rachel at the research site

while she was receiving the second of six treatments. She reported having taken an anti-anxiety medication earlier in the day to help her relax. Despite being under the influence of a psychotropic medication, Rachel appeared lucid and completely engaged throughout the interview process; however, she reported being tired toward the end of the 80-minute interview session. Rachel agreed to meet again in one month for a follow up interview.

### ***Barbara***

Barbara, the fifth subject interviewed for this study, is a 58 year old, African-American female divorced with two children ages 26 and 36. She has a high school education and was employed as an airport customer service representative prior to being diagnosed with breast cancer. At the time of the interview, Barbara was unable to work due to her medical condition and was unemployed. She depends on disability and social security payments for income which amounts to less than \$15,000 annually. Barbara was raised in the Baptist Church and has continued to practice in this religious faith throughout her life.

Barbara was recently diagnosed with Stage III breast cancer that was initially treated with surgery. Following surgery, she began receiving chemotherapy to treat her advanced disease. Barbara is expected to begin radiation therapy after completing her chemotherapy regimen. She was referred by the nurse of her medical oncologist.

As a condition of acceptance into this study, Barbara was screened for psychosocial distress. Despite being diagnosed with Stage III cancer, she scored on the *BSI 18* in the low range for depression and the moderate range for anxiety. Based on the results of the screening process, I determined that Barbara had no emotional or psychological condition that would preclude her from participating in this research study.

I scheduled an interview with Barbara and met with her as she received chemotherapy treatment. The one hour interview took place in a private room in the infusion area of the research site and adhered to a semi-structured interview protocol. Prior to beginning the interview, I presented Barbara with the informed consent form and explained in detail the contents of the form to her. Barbara read the informed consent and signed it without asking any questions. She appeared comfortable throughout the interview and was receptive to answering all questions.

Given the advanced stage of disease, I was sensitive to the potential for emotional and psychological distress and throughout the interview periodically “checked-in” with Barbara to assess her psychosocial state. At no point during the interview did the subject exhibit or express having emotional or psychological distress. Barbara agreed to meet with me again in one month for a short follow up interview.

### *Susan*

Susan is a 49 year old, African-American woman divorced with three children ages 19, 23, and 24. She achieved a high school diploma and attended one year of college before quitting. Prior to being diagnosed with breast cancer, Susan worked as a supervisor at a community gymnasium. At the time of the interview Susan was unable to work due to her physical condition as a result of her medical treatments; however, she reported wanting to return to her job once she has recovered from cancer treatment and is able to work. Susan depends on family and friends for financial support while she is unemployed. Susan was raised in the Baptist Church and reported maintaining a strong religious faith throughout her adult life.

Susan has been diagnosed with Stage I breast cancer that was initially treated with surgery. At the time when Susan was interviewed for this study, she was receiving chemotherapy to treat her disease. Radiation therapy is planned for Susan following the completion of her chemotherapy regimen. She was referred to this study by her medical oncologist. At the end of the session, Susan agreed to meet with me in one month for the purpose of conducting a follow up interview.

### *Summary of Participants*

The patient population of the outpatient clinic where the research was conducted is comprised of 81% women; of those 60% have been diagnosed with breast cancer. The relatively high number of female patients in this study resulted from the fact that individuals with lung cancer and prostate cancer—the two most common diagnoses of cancer in men—are not normally treated at the research setting; instead they are seen for treatment at another medical facility. Approximately one-third of all patients treated at the research site meet the qualifications for Medicaid insurance, meaning they have a lower socioeconomic status that corresponds to a significant financial resource need. In terms of race and ethnicity, the patient population at the research site is comprised of a nearly equal number of individuals who are Caucasian and African-American. Based on a comparison of these statistics to the personal characteristics of the participants, the sample selected for this study closely resembled the population of cancer patients receiving treatment at the research site.

### *Personal Characteristics*

The personal characteristics of the participants were obtained through a questionnaire administered prior to the initial interview. A full account of the

participants' characteristics is listed in Table 1 and Table 2. As a finding of this study, the data collected on the background of participants were considered relevant to determining the relationship between a personal characteristic and a corresponding supportive care need.

Of the six individuals listed in Table 1 who participated in this research study, five were females. The participants ranged in age from 40 years to 58 years old. The sample was equally divided between blacks and whites with three individuals selected from each racial group. Three of the participants in this study were married, one single and two divorced. All of the participants reported having at least one child.

Table 1

*Participants' Personal Characteristics*

Name	Age	Gender	Ethnicity	Marital Status	Ages of Children
John	48	Male	Black	Single	21
Cheryl	41	Female	White	Married	9
Karen	40	Female	White	Married	2
Rachel	48	Female	White	Married	15
Barbara	58	Female	Black	Divorced	26, 36
Susan	49	Female	Black	Divorced	19, 23, 24

In Table 2, background information is presented on the participants' level of education, religious affiliation, employment status, and annual income. The educational level of the individuals in this study ranged from a high school degree to one participant

who completed medical school. While only one of the participants stated they were employed at the time of this study, every individual reported being unable to work because of the physical symptoms associated with cancer treatment.

Table 2

*Participants' Education, Religion, Employment, and Annual Income*

Name	Education	Religion	Employment	Annual Income
John	3 years of college	Baptist	Unemployed/disabled	under \$10,000
Cheryl	Bachelors degree	Catholic	Unemployed/disabled	\$45 - \$50,000
Karen	Masters degree	Catholic	Unemployed/retired	\$40 - \$45,000
Rachel	Medical degree	Jewish	Employed/not working	over \$100,000
Barbara	High school diploma	Baptist	Unemployed/disabled	under \$15,000
Susan	1 year of college	Baptist	Unemployed/disabled	under \$10,000

***Cancer Diagnosis and Treatment Plan***

The information in Table 3 represents a summary of the cancer diagnosis and treatment plan for each individual in this study. Of the five female participants, three of them received a diagnosis of breast cancer. Three of the participants were determined to have advanced disease as designated by a Stage III or Stage IV diagnosis. The treatment plan for five of the six participants included surgery with all but one patient being treated with chemotherapy. Three of the participants were scheduled to receive radiation therapy as part of their treatment regimen. One of the individuals in this study had previously been diagnosed with thyroid cancer that was successfully treated. She recently received a

diagnosis of Stage IV ovarian cancer. Three of the participants reported believing their cancer could not be cured and as such considered their medical condition to be terminal.

Table 3

*Participants' Diagnosis and Treatment Plan*

Name	Primary Cancer Site	Disease Stage	Treatment Received or Planned
John	Lung	Stage IV	Chemotherapy, Radiation
Cheryl	Thyroid, Ovaries	Stage IV	Surgery, Chemotherapy
Karen	Cervix	Stage I	Surgery
Rachel	Breast	Stage I	Surgery, Chemotherapy
Barbara	Breast	Stage III	Surgery, Chemotherapy, Radiation
Susan	Breast	Stage I	Surgery, Chemotherapy, Radiation

**Data Collection Methods**

The aim of this phenomenological study was to examine the participants' personal experience by taking a holistic review of their perceived supportive care needs at specific intervals during the cancer treatment process. To accomplish this objective, the perceived supportive care needs of cancer patients were assessed on the factors that comprise *The Indivisible Self: An Evidence-Based Model of Wellness* (IS-Wel; Witmer et al., 1998), a paradigm that explains the nature of human functioning within the context of the environment (Myers & Sweeney, 2005).

Data were collected from participants at two specific times employing two different strategies: (a) administering written questionnaires and self-assessment

instruments; and (b) conducting interviews. The first method of data collection involved administering the Personal Characteristics and Treatment Plan Questionnaire, a written questionnaire designed to obtain information on the participants' personal characteristics and their cancer diagnosis and treatment plan. In addition, a second instrument, the Psychosocial Distress and Coping Skills Self-Assessment, was administered to participants to assess the constructs of psychosocial distress and coping skills. A third written instrument, the Supportive Care Needs Assessment, was administered after one month of treatment to assess the supportive care needs of participants. Collectively, these three self-assessment instruments produced background information on the individuals who participated in this study and data on the participants' perceptions of themselves, their cancer experience and their needs during treatment. Participants' responses to the assessment instruments were explored in greater detail during the interview process.

A second strategy that was employed involved conducting semi-structured interviews on two occasions during the participants' treatment regimen. Open-ended, global and probing questions designed to elicit a descriptive narrative of the participants' cancer experience were scripted in an interview protocol and revised after the initial interview was conducted with John, the first participant interviewed for this study. A second, follow up interview was held after participants had completed at least one month of cancer treatment. All interviews were conducted as purposeful conversations to encourage an in-depth discussion of the topics under consideration in this research study.

### *Questionnaire*

Participants were asked to complete a short questionnaire consistent with other research studies in the field of psycho-oncology (Moadel et al., 2006; Newell et al., 1999;

Sanson-Fisher et al., 2000; Whelan et al., 1997). Personal characteristics/background data were collected on the age, gender, ethnicity, marital status, number of dependents, socioeconomic status, employment status, and education level of the participants in the study. Additional information was obtained on disease diagnosis and treatment plan with a focus on primary tumor site, disease stage, disease metastasis, disease recurrence, and cancer treatments planned and/or received. The data on the personal characteristics and medical information of participants were organized into tables and reported in the findings of this study.

### ***Self-assessment Instruments***

This study relied on the use of self-reported assessment instruments to examine how recently diagnosed patients perceive their supportive care needs and their ability to cope with cancer treatment. Three different instruments were administered at two points during this study to collect the participants' self-assessments on: (a) psychosocial distress and coping skills; (b) factors of wellness; and (c) supportive care needs.

### ***Psychosocial Distress and Coping Skills Self-assessment***

Surveys conducted in outpatient clinics have shown that between 20% and 40% of cancer patients have significant levels of distress (National Comprehensive Cancer Network, 2005). Given the prevalence of psychological and emotional distress, participants were asked to self-report their level of anxiety and depression on a rating scale from 1 to 10. The instrument administered in this study for assessing psychosocial distress was adapted from a screening tool developed by the National Comprehensive Cancer Network (NCCN). The self-assessment instrument further examined the

participants' ability to cope with life challenges that includes cancer diagnosis and treatment.

***Self-assessment of Wellness Scale***

A simple means of assessing patients' needs is through the use of scaling questions (Myers & Sweeney, 2005). In the context of this study, scaling questions were used to get the participants' perceptions through an answer rating scale. The informal method of assessing individuals developed by Witmer et al. (1998) based on factors of wellness form the foundation for the assessment instruments administered in this research study. Chart 1 represents an example of the wellness factor.

Chart 1

*A Factor of Wellness*

<b>Spirituality</b>	<i>Circle the number that best reflects your overall wellness related to spirituality and your satisfaction with your spirituality.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

To operationalize the *IS-Wel* so that participants were able to understand the relevance of wellness to individuals diagnosed with an illness such as cancer, explanations of each of the 17 factors of wellness were added. These definitions were taken from *The Five Factor Wellness Inventory Manual* (Myers & Sweeney, 2005) and are critical to helping participants understand the intended meaning of the factors within the context of this study. Chart 2 is an example of an operationalized self-assessment factor of wellness.

Chart 2

*An Operationalized Factor of Wellness*

<b>Spirituality</b>	Personal beliefs and behaviors that are practiced as part of the recognition that we are more than the material aspects of mind and body. Dimensions include belief in a higher power; hope and optimism, worship, prayer, and/or meditation; purpose in life, love (compassion for others); moral values; and transcendence, or a sense of oneness with the universe (Myers & Sweeney, 2005, p. 11).									
	<i>Circle the number that best reflects your overall spiritual wellness and your satisfaction with your spiritual wellness.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

After administering the self-assessment instrument to the first participant of this study, I recognized the need to simplify the language used in the explanation of each of the factors of wellness. Changes were made and tested with Cheryl, the second individual interviewed in this study. Following the interview with Cheryl, I evaluated the revised self-assessment instrument for its applicability to the data collection process. I decided the revised instrument was suitable for the remaining interviews.

Chart 3

*A Revised, Operationalized Factor of Wellness*

<b>Spirituality</b>	Belief in a higher power; using worship, prayer, and/or meditation to help you during difficult times; having a compassion for others; relying on moral beliefs and values when making decisions about what to do									
	<i>Circle the number that best reflects your overall wellness related to spirituality and your satisfaction with your spirituality.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

The self-assessment instrument required participants to self-report their current level of wellness on each factor on a linear scale of 1 to 10, with 1 being low and 10 being high (Myers & Sweeney, 2005). The use of scaling questions makes it easier for participants to self-report their wellness in all 17 of the factors of the *IS-Wel* (Myers & Sweeney). Myers and Sweeney found it is useful to have individuals assess themselves on two rating scales for every wellness factor, responding first to “How well do you feel?” and second to “How satisfied are you with your level of wellness in this area?”

Each of this study’s participants was administered the assessment immediately before being interviewed. The assessment generally took participants ten minutes to complete. The responses provided on the two assessments served as information that the researcher explored in greater detail during the semi-structured interviews. Another important reason the assessment was administered prior to the interview was to focus attention on the 17 factors of wellness so that participants were familiar with the wellness factors making them better prepared to discuss these topics during the interview process.

### ***Supportive Care Needs Assessment***

A self-assessment instrument was developed from the results of the initial interview with individuals recently diagnosed with cancer as a way of collecting data on the participants’ perceptions of their supportive care needs. The domains that were examined with this instrument included physical needs, psychosocial needs, social support needs, communication and information needs, sexual and intimacy needs, occupational/work-related needs, financial resource needs, cultural needs, and spiritual/existential needs.

Participants were asked to provide a numerical rating on each domain of need based on a linear scale from 1 to 10, with 1 representing “low” and 10 representing “high.” The use of a rating scale made it simple for participants to respond to the following items: a) “Rate your [domain of supportive care need] before beginning cancer treatment;” and b) “Rate your [domain of supportive care need] at the present time.” The data resulting from these two assessment items provided insight into how participants’ perceptions of their supportive care needs change during cancer treatment.

A third scaling item was included on the instrument that asked participants to report their perceptions on the importance of fulfilling their supportive care needs by rating on a scale of 1 to 10—with 1 being “not important” and 10 being “very important”—the following question: “During your cancer treatment, how important has it been for you to get help with your [supportive care needs]?”

In addition to examining supportive care needs, the assessment instrument explored the participants’ perceptions of their coping skills. Participants were asked to rate on a scale from 1 to 10—with 1 representing “not well” and 10 representing “very well”—the topic, “Rate how well you believe you have coped with cancer treatment thus far.” The goal of this rating was to provide insight into how individuals participating in this study perceive their ability to cope with cancer.

The final section of the instrument involved the factors of wellness and coping. Specifically, participants were asked to respond to 15 of the 17 factors of wellness, as conceived by Witmer et al. (1998) in *The Indivisible Self: An Evidence-Based Model of Wellness*, and rate how important each factor had been in helping them cope with cancer treatment. Based on the responses from the study’s six participants during the first

interview, two factors—cultural identity and gender identity—were considered by participants to be irrelevant to their situation and therefore, omitted from this instrument. A rating scale from 1 to 10—with 1 being “not important” and 10 being “very important”—was used to describe the level of importance participants placed on each wellness factor included in the instrument. Data from the first round of participant interviews provided concrete examples of how 15 of the 17 factors of wellness had been put into practice to facilitate coping.

Each of this study’s participants was administered the supportive care needs assessment shortly before being interviewed. The responses provided by participants served as topics for further examination during the follow up interview. Each of the six participants received instructions to assist them in the completion of the assessment instrument. All participants completed the supportive care needs assessment in less than 15 minutes.

### *Interviews*

The research design of this study was a descriptive phenomenological method that was used to investigate the experiences of individuals entering cancer treatment. Open-ended, probing questions were used to facilitate the gathering of rich and compelling dialogue that led to a meaningful understanding of the essence of the experience of cancer patients during treatment. Semi-structured interviews allowed the researcher to ask probing, clarifying questions, and to facilitate the expression of the participants’ experiences with minimal interruption. The interviews were conducted as purposeful conversations with the researcher ensuring that each participant was interviewed in a comfortable and confidential manner.

Research interviews for this research study were conducted in a private room within the cancer center's outpatient clinic. Each participant was interviewed alone to assure privacy and to invite an open and honest discussion. Interviews were recorded with a digital voice recorder and transcribed verbatim. The first interview required between 80 and 90 minutes to complete. A second, follow up interview lasted between 30 and 40 minutes.

### ***Initial Interview***

A semi-structured interview format was utilized to elicit full descriptions of the participants' experiences through an examination of their perceived supportive care needs during cancer treatment. A set of questions and inquiring statements were prepared for use in the initial round of interviews as a way of standardizing the data collection process. A revised set of questions and statements were developed and implemented following the interview session with John, the first participant interviewed in this study. The revised interview protocol essentially provided this study with a more structured format from which to collect the research data.

The open-ended, global questions that served as the foundation for the first interview were based on the five second order factors of the *IS-Wel* (Witmer et al., 1998) namely, the creative self, coping self, social self, essential self, and physical self. The global interview questions or statements included:

- Creative Self: Describe your thoughts and feelings about your life at present.  
How did your cancer diagnosis alter your thoughts and feelings about your life?

- Coping Self: How are you able to cope with life's challenges? How have you been able to cope with cancer thus far?
- Essential Self: What do you think is the meaning of your cancer experience?
- Social Self: Describe the support you receive from other people in your life. How has your social support (e.g., family, close friends, co-workers) helped you cope with cancer diagnosis and treatment?
- Physical Self: Describe your perception of your physical well-being in the past, present, and future.

Probing interview questions were used to encourage participants to explore subject matter in greater detail with as little prompting from the researcher as possible (Smith & Osborn, 2003). The 17 third order factors of the *IS-Wel* (Witmer et al., 1998) used in the interview process consisted of thinking, emotions, control, work, positive humor, leisure, stress management, self-worth, realistic beliefs, friendship, love, spirituality, gender identity, cultural identity, self-care, exercise, and nutrition. These factors formed the basis for the probing questions participants were asked in the initial interview. Probing questions or statements included:

*Factors of Creative Self:*

- Thinking: How has your thinking helped you to solve problems that have come your way? In what way(s) have you used your thinking to help you cope with a cancer diagnosis?
- Emotions: Describe the emotions you have had since being diagnosed with cancer. In what way(s) do you normally express your emotions? How have

your emotions helped you to cope or made coping more difficult following your cancer diagnosis?

- Control: What level of control do you believe you have over your life? Was your view of control altered by being diagnosed with cancer? If so, how?
- Work: What type of work do you do, or have done in the past? Describe your level of satisfaction with the work that you do now or have done in the past. If you are not working at present, describe what you miss about work? If you have had a change in your work status because of your cancer diagnosis/treatment, describe what you are now doing with the time you used to be dedicated for work.
- Positive Humor: Describe how you use humor in a positive way to help deal with life's challenges. How have you used positive humor to help you cope with cancer?

*Factors of Coping Self:*

- Leisure: How do you like to spend your free time? How do leisure activities add to your life? How has leisure activities helped you to cope with cancer?
- Stress Management: How are you normally able to handle stress? How has cancer affected your ability to manage stress? In what way(s) have you learned to manage stress differently following a cancer diagnosis?
- Self-Worth: How has cancer affected your self-worth? How important is it for you to see yourself in a positive manner? How has cancer made it more difficult to maintain a positive self-image?

- **Realistic Beliefs:** How would you characterize your ability to perceive reality accurately? How has cancer affected your ability to maintain a realistic perspective?

*Factors of Essential Self:*

- **Spirituality:** Describe your spiritual faith. How strong a faith do you believe you have? When confronted with adversity in your life how have you used your faith to help you cope? How has cancer affected your spiritual beliefs or faith? How has your spiritual faith helped you to cope with cancer?
- **Gender Identity:** Describe how comfortable you are as a woman. In what way(s) has cancer affected your identity as a woman?
- **Cultural Identity:** Describe how you see yourself from a cultural perspective. How has cancer affected your cultural perspective?

*Factors of Social Self:*

- **Friendship:** Describe the social relationships that are important to you. How have these friendships helped you since being diagnosed with cancer?
- **Love:** How much do you love and how much do you feel loved by others? What role do you think love has played in helping you to cope with difficulties and challenges you have faced during your life? How has your view of love changed since being diagnosed with cancer?

*Factors of Physical Self:*

- **Self-Care:** Discuss the importance of taking care of yourself. How has a cancer diagnosis changed the way you care for yourself?

- Exercise: What value do you place on physical exercise? How has being diagnosed with cancer altered your view of exercise?
- Nutrition: Describe how important proper nutrition is to you in your everyday lifestyle. How has cancer changed your view of proper diet and nutrition?

### ***Follow-up Interview***

A second interview was conducted with subjects after they completed at least one month of their prescribed cancer treatment regimen. The purpose of the follow-up interview was to explore four topics relative to the participants' perceptions of their cancer experience, namely: (a) what supportive care needs participants had early in the treatment process; (b) how their needs changed over the course of their cancer treatment; (c) what importance participants placed on having their supportive care needs met; and (d) how the participants incorporated the factors of wellness into helping them cope with their cancer experience.

The follow-up interview was structured into two content areas. First, the supportive care needs of participants were discussed. Participants were asked to expand on the answers they provided on the supportive care needs self-assessment. The goal of this in-depth inquiry was to gain insight into what cancer patients perceive as their supportive care needs and how they were able to get their needs met. Further, the importance that participants placed on their supportive care needs was examined. Data were collected on unmet needs; specifically, participants were asked, what perceived barriers kept supportive care needs from being satisfied.

A second content area of the follow-up interview involved the relationship between the factors of wellness and coping with cancer. Participants were asked in the

self-assessment instrument to apply fifteen of the seventeen original wellness factors to their experience with cancer. The responses they provided served as the framework for the follow up interview. Participants were asked to discuss how they applied wellness to help them with their illness. The factors of wellness that were addressed in the follow-up interview included:

- Thinking: using your thoughts and analytical ability to help you understand your experience; not over-thinking what you are experiencing
- Emotions: letting out your emotions when appropriate; not ignoring your feelings but embracing them in a positive way
- Friendships: allowing friends to help you when you need the help; staying in contact with close friends and not shutting them out
- Work: continuing to stay involved in work-related activities even though you are not working; maintaining contact with co-workers
- Leisure: using leisure activities to distract you from your illness; trying some new hobby or activity that you have not tried before
- Stress management: being aware of the stress you are feeling and managing it in an appropriate way
- Self-worth: maintaining a positive view of yourself in spite of the physical changes you may be experiencing
- Realistic beliefs: keeping realistic thoughts about what you are experiencing; checking unrealistic thoughts when they enter your mind
- Positive humor: using laughter to relieve stress; continuing to enjoy life even during a difficult experience

- Control: staying in control of your thoughts and emotions by not letting them get control of you; giving up control to others when appropriate
- Self-care: taking care of yourself in spite of your illness; maintaining a desire to be attractive
- Exercise: remaining physically active as much as that is presently possible; acknowledging the importance of exercise to good health
- Nutrition: eating a proper diet as much as that is presently possible; recognizing the importance of nutrition to good health
- Spirituality: relying on your spiritual faith to get you through; putting into practice your spiritual beliefs when confronted with a big challenge
- Love: allowing those around you to love you; loving others back for all the love and support they give you

The goal of the data collection process was to create a narrative of the participants' cancer experience. The variety of methods used in collecting data for this study resulted in a thorough examination of the perceptions of six individuals recently diagnosed with cancer as they progressed through their treatment. The self-reported assessments administered to participants generated data that received a detailed examination through a two-interview process. The results of the data collection format were to produce transcribed data that illuminated the experiences of cancer patients attempting to cope with the diagnosis and treatment of their disease.

### **Data Analysis Methods**

According to Smith and Osborn (2003) the primary assumption in IPA is that the researcher seeks to learn about the participant's social and psychological world. The

central focus is on meaning, and the purpose of IPA research is to understand the content and complexity of those meanings instead of trying to measure the rate of occurrence. To find the meanings of the participants' experiences, the researcher must engage in an exhaustive process of interpreting the transcribed text of one interview before methodically moving on to the next, case by case, until all interviews have undergone an in-depth examination (Smith et al., 1999). This extensive, idiographic case-study approach to analysis is the very essence of IPA research.

Transcripts of the interviews were analyzed following an IPA approach (Smith, Jarman, & Osborn, 1999). Over the past five years, IPA had been used extensively in examinations of the subjective experience of individuals with physical illness (Smith et al., 2006; Wallace et al., 2007). A six-step analytical process established by Smith et al. (1999) was followed to conduct a thorough analysis of the transcribed data, drawing out themes related to the topic under investigation in this study. IPA analysis remains true to the words of participants by including in the final written report verbatim examples from interview transcripts to illustrate emergent themes (Smith & Osborn, 2003).

It should be noted that qualitative analysis is inescapably a personal process whereby analysis is the interpretative effort of the researcher (Smith & Osborn, 2003). IPA follows such a qualitative approach as it is not a rigid methodology. Researchers can adapt IPA to suit their own personal analytical style. While IPA is flexible as an approach, it does follow six separate steps in the analysis and reporting of transcribed data.

### ***Preliminary Step: Transcribing Data***

According to Bedford and Landry (in press), the act of transcribing the spoken word serves as the point at which data analysis begins. The researchers recognize the difficulty in replicating the precise intent of a verbal conversation into a “written transcript” (Bedford & Landry). The nuances of verbal and nonverbal language often get omitted when transcribed. Despite this limitation, Bedford and Landry recognize the important contribution of the transcription experience to the overall data analysis process. In their recent paper, they lay out specific steps for transcribing data; however, they acknowledge the ways in which experience is transformed during transcription will be unique to each researcher.

### ***Step One: Looking for Themes in the First Case***

In the first step of IPA, the researcher reads the transcript several times recording notes in one of the margins on anything the participant said that appears interesting or significant. It is important during this stage of the analysis for the researcher to become as intimate as possible with the participant’s story (Smith et al., 1999). The process requires the transcript to be read several times with new insights likely to surface with each reading. After all notes have been made on the entire interview, emerging theme titles are then pulled from the notes and documented in the other margin. Key words are used to capture the essence of what is being found in the text. According to Smith and Osborn (2003) at this point, the entire transcript is treated as potential data and no attempt is made to omit or select particular passages for special attention.

### ***Step Two: Connecting the Themes***

The primary aim of this step of interpretative phenomenological analysis is to create some order from the collection of concepts and ideas that have been pulled out of the participant's responses (Smith et al., 1999). To accomplish this task, the researcher creates a list of emerging themes and attempts to establish a connection between them. Some of the themes may be clustered together while others may emerge as major concepts. As themes are organized into clusters, the results are compared to the actual transcribed words of the participants to make certain the connections fit (Smith & Osborn, 2003).

### ***Step Three: A Table of Themes***

The third step of IPA involves further organization of themes into a table. The clustering process that took place in during the second step of the IPA process produced groupings that are given a name and represent major themes. In creating the table, some themes may be eliminated that do not fit in the emerging structure or they are not well supported by evidence within the transcript (Smith & Osborn, 2003).

### ***Step Four: Continuing the Analysis with Other Cases***

Because this research study included more than a single participant, an analysis was conducted on the second transcript. At this point, it is either possible to use the list of themes from the first case or start the process from the beginning (Smith & Osborn, 2003). This study followed an individual case-study approach that started the process anew with each case, going through the steps previously stated to produce a list of themes. Following this course, the list of themes for each interview could be read together and a consolidated list of themes for all cases produced (Smith et al., 1999).

### ***Step Five: A Master List of Themes for the Cases***

Once the list of themes from all cases has been created, the next step in the analytical process involves the emergence of a master list. According to Smith et al. (1999) determining which themes should be on the final list depends on the decision criteria followed by the researcher. For this research study, the text which supported the themes was deemed important when a theme was selected to be included in the master list. In addition, the researcher placed value on how a particular theme helped to illuminate other aspects of the story.

### ***Step Six: Writing Up the Findings***

The final stage of IPA involves moving from the master themes to a write-up—a narrative account that highlights the meanings found in the participants’ experience (Smith et al., 1999). Analysis continues during the writing phase as the themes are explained, illustrated, and developed. According to Smith and Osborn (2003) the table of themes serves as the foundation for the narrative argument which is “interspersed with verbatim extracts from the transcripts to support the case” (p. 77). For there to be an accurate account documented in the final write-up, a clear distinction must be made between what the participant said and the researcher’s interpretation of it (Smith et al.).

### **Summary**

The methodology used in this study was not static and evolved throughout the research process. Specifically, the procedures used to gather data from the first participant served to inform the interviews that followed. The follow-up interview protocol was developed after the data from the first interview were reviewed and evaluated. By using the results of the first series of interviews to create the format for the

second set of interviews, questions were worded in a way that enlisted information to fill in any gaps in the participant's story. Further, the findings from the initial interview process provided information that led to the creation of the supportive care needs assessment instrument. In this way, the study's methodology was purposely flexible which produced research that shifted with the focus of the participants. The semi-structured interview process allowed for real time adaptation that maximized the potential for information gathering and enabled participants to tell the story of their cancer experience.

## **CHAPTER FOUR**

### **RESULTS**

#### **Introduction**

The purpose of this study was to understand to experiences of recently diagnosed cancer patients as they undergo treatment for their disease. The factors of the *IS-Wel* (Witmer et al., 1998) model of wellness were used to frame the interviews with the participants in this study in an effort to examine the perceived supportive care needs reported by patients at specific times during treatment. A holistic needs assessment was utilized to explore the full range of supportive care needs. In this chapter, the experiences of the study's participants and the results of the data analysis are reported.

Chapter Four is divided into four sections. First, the results of a case study analysis of each of the six research participants are presented. The case studies followed the first three steps of the IPA approach that focuses on the themes and meanings emerging from the data. Second, the findings of a cross-case analysis are presented. Steps four and five of the IPA model was used to analyze cases with the goal of creating a master list of themes based on all the data collected. In the third section, the results of the data analysis are applied to answer the research questions of this study. Presented in the last section are summary conclusions reached from an analysis of the research data.

#### **Case Studies of Participants**

An in-depth analysis of the interview transcript for each participant was undertaken. The order of the cases studies beginning with John and ending with Susan

follows the same sequence as when the interviews were conducted. Adhering to the first three steps of Interpretative Phenomenological Analysis, a case study approach was followed to analyze the data collected from written assessments and interviews with each participant. Specifically, the first step of IPA required the transcribed interviews be read several times. After each reading, notes were recorded in the margins of the transcripts on the themes that emerged from the data. Additionally, any of the factors of wellness and the participants' perceptions of their supportive care needs that surfaced in the data were documented in the margin of the transcripts. Actual quotes from each participant were highlighted and included as support for the findings in answering the research questions of this study.

As part of step two, each theme from the initial list was reviewed for commonality to other themes and for a connection with the purpose of this study. Themes that were not considered relevant were removed from the list. In keeping with the primary aim of the second step of IPA, themes were organized into groups based on the interpretation of the intended meaning of the participant. Descriptive titles were given to the groups to indicate major themes that emerged from the data. These major themes were compared to the actual transcribed words of the participant to confirm the presence of a connection. As a third step, another review of the data was conducted to ascertain the importance each participant placed on the major themes that emerged from the written assessments and interviews. Groups of themes were removed to arrive at a final list of major themes. A final table was constructed of themes interpreted to be most significant for each participant. The identical three-step interpretative process was followed for all six participants in this study.

## **Case Study of John**

When I interviewed John, I found him to be very willing to share personal details of his cancer experience. He explained in depth the thoughts and emotions he has had since being diagnosed with Stage IV lung cancer. To provide perspective on John, it should be noted that he was diagnosed and has been living with HIV for the past 30 years. The uncertainty that comes with HIV disease in some way seemed to have helped prepare John to better cope with his cancer diagnosis and treatment. John reported having long struggled with his eating habits which impacted his ability to maintain sufficient weight. For example, at the time of the initial interview, John weighed 116 pounds. The physiological challenge for John to keep on weight seemed to have taken a toll on him psychologically and emotionally. I took into account the implications of John's experience with HIV diagnosis and treatment when interpreting the meaning of his words from the transcribed interviews.

### ***Emerging Themes***

An interpretation of the transcripts of the two interviews with John resulted in 49 individual themes emerging from the data. These themes represent John's perception of his cancer experience and reflections on his life. The themes that emerged from the interview transcripts come from the perspective of a person recently diagnosed with Stage IV lung cancer as he was undergoing chemotherapy treatment as a way of managing his disease. From the standpoint of medical statistics, John was told that a person with his cancer diagnosis has a 30% chance of surviving five years. Based on the responses John provided during the interviews, the relatively low survival rate seemed to have a significant influence on his perspective regarding a number of topics discussed.

The life-threatening aspect of his illness was evident when John stated, “I have a 30 to 70 percent chance of surviving with survival being 30 percent. I don’t think I’m going to survive it [cancer].” A complete list of themes that surfaced during the interviews with John is presented in Table 4.

Table 4

*List of Emerging Themes from Case Study of John*

---

- |   |  |
|---|--|
| • Sense of failure in life                  | • Changes in the way of thinking           |
| • Feelings of guilt about things unfinished | • Meaning of cancer                        |
| • Life is incomplete                        | • Using faith to cope with cancer          |
| • Taking life for granted                   | • Use of humor as a way of coping          |
| • Changes in perspective on life            | • Using thoughts to control emotions       |
| • Accepting that death is eminent           | • Accepting responsibility                 |
| • Possibility of death due to cancer        | • Resilient behavior                       |
| • Facing a life-threatening illness         | • Learning about cancer                    |
| • Inevitability of death                    | • Coping with stress                       |
| • Challenged by cancer to survive           | • Coping with adversity                    |
| • How to survive cancer treatment           | • Complying with cancer treatment          |
| • Adjusting to a new life with cancer       | • Managing stress                          |
| • Loss of the ability to work               | • Giving up/not willing to make the effort |
| • Loss of fighting spirit                   | • Fear of leaving life unfinished          |
| • Non-compliant with treatment              |  |

(Table 4 cont.)

- Inability to cope with physical pain due to cancer treatment
- Adopting a fighting spirit
- Changes in self-worth due to cancer treatment
- Psychological impact of cancer
- Avoiding responsibility
- Death and the connection to God
- Meaning of faith
- Faith providing strength to fight
- Using faith to cope with cancer
- Recognition of importance of social support
- Interacting with family and friends to facilitate coping
- Support from friends and other people during difficult times
- Not having to depend on others
- Being dependent on others
- Importance of proper nutrition
- Importance of physical activity
- Importance of diet and exercise
- Struggle to eat when sick
- Physical impact of cancer treatment
- Changes in lifestyle

---

### *Connecting the Themes*

In reviewing the individual themes that emerged from the interviews with John, connections between them became evident. The interpretative process I undertook at this point in IPA produced groups based on common themes such as death, coping, spirituality, and self-care. The themes were organized into nine clusters. Each of the clusters of themes listed in Table 5 represents a significant or major theme that emerged from the transcribed interviews with John.

Table 5

*Clusters of Themes from Case Study of John*

---

*Major Theme #1*

- Sense of failure in life
- Feelings of guilt about things not finished
- Changes in perspective on life
- Life is incomplete
- Taking life for granted

*Major Theme #2*

- Accepting that death is eminent
- Inevitability of death
- Facing mortality/possibility of death

*Major Theme #3*

- Adjusting to a new life with cancer
- Changes in self-worth due to cancer treatment
- Changes in thinking
- Psychological impact of cancer
- Changes in lifestyle

*Major Theme #4*

- Fighting spirit
- Using faith to cope with cancer
- Resilient behavior
- Accepting responsibility
- Use of humor as a way to cope
- Learning about cancer
- Using thoughts to control emotions

*Major Theme #5*

- Coping with stress
- Managing stress
- Coping with adversity
- Complying with cancer treatment

*Major Theme #6*

(Table 5 cont.)

- Giving up/not willing to make the effort
- Loss of fighting spirit
- Avoidant behavior
- Inability to cope with physical pain from cancer treatment
- Avoiding responsibility
- Non-compliant with treatment

*Major Theme #7*

- Death and the connection to God
- Meaning of faith
- Meaning of cancer
- Faith providing strength to fight
- Using faith to cope with cancer

*Major Theme #8*

- Recognition of importance of social support
- Interacting with family and friends to facilitate coping
- Support from friends and others during difficult times
- Not having to depend on others
- Being dependent on others

*Major Theme #9*

- Physical impact of cancer
- Importance of diet and exercise
- Not being able to gain weight
- Importance of proper nutrition
- Struggle to eat when sick

---

The resulting nine groups of themes that emerged from the data were supported by John's words as transcribed from the recorded interviews. I selected these quotes as evidence to support the major themes interpreted from the data. The process of selecting actual quotes required an exhaustive review of the transcribed interviews with John to

make certain his words were analyzed in the context in which they were meant.

Following IPA, each of the major themes was assigned a descriptive title that conveys the essence of the meaning. Table 6 represents the connection between the clusters of themes and John's actual statements.

Table 6

*Connection between Themes and Transcribed Statements from Case Study of John*

---

*Major Theme #1—Reflections on life*

“It [cancer] does seem to have changed my perspective on life.”

*Major Theme #2—Survival, mortality, and death*

“Cancer has made me more positive by putting me in the direction that I want my life to go now. I used to have the attitude that I would live forever. I think I believed that I'd never die. Cancer made me think about life differently. I realize now I'm going to die one day.”

*Major Theme #3—Changes as the result of cancer*

“I think I've learned how to adjust to a new life after being diagnosed.”

*Major Theme #4—Effective coping strategies*

“My faith plays a big part in helping me deal with this [cancer]. Without my faith, I don't know if I would make it.”

*Major Theme #5—Challenges presented by cancer*

“But for a cure to truly be a cure, you have to abide by the guideline for treating your cancer.”

*Major Theme #6—Ineffective coping strategies*

(Table 6 cont.)

“I can handle it [cancer treatment] until the point when I get in pain. When I get into pain, it’s a totally different thing.”

*Major Theme #7—Spirituality and existential meaning*

“For me, my disease hasn’t affected my spiritual belief. If anything, my faith has gotten stronger. It has helped me a lot at this time.”

*Major Theme #8—Role of family and friends*

“I believe they [my family] helped me to become the type of person that I am today, someone who is able to deal with HIV and cancer, whereas many people couldn’t.”

*Major Theme #9—Taking care of the physical self*

“I’ve lost a lot of weight since I became sick and know I need to eat more to get my weight back up.”

---

***Table of Themes***

Adhering to an IPA approach, three clusters of themes from step two presented in Table 6 were eliminated as I concluded they were not well supported by the evidence within the transcript as rising to the level of a major theme. Further, effective and ineffective strategies for coping were combined into one single major theme. Based on a thorough review of John’s transcribed statements, the themes he emphasized reflected on his life, survival and death, coping strategies, spirituality, and self-care. The resulting table of major themes is supported by the individual themes that emerged from the assessment and interview process conducted with this study’s first participant.

Table 7

*Table of Themes from Case Study of John*

---

*Reflecting on life*

- Taking life for granted
- Changes in perspective on life
- Life is incomplete

*Survival, mortality, and death*

- Facing mortality/possibility of death
- Challenge to survive cancer
- Accepting that death is eminent

*Coping strategies*

- Fighting spirit
- Using faith to cope with cancer
- Use of humor as a way of coping
- Resilient behavior
- Learning about cancer
- Accepting responsibility
- Using thoughts to control emotions

*Spirituality and existential meaning*

- Death and the connection to God
- Meaning of cancer
- Using faith to cope with cancer
- Inevitability of death

*Self-care*

- Importance of diet and exercise
  - Struggle to eat when sick
  - Coping with the side effects of cancer treatment
-

### *Summary of the Case Study of John*

The five major themes from this case study provide an insight into John's experience with cancer diagnosis and treatment. Cancer presented John with an opportunity to reflect on his life. Because of John's advanced stage of disease, the topics of survival, mortality, and death became relevant to his situation. The very nature of a disease such as cancer facilitates the need to adopt strategies for coping. This was a theme that John discussed throughout the interview process as evidenced his statement, "Now I've got cancer and I'm doing all that I can do to fight it." Another major theme that emerged from the interviews involved self-care. John acknowledged the importance of proper nutrition and the struggle he has had to gain weight when he said, "I recognize the need to take care of myself. Eating right, exercising regularly. Proper nutrition is very important to me. It's just difficult for me to eat right [because of cancer treatment]." Spirituality is a theme John emphasized as important. As John stated, "My faith plays a big part in helping me deal with this. Without my faith, I don't know if I would be able to make it."

### **Case Study of Cheryl**

Cheryl was initially referred to me by her surgical oncologist for supportive counseling following her diagnosis of Stage IV ovarian cancer. I found Cheryl to be very forthcoming with information and willing to discuss her cancer experience openly and without hesitation. She often expressed emotions throughout the interview process which provided me with additional opportunities to probe deeper for greater understanding. Cheryl was able to articulate the experience of a woman with a terminal illness fighting to survive while continuing to enjoy the life that remains. Her insights represented those

of a person who had a family history of ovarian cancer and came to the realization that she too would one day be diagnosed with the disease. Throughout the interview process, Cheryl tried to be strong but the magnitude of her situation made that difficult at times. She impressed me as someone focused on the quality of her life, not the quantity of time remaining in her life.

### *Emerging Themes*

The same process followed with the case study of John was utilized to analyze the data collected from Cheryl. Specifically, the written assessments and interview transcripts were reviewed two times to ascertain individual themes. These themes were organized to produce major themes representing the key points that surfaced during the interviews. In addition, Cheryl's perceptions of her supportive care needs were recorded in the margins of the transcripts. Further, Cheryl's statements were compared to the 17 factors of wellness and any connections were noted. Quotes from Cheryl were taken from the transcripts and included as supportive documentation in answering the research questions of this study.

The information presented in Table 8 represents a list of 66 themes that surfaced from an analysis of the transcripts of the two interviews with Cheryl. These themes provide insight into Cheryl's life and her cancer experience. The themes that emerged from the interview transcripts are those of a person diagnosed with thyroid cancer two and a half years ago which was successfully treated. More recently, Cheryl was diagnosed with Stage IV ovarian cancer and was undergoing chemotherapy treatment as a way of managing, but not curing, her disease. Cheryl appeared to comprehend the reality

of her situation when she stated, “When you have a terminal illness, and mine is terminal, the hardest part of this experience is not knowing when the end will come.”

Table 8

*List of Emerging Themes from Case Study of Cheryl*

---

- Uncertainty about the future
- Accepting the inevitability of death that comes with terminal illness
- Changes in lifestyle
- Using logic to maintain control
- Learning from adversity
- Limitations resulting from cancer treatment
- Facing mortality
- Challenge to endure cancer treatment
- Lifestyle changes
- Difficulty adjusting to changes in lifestyle
- Replacing losses that come with cancer
- Losing a sense of self
- Expressing emotions in a beneficial way
- Using writing to express emotions
- Importance of faith in God
- Taking care of needs
- Maintaining control over treatment decisions
- Letting go of emotions
- Giving things over to God
- Giving up control of things that cannot be controlled
- Learning to adjust to life with cancer
- Losing a sense of self
- Remaining positive despite cancer
- Accepting the changes that come with cancer
- Confronting the possibility of death

(Table 8 cont.)

- Learning to cope with challenges
- Looking for the humor in any situation
- Adversity strengthens relationships
- Influence of others in learning to cope
- Coping with life's challenges
- Guilt for not feeling well
- Lacking the energy to do things
- Keeping cancer in perspective
- Finding ways not to think about cancer
- Using leisure activities as a distraction
- Sharing experiences with loved ones
- New stress caused by cancer
- Difficulty managing stress
- Not letting things build up inside
- Physical symptoms of cancer creates stress
- Using humor to help with coping
- Affects of cancer treatment on a woman's identity
- Impact of cancer on intimacy
- Impact of physical changes on a woman's identity
- Love and support from family
- Talking with loved ones about difficult topics
- Importance of physical activity
- Increased awareness of feelings due to cancer
- Importance of feeling normal
- Changes in physical appearance due to cancer treatment
- Challenge that cancer presents to nutrition
- Importance of a normal routine
- Importance of self-care
-

(Table 8 cont.)

- Maintaining a realistic perspective about life
- Preparing yourself and others for what may come
- Being realistic about cancer
- Maintaining control despite cancer
- Cancer brings a person closer to God
- Relying on spiritual faith to cope
- Importance of diet to fight cancer
- Peace of mind that comes from faith
- Cancer is a humbling experience
- Knowing that people care
- Importance of friendships
- Love and support from friends
- Changes in sexual activity due to cancer

---

### *Connecting the Themes*

I conducted a comprehensive review of the transcribed interviews with Cheryl and the themes that emerged from the transcripts were organized into 14 major themes. Each of the major themes in Table 9 represents a significant topic discussed in detail during the interview process. The connections between themes in the case study of Cheryl centered on such concepts as uncertainty, mortality, loss, control, faith, sexuality, and normalcy. I took into account Cheryl's advanced stage of disease when interpreting the meaning of her transcribed words, particularly when she discussed topics associated with the life-threatening nature of cancer. Maintaining an awareness of her late stage diagnosis and the poor prognosis Cheryl received from her medical oncologist was important to accurately group the individual themes keeping them in the proper context.

Table 9

*Clusters of Themes from Case Study of Cheryl*

---

*Major Theme #1*

- Preparing for what may come
- Uncertainty about the future
- Changes in lifestyle
- Learning from adversity

*Major Theme #2*

- Accepting the inevitability of death that comes with terminal illness
- Confronting the possibility of death
- Facing mortality

*Major Theme #3*

- Expressing emotions in a beneficial way
- Using writing to express emotions
- Letting go of emotions
- Increased awareness of feelings due to cancer

*Major Theme #4*

- Difficulty adjusting lifestyle changes
- Replacing losses that comes with cancer
- Losses attributed to cancer
- Accepting the changes that come with cancer
- Limitations imposed on lifestyle

*Major Theme #5*

- Learning to cope with challenges
- Influence of others on learning to cope with cancer
- Learning to adjust to life with cancer

*Major Theme #6*

(Table 9 cont.)

- Keeping cancer in perspective
- Finding humor in any situation
- Remaining positive even with cancer
- Finding ways not to think about cancer
- Talking to loved ones about difficult topics

*Major Theme #7*

- New stress caused by cancer
- Difficulty managing stress
- Not letting things build up inside
- Physical symptoms of cancer creates stress

*Major Theme #8*

- Being realistic about cancer
- Maintaining a realistic perspective about life
- Maintaining control despite cancer
- Maintaining control over treatment decisions
- Giving up control of things that cannot be controlled

*Major Theme #9*

- Cancer brings a person closer to God
- Relying on spiritual faith to cope with cancer
- Peace of mind that comes from faith
- Importance of faith in God
- Giving things over to God

*Major Theme #10*

- Affects of cancer treatment on a woman's identity
- Impact of physical changes on a woman's identity

(Table 9 cont.)

- Changes in sexual activity due to cancer
- Impact of cancer on intimacy

*Major Theme #11*

- Knowing that people care
- Love and support from family
- Importance of friendships
- Sharing experiences with loved ones
- Love and support from friends

*Major Theme #12*

- Changes in physical appearance due to cancer treatment
- Importance of physical activity
- Importance of self-care
- Lacking the energy to do things
- Challenge that cancer presents to nutrition
- Challenge to endure the side effects of cancer treatment

*Major Theme #13*

- Importance of a normal routine
- Importance of feeling normal

---

At this point in IPA, I interpreted the meaning of the participant's statements made during the interviews and assigned a title to each of the major themes. I found it difficult to eliminate themes as the interview with Cheryl produced a large number of major topics that she supported with relevant statements. In Table 10, actual quotes taken from the interviews with Cheryl are presented to reinforce the major themes that emerged. Because Cheryl considered the prognosis of her disease to be terminal, the major themes that emerged from the interview transcripts centered on issues such as

mortality, death, uncertainty, spirituality, and faith. The emotionally-charged statements in Table 10 exemplify the perspective of someone attempting to cope with a life-threatening illness. Cheryl articulated her thoughts and feelings on a variety of topics and did so in an open and honest manner.

Table 10

*Connection between Themes and Transcribed Statements from Case Study of Cheryl*

---

*Major Theme #1—Uncertainty about the future*

“The hard thing is not knowing when it [death] will be. But that’s for everybody. Yet in some ways I feel a lot luckier because I have so much support.”

*Major Theme #2—Mortality and death*

“I think when you have a terminal illness, because mine is terminal, and I don’t know when. It could be years.”

*Major Theme #3—Expressing emotions*

“I guess being sick makes you more aware of your feelings and I know it’s made me more conscious of them. I also think I’m more prone to expressing my feelings and telling people I love them than ever before. Not that I didn’t say I love you before; it’s just now I feel more compelled to say it. Maybe that is some benefit of being diagnosed with a terminal disease.”

*Major Theme #4—Changes brought on by cancer*

“In the beginning, I had no idea it would be going on this long. I thought I’d be doing my treatments and I’d be back to work. Now I know differently. This is my life now. And I accept that this is my life now.”

(Table 10 cont.)

*Major Theme #5—Learning how to cope*

“I now better able to handle those types of challenges [like cancer], partly from watching my mother deal with her disease and partly from what I’ve learned from mine.”

*Major Theme #6—Coping strategies*

“I have found that I have a number of things that help me to cope with life’s challenges. Specifically, I rely on my humor, my spirituality, the support from my family, and my inner belief that I’m a really, really strong person.”

*Major Theme #7—Coping with stress*

“Dealing with cancer treatments and feeling bad afterwards causes me stress at times. Sometimes I’m too tired or don’t feel well enough to do the things I know they want me to do.”

*Major Theme #8—Maintaining control*

“I believe the control that I have is taking care of myself as much as I can. In the end I do want control over the treatment that I have. But I also know that if my cancer comes back, I’ve learned to let go of the things that I cannot control.”

*Major Theme #9—Spirituality and faith*

“I use my religious faith to help me cope with cancer and have probably relied on my faith throughout my life whenever I had something go wrong. Lately, I’ve tried not to depend on faith only when there’s something wrong in my life but I think I’ve tried to keep faith and religion as a central focus in everything I do.”

*Major Theme #10—Sexuality and cancer*

(Table 10 cont.)

“I feel great as a woman except for the changes brought about by my treatments that have affected sexuality. I see that as a big challenge for me as a woman. Sex and sexuality are problems that I think I will continue to deal with as I go through treatment.”

*Major Theme #11—Support from family and friends*

“To have cancer and to have so much support makes me humbled by the whole experience. It just shows how much people care.”

*Major Theme #12—Physical impact of cancer*

“When I think of receiving 24 treatments, I think to myself, how much do I have to take? How long is this going to last?”

*Major Theme #13—Normalcy and routine*

“I continue on with my life. To continue getting up and doing my normal routine. Taking a bath and getting dressed. Those things became very important to me.”

---

***Table of Themes***

Following an IPA approach, themes are further evaluated by revisiting the transcriptions of the interviews with Cheryl. As a result, seven of the initial 13 major themes that emerged from the data were eliminated because I determined that they were not well supported by Cheryl’s transcribed words as being significant. Table 11 represents a final table of major themes supported by the themes that emerged from written assessments and the two interviews with Cheryl. Given the advanced stage of her disease, Cheryl naturally focused on mortality, death, control, spirituality, and faith.

Other major themes that remained centered on such topics as sexuality, normalcy, routine, and the physical impact of cancer.

Table 11

*Table of Themes from Case Study of Cheryl*

---

*Mortality and death*

- Accepting the inevitability of death that comes with terminal illness
- Confronting the possibility of death
- Facing mortality

*Maintaining control*

- Maintaining control despite cancer
- Maintaining control over treatment decisions
- Giving up control of things that cannot be controlled

*Spirituality and faith*

- Cancer brings a person closer to God
- Relying on spiritual faith to cope with cancer
- Peace of mind that comes from faith
- Giving things over to God

*Sexuality and cancer*

- Changes in sexual activity due to cancer
- Impact of cancer on intimacy

*Support from family and friends*

- Importance of friendships
- Love and support from family

(Table 11 cont.)

*Physical impact of cancer*

- Changes in physical appearance due to cancer treatment
- Importance of self-care
- Challenge to endure the side effects of cancer treatment
- Importance of diet to fight cancer

*Normalcy and routine*

- Importance of a normal routine
  - Importance of feeling normal
- 

***Summary of the Case Study of Cheryl***

The seven major themes that emerged from the data in the case study of Cheryl provided the reader with insight into the perspective of a person trying to cope with an untreatable illness. Being diagnosed with cancer provided Cheryl with an opportunity to reflect on her life experiences. Given that Cheryl's disease is in an advanced stage, Cheryl shared her views on preparing for death when she stated, "For me, being realistic about my chances helps me to prepare and to prepare my loved ones for what lies ahead as much as they can be prepared." Another major theme emphasized in the interviews with Cheryl involves the impact of cancer treatment on her physical well-being. On this subject Cheryl remarked, "I've had some difficulty with body image issues during the course of my treatment. I was a lot worse before than I am now." Cheryl emphasized the importance of normalcy and routine to help her adjust to a life with cancer. Other major themes that emerged from the transcripts focus on the constructs control, support, love, sexuality, and faith.

## **Case Study of Karen**

Karen entered this study through a referral from the nurse of her medical oncologist. I found Karen to be very open to the interview process as demonstrated by her willingness to share intimate details of her cancer experience. She had received an early diagnosis of cervical cancer that was treated with surgery only. Because of her Stage I diagnosis, Karen did not have the same concerns as John or Cheryl—issues that focused on topics such as death, mortality, and quality of life at the end of life. Instead, her primary focus was on getting well quickly so she could continue to care for her two year old daughter. Another topic that was prevalent in the transcribed interviews with Karen centered on the loss of her ability to become pregnant due to the hysterectomy performed to remove cervical cancer. Karen became very emotional during the interview when she discussed not being able to have another child.

### ***Emerging Themes***

The transcripts of the interviews with Karen revealed 41 individual themes. These themes are derived from the perspective of a woman diagnosed with Stage I cervical cancer that was treated with surgery only. The themes that emerged from the data represent Karen's views on her cancer experience and the impact this event has had on her perspective on life. An important theme for Karen involved the unpredictability of cancer as she stated during the interview, "Cancer has shown me that you can do all the right things and still get the disease. I have learned to enjoy each moment of each day knowing that at any time life can throw you a big curve ball." Karen's perspective on life changed following a diagnosis of cancer as exemplified by her statement, "Surviving a big thing like cancer makes other problems much more manageable." These themes and

others that emerged from the transcripts of the interviews with Karen are documented in the following table.

Table 12

*List of Emerging Themes from Case Study of Karen*

---

- Fear of dying from cancer
- Uncertainty in life
- Unpredictability of life
- Uncertainty associated with cancer
- Losses experienced due to cancer
- Appreciation for life following cancer diagnosis
- Surviving cancer
- Fears associated with cancer
- Anxiety caused by cancer
- Coping with cancer through information
- Taking control of life
- Control over things that happen in life
- Losses from life events
- Managing stress
- Importance of relationships with co-workers
- Use of humor to cope with life's challenges
- Use of humor to cope with cancer
- The love of God
- Use of faith to cope with challenges
- Learning about cancer treatment
- Knowledge equals control
- Possibility of recurrence of cancer
- Physical changes due to cancer
- Using leisure activities as a distraction
- Realization some things cannot be controlled
- Ability to deal with adversity

(Table 12 cont.)

- Impact of cancer on self-worth
  - Learning from cancer experience
  - Surviving cancer is empowering
  - Giving up control to God
  - Using faith to cope
  - Faith strengthened by cancer
  - Comfort received by cancer
  - Impact of cancer treatment on being a woman
  - Support from family and friends
  - Love and support from others to cope with cancer
  - Importance of self-care
  - Importance of exercise
  - Benefit of exercise to recover from cancer treatment
  - Connection between diet and cancer
  - Importance of nutrition
- 

### *Connecting the Themes*

After reviewing the transcribed interviews with Karen, I began the process of organizing her words into major themes. Specifically, there were 41 individual themes that emerged from Karen's words. I further interpreted the transcripts as the individual themes were reduced to nine clusters of themes. Each group of themes represented a significant theme from the interviews with Karen. In determining the major themes from the data, I considered all the information that surfaced during the interviews with Karen. Adhering to the hermeneutic philosophy that serves as the underlying principle of the interpretative process in IPA, I attempted to understand Karen's perception of her cancer experience.

Table 13

*Clusters of Themes from Case Study of Karen*

---

*Major Theme #1*

- Anxiety caused by cancer
- Fear of dying from cancer
- Various fears associated with cancer

*Major Theme #2*

- Uncertainty in life
- Unpredictability of life
- Uncertainty associated with cancer

*Major Theme #3*

- Losses from life events
- Losses experienced due to cancer
- Physical changes due to cancer

*Major Theme #4*

- Ability to deal with adversity
- Managing stress
- Using leisure activities as a distraction
- Learning about cancer treatment
- Using humor to cope with cancer
- Using faith to cope with challenges
- Coping with cancer through information

*Major Theme #5*

- Appreciation for life following cancer diagnosis
- Learning from cancer experience
- Surviving cancer is empowering

*Major Theme #6*

- Taking control of life as much as that is possible
- Control over things that happen in life

(Table 13 cont.)

- Knowledge and experience equals control
- Realization some things cannot be controlled

*Major Theme #7*

- Using faith to cope
- Faith strengthened by cancer
- Comfort received from faith
- The love of God
- Giving up control to God

*Major Theme #8*

- Support from family and friends
- Love and support from others to cope with cancer
- Importance of relationships with co-workers

*Major Theme #9*

- Importance of self-care
- Importance of nutrition
- Importance of exercise
- Physical changes due to cancer
- Connection between diet and cancer
- Benefit of exercise to recover from cancer treatment

---

Actual quotes taken from the interviews with Karen are presented in Table 14 to reinforce the major themes that emerged from the data. Despite having an early diagnosis of cancer that required treatment with surgery only, Karen spoke about such subjects as fear, anxiety, uncertainty, and loss. Additionally, during the interviews she discussed topics that centered on coping, learning, faith, and support. Each of these

concepts represents a major theme that surfaced from a thorough review of the transcribed interviews with Karen.

Table 14

*Connection between Themes and Transcribed Statements from Case Study of Karen*

---

*Major Theme #1—Fear and anxiety*

“When I was first diagnosed I was very scared that there was a chance I might not be around to raise my daughter.”

*Major Theme #2—Uncertainty in life due to cancer*

“My cancer experience made me learn not to sweat the small stuff and I worry less about what the future holds because I know it can all change on a dime.”

*Major Theme #3—Losses because of cancer*

“My surgery left me unable to have another child and that is something I still am coping with.”

*Major Theme #4—Coping with cancer*

“Cancer has helped me to manage the rest of my life better. If I can get through cancer, I can cope with anything.”

*Major Theme #5—Learning from cancer*

“Like with any other adversity in my life, I try to learn from the experience and apply it to my life making me stronger. After my diagnosis, I appreciate my life better and wanted to become a better wife, mother and a better person – physically, mentally, and spiritually.”

*Major Theme #6—Maintaining and giving up control*

(Table 14 cont.)

“My faith is often put to the test because having faith means sometimes giving up control which is a challenge for me. Prayer helped me feel like I was doing something to help my cause, since there was very little that was in my control.”

*Major Theme #7—Faith and God*

“Cancer has strengthened my faith and reconnected me to my Catholic faith.”

*Major Theme #8—Love and support from family and friends*

“A wonderful benefit of having cancer was being reminded of all the people who love and care about me.”

*Major Theme #9—Taking care of the physical self*

“When I was first diagnosed and had surgery I felt like a sick person. Exercising again made me feel strong and healthy and I was compelled to challenge myself in ways that I hadn’t before cancer.”

---

***Table of Themes***

Adhering to the IPA process, the major themes that were initially produced from the data were reviewed to ascertain if they were well supported by the transcribed evidence. As a result, four of the original nine major themes were not included in the final table of themes as indicated in Table 15. The five remaining themes on such topics as uncertainty, learning, control, faith, and love provide insight into the manner in which Karen perceived her cancer experience.

Table 15

*Table of Themes from Case Study of Karen*

---

*Uncertainty in life due to cancer*

- Uncertainty tied to cancer
- Unpredictability of life

*Learning from cancer*

- Appreciation for life following cancer diagnosis
- Learning from cancer experience
- Surviving cancer is empowering

*Maintaining and giving up control*

- Taking control of life
- Knowledge equals control
- Control over things that happen in life
- Realization some things cannot be controlled

*Faith and God*

- Using faith to cope
- Giving up control to God
- Comfort received from faith
- Faith strengthened by cancer

*Love and support from family and friends*

- Love and support from others to cope with cancer
  - Importance of relationships with co-workers
- 

***Summary of the Case Study of Karen***

During the interviews, Karen focused on five major themes that represent diverse subjects. Specifically, she discussed the uncertainty associated with cancer following diagnosis. Karen noted, “While my oncologist told me surgery would give me a 99

percent chance of being cured, there's always that one percent chance cancer could return." Another of the major themes that emerged from Karen's transcribed words involved maintaining control when faced with the challenge cancer brings. She stated, "So while I believe my life was in control, cancer showed me just how little control I actually have. I can only control how I choose to deal with it." Faith in God and love and support from family and friends are two major themes that are consistent with what was reported in the previous case study with Cheryl.

### **Case Study of Rachel**

I was initially referred to Rachel by her medical oncologist to help her with some supportive care needs. As a physician, she was very interested in this research study and quickly agreed to participate. I conducted the initial interview with Rachel during her second chemotherapy treatment. She was highly anxious throughout the interview and appeared distracted at times due to the fact that she was receiving treatment. Rachel took anti-anxiety medication prior to the interview which helped to lower her anxiety and make the process less burdensome to her. The interview process served as a distraction from her treatment and helped her to focus attention on her supportive care needs. Because of her background as a physician, Rachel offered a unique perspective on the cancer experience. Her training in oncology as a medical resident presented a challenge as she had witnessed the pain and suffering of her patients. In addition, Rachel had served as a caregiver for her mother who died from breast cancer. These experiences left Rachel with psychological and emotional supportive care needs as she entered cancer treatment.

### *Emerging Themes*

A review of the transcripts of the interviews conducted with Rachel resulted in 42 themes emerging from the data. These themes come from the perspective of a woman diagnosed with Stage I breast cancer. Contributing to her perception of her illness was the fact that Rachel is a medical professional with training in oncology. Her medical background provided Rachel with the knowledge to fully comprehend her cancer diagnosis. However, the experience caring for cancer patients served as a reference point that made coping with cancer treatment difficult at times for Rachel as she stated in the initial interview, “At times I go back to my experience as an intern and a resident at Charity Hospital. I remember how sick many of my patients got from the chemo. I know my experience will be different but I just can’t get those thoughts out of my mind. No matter how much I try, I can’t get over that.”

With a history of cancer in her family, Rachel anticipated one day being diagnosed with cancer as indicated by her statement, “Given my family history with cancer and particularly that my mother had breast cancer and I had the gene that linked me to breast cancer, I expected to have breast cancer. There was no big surprise.” Another significant theme that emerged involved the connection between an early diagnosis and treatment outcome. On this topic, Rachel said in the initial interview, “The fact that my cancer was diagnosed at such an early time is just a miracle. The fact that I get to deal with it in the way that I’m dealing with it and not something that is much more severe, I feel like I’ve gotten all the breaks.” Table 16 has a complete list of themes that emerged from the transcribed interviews with Rachel.

Table 16

*List of Emerging Themes from Case Study of Rachel*

---

- Appreciation for life
- Receiving a early diagnosis
- Receiving a good prognosis
- Anticipating a cancer diagnosis
- Using thinking to cope
- Emotional impact of cancer
- Maintaining control over emotions
- Lack of control over events in life
- Regaining control in life
- Importance of work
- Appreciation for career
- Inability to work due to cancer treatment
- Influence of cancer on perspective
- Use of humor to cope
- Coping with challenges in life
- Coping with challenges caused by cancer
- Love from family
- Coping with cancer through faith
- Relying on faith in God
- Getting comfort from faith
- Physical impact of cancer
- Preparing for cancer treatment
- Support from family
- Physical impact of cancer treatment
- Keeping life in perspective
- Using leisure activities to relax
- Managing stress
- Spiritual belief in God
- Comfort from God's presence
- Support received from others
- Love and support from family and friends
- Interaction with others as distraction from cancer
- Love for people at work
- Importance of self-care

(Table 16 cont.)

- Importance of proper diet during cancer treatment
- Importance of self-care during cancer treatment
- Eating a proper diet
- Impact of treatment on diet
- Support from cancer survivors
- Using medication for anxiety
- Meaning of cancer
- Importance of exercise during cancer treatment

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### *Connecting the Themes*

The comprehensive review I undertook in reviewing transcribed interviews with Rachel produced ten major themes. Each of these major themes in Table 17 represents important concepts that were emphasized by Rachel during the interview process. In the case of Rachel connections between themes focused on constructs such as control, coping, meaning, love, support, faith, and spirituality. Rachel's early diagnosis was considered when I interpreted her words and assessed her perspective of her cancer experience.

Table 17

### *Clusters of Themes from Case Study of Rachel*

---

#### *Major Theme #1*

- Receiving an early diagnosis
- Receiving a good prognosis
- Anticipating a cancer diagnosis due to family history with cancer

#### *Major Theme #2*

(Table 17 cont.)

- Maintaining control over emotions

- Emotional impact of cancer

*Major Theme #3*

- Coping with challenges from cancer
- Using medication for anxiety
- Managing stress
- Using leisure activities to relax

- Coping with challenges in life
- Use of humor to cope
- Use of thinking to cope
- Coping with cancer through faith
- Preparing for cancer treatment

*Major Theme #4*

- Lack of control over events in life

- Regaining control in life

*Major Theme #5*

- Meaning of cancer
- Spiritual belief in God
- Comfort from God's presence

- Relying on faith in God
- Getting comfort from faith

*Major Theme #6*

- Support received from others
- Interaction with others as a distraction from cancer
- Support from family

- Support from cancer survivors
- Love and support from family and friends
- Love from family

*Major Theme #7*

- Influence of cancer on perspective

- Keeping life in perspective

*Major Theme #8*

(Table 17 cont.)

- Using cancer experience to benefit work
- Importance of work
- Inability to work due to cancer treatment

*Major Theme #9*

- Importance of self-care
- Importance of proper diet during cancer treatment
- Importance of self-care during cancer treatment
- Importance of exercise during cancer treatment
- Eating a proper diet
- Impact of cancer treatment on eating habits

*Major Theme #10*

- Physical impact of cancer treatment
- Physical impact of cancer

---

Adhering to IPA, I interpreted the transcribed interviews with Rachel to determine the meaning of her statements. The result of this in-depth examination was the assignment of names to the ten major themes that emerged from the data. Further, a quote was selected from Rachel's transcribed words to represent each of the major themes presented in Table 18. Rachel's background as a physician as well as her experience caring for her mother who died from cancer provided me with a contextual framework from which to interpret her statements. The major themes that emerged from the interviews with Rachel focused on a variety of topics including diagnosis, emotions, coping, control, faith, and love. At times during the interview process, she became

emotional as evidenced by some of her comments presented in Table 10. Rachel provided a unique perspective of a person who was used to taking care of others but had to adjust to a role reversal and allow others to take care of her. She expressed her thoughts and feelings clearly and without hesitation and did so in a manner that was deeply personal.

Table 18

*Connection between Themes and Transcribed Statements from Case Study of Rachel*

---

*Major Theme #1—Diagnosis of cancer*

“At first no one could figure out why I wasn’t shocked and crying. But with my family history, I really expected to be told one day that I would have breast cancer. So I was not surprised.”

*Major Theme #2—Emotional impact of cancer*

“You know you think when your hair is all shaved off you going to I’m going to look in the mirror and burst into tears, but maybe not. Maybe I will be able to deal with it and not get emotional. I don’t know yet.”

*Major Theme #3—Coping with cancer*

“I’ve tried to figure out where I stand. Analyze what the situation is. What are the options? Pick the best options but also with a lot of emotional support. And discussing all these things with the people around me; the people that matter.”

*Major Theme #4—Control and lack of control*

“So cancer has definitely opened my eyes to what I have control over and what I cannot control.”

*Major Theme #5—Faith in God*

(Table 18 cont.)

“The Lord watches over me. I believe he kept me from becoming more ill. I cannot explain why the next lady is going to be sicker than me. I don’t know why I got chosen. But knowing this strengthens my faith.”

*Major Theme #6—Support from others*

“Besides family, I’ve received support from my patients, other physicians, friends, people at work and so many others.”

*Major Theme #7—Change in perspective*

“When you have an illness like what I have, you realize that normal challenges in life aren’t as big of a deal as they may appear. A serious illness like cancer helps you to keep things in perspective.”

*Major Theme #8—Love of work*

“I love my work. I miss my work. I go on vacation and cannot wait to get back to work. I love everything about the work that I do.”

*Major Theme #9—Importance of self-care*

“Being diagnosed with cancer and going through treatment has definitely made me more aware of the need to take care of myself.”

*Major Theme #10—Physical impact of cancer treatment*

“My physical well-being is okay; however, right now I feel I’m a bit chopped up. I just have to learn to deal with that. But that will get better over time, I’m sure. I’m really not worried about it. I kind of see my physical self as being kind of like, it is what it is.”

### *Table of Themes*

Reading and rereading the transcriptions of the interviews with Rachel resulted in six of the initial ten major themes being eliminated. I concluded that Rachel's transcribed words supported the final four major themes presented in Table 19. The final table of major themes is supported by individual themes that emerged from the interviews with Rachel. The topics she emphasized focused on control, faith, support, and work. Rachel's love for her work was a reoccurring theme that surfaced throughout the interview process.

Table 19

#### *Table of Themes from Case Study of Rachel*

---

##### *Control and lack of control*

- Lack of control over events in life
- Regaining control in life

##### *Faith in God*

- Meaning of cancer
- Comfort from God's presence
- Spiritual belief in God
- Relying on faith in God

##### *Support from others*

- Support received from others
- Support from cancer survivors
- Interaction with others as a distraction from cancer
- Love and support from family and friends

##### *Love of work*

- Importance of work
  - Inability to work due to cancer treatment
  - Love for people at work
-

### *Summary of the Case Study of Rachel*

The four major themes from this case study provide insights into Rachel's experience with cancer diagnosis and treatment. Cancer presented her with an opportunity to reflect on family, work, faith, and life. Because Rachel's family history of cancer, she expected to one day have breast cancer; however, as Rachel told me, "I just didn't think I would be diagnosed so soon." Her previous experience with cancer as a medical resident and as a caregiver required that Rachel develop strategies for coping with her disease that matched her unique perspective. A major theme that emerged from the interviews with Rachel centered on her love for her family and for her work. Rachel stated, "I have a wonderful life. I have my job and my career. I have a wonderful husband, and a great 15-year old son. Even with a diagnosis of breast cancer, I couldn't feel more blessed."

### **Case Study of Barbara**

Barbara was initially referred to me by the nurse of her medical oncologist for supportive counseling following her diagnosis of Stage III breast cancer. Barbara appeared anxious when I initially interviewed her for this study. She became emotional at various times during the interview process especially when she discussed her fear of not surviving cancer. Barbara reported, "I've known people to die from cancer." Another complication for Barbara, she was diabetic and told me, "I've known people to die from diabetes also." These two potentially life-threatening illnesses have consumed her thoughts as she was focused on death and dying. As Barbara said, "The fear of dying is always in the back of my mind. Since getting diabetes, and now cancer, that thought is always on my mind." A possible explanation for the difficulty she had coping with a

diagnosis of cancer occurred when she stated, “Being diagnosed with cancer especially has made me think about death and the possibility of dying. What really concerned me about my cancer is that my cancer was diagnosed as a Stage III. My cancer was a Stage III even though it was real small, it was a Stage III. And that’s kind of serious.” For Barbara, being diagnosed with cancer was indeed a frightening experience that seemed to control every aspect of her life. As she told me, “Cancer was a big shock to me. I know I had other health issues but I never thought I’d have cancer.” It was with this insight that I interpreted the transcribed interviews with Barbara.

### *Emerging Theme*

The interpretative process that was used in the four previous case studies was applied to analyze the transcribed interviews with Barbara. Namely, the written assessments and interview transcripts were read and reread to determine the themes that were present. These individual themes were grouped together to produce major themes that represented important points that emerged during the interviews with Barbara. Direct quotes were taken from the transcripts and included as support for answering the research questions of this research study.

A total of 51 individual themes emerged from an exhaustive review of Barbara’s transcribed words. These themes were compiled into a list presented in Table 20 and provide insight into Barbara’s life and her experience with cancer. The themes that surfaced represent the perspective of a person diagnosed with Stage III breast cancer and being treated with surgery, chemotherapy, and radiation therapy. The extensive treatment regimen she was receiving indicated the advanced stage of her disease. Her seemingly phobic reaction to her cancer experience was a dominant theme throughout the list of

themes that emerged from the interviews with Barbara.

Table 20

*List of Emerging Themes from Case Study of Barbara*

---

- Possibility of death from cancer
- Fear of death and dying
- Thoughts about death
- Surviving cancer
- Understanding a cancer diagnosis
- Understanding the need for cancer treatment
- Understanding how cancer treatment works
- Physical impact of cancer treatment
- Challenge of controlling emotions
- Releasing emotions to relieve stress
- Control of events in life
- Response to cancer diagnosis
- Impact of cancer on views of control
- Managing stress from cancer
- Fear and uncertainty about cancer
- Experiences with others who have had cancer
- Learning to control fear
- Satisfaction with work
- Using humor to cope
- Using laughter to relieve stress
- Using faith to cope with life's challenges
- Psychological impact of cancer
- Emotional impact of cancer
- Learning to cope with cancer
- Facilitating coping through communication and information
- Using leisure activities to cope
- Using distractions to facilitate coping
- Being able to manage stress in life
- Relieving stress from cancer

(Table 20 cont.)

- Impact of cancer on self-worth
- Changes in self-worth due to cancer treatment
- Sense of self-worth
- Keeping a realistic perspective
- Unrealistic thoughts about cancer
- Importance of support from family
- Maintaining a positive outlook
- Importance of support from friends
- Love of family
- Love from friends
- Importance of love
- Impact cancer has on family relationships
- Change in perspective because of cancer experience
- Belief in God to comfort and heal
- Using faith to cope with illness
- Using prayer and faith to cope with cancer experience
- Impact of cancer on love and support from family
- Desire to be physically healthy following treatment
- Importance of self-care
- Impact of cancer on diet and exercise
- Importance of exercise to recover from illness
- Importance of good nutrition to combat illness

---

### *Connecting the Themes*

After conducting a thorough review of the transcribed interviews with Barbara, the next step in the process was to group individual themes into major themes. In this case, I organized Barbara's words to eight major themes. Each of these clusters of

individual themes represents an important topic covered during the interviews. In deciding on the major themes, I took into account all the background information Barbara had shared with me particularly her preoccupation with death as it related to the diagnosis and treatment of cancer. Keeping Barbara's perspective in mind helped me to focus on her intended meaning of the words she used during the interviews when connecting the individual themes.

Table 21

*Clusters of Themes from Case Study of Barbara*

---

*Major Theme #1*

- Possibility of death from cancer
- Fear of death and dying
- Fear and uncertainty about cancer
- Thoughts about death
- Surviving cancer
- Learning to control fear

*Major Theme #2*

- Emotional impact of cancer
- Challenge of controlling emotions
- Releasing emotions to relieve stress

*Major Theme #3*

- Understanding how cancer treatment works
- Understanding a cancer diagnosis
- Understanding the need for cancer treatment

*Major Theme #4*

- Managing stress from cancer
- Using leisure activities to cope
- Learning to cope with cancer
- Control of events in life
- Using distractions to facilitate coping

(Table 21 cont.)

- Using laughter to relieve stress
- Facilitating coping through communication and information

*Major Theme #5*

- Change in perspective because of cancer experience
- Changes in self-worth due to cancer treatment
- Keeping a realistic perspective
- Unrealistic thoughts about cancer
- Impact of cancer on views of control
- Response to cancer diagnosis

*Major Theme #6*

- Using faith to cope with illness
- Using prayer and faith to cope with cancer experience
- Using faith to cope with life's challenges
- Belief in God to comfort and heal

*Major Theme #7*

- Importance of support from family
- Love from family
- Maintaining a positive outlook
- Love from friends
- Importance of support from friends
- Importance of love
- Impact cancer has on family relationships

*Major Theme #8*

- Physical impact of cancer treatment
- Desire to be physically healthy following treatment
- Importance of good nutrition
- Importance of self-care

(Table 21 cont.)

- Impact of cancer on diet and exercise
  - Importance of exercise to recover from illness
- 

At this point in the interpretive process, I assigned meaning to Barbara's transcribed statements then titled each of the major themes. In Table 22, actual quotes from Barbara are presented to reinforce the major themes. Because Barbara considered her cancer diagnosis to be life-threatening, the major themes that emerged from the interview transcripts centered on such existential concerns as death, survival, and faith. The statements in Table 22 reflect the perspective of someone facing a second major illness and trying to cope with the fear of not surviving cancer.

Table 22

*Connection between Themes and Transcribed Statements from Case Study of Barbara*

---

*Major Theme #1—Fear of dying from cancer*

“The thought that I might die crosses my mind constantly. The thought that I'm going to die from the cancer is always there.”

*Major Theme #2—Emotional impact of cancer*

“My emotions have been up and down. One minute I might be jolly and happy, and the next minute I might have a crying episode where I want to cry. So my emotions have been up and down. One minute I'm okay and the next minute I might be depressed.”

*Major Theme #3—Understanding cancer diagnosis and treatment*

(Table 22 cont.)

“My doctor wants me to take the chemo treatments in case some of the cancer has spread to other parts of my body. That the chemo will kill those cells kind of relieved my mind some.”

*Major Theme #4—Coping with the impact of cancer*

“When I got cancer, it seemed as if there was this weight on my shoulders; a weight that was holding me down. I do the best I can to deal with it.”

*Major Theme #5—Changes in perspective because of cancer experience*

“I think this experience will change how I see myself. I think I will be a stronger person and I will be able to do a lot more. It’s going to make me stronger and be able to look at things from a different perspective in life.”

*Major Theme #6—Importance of faith and prayer*

“When I talk with the Lord and I think that he’s going to heal me from this. He’s not going to let me die from cancer or he’s not going to let me die from diabetes. That puts my mind at ease when I do that.”

*Major Theme #7—Love and support of family and friends*

“I’m going through a whole lot now and they know that I need their support and I need that extra love from them.”

*Major Theme #8—Impact of cancer on self-care*

“It’s very important that I take good care of myself because I only have one me. If I don’t take care of me, then there won’t be a ‘me’ anymore.”

### *Table of Themes*

Following the steps in IPA, three clusters of themes presented in Table 22 were eliminated as I concluded they were not well supported by the transcripts as rising to the level of a major theme. Based on a comprehensive review of the transcribed interviews with Barbara, the themes that dominated focused on her fear of death, changes in perspective due to cancer, faith and prayer, and love and support from family. The resulting table of major themes is supported by the individual themes that emerged from the assessment and interview process.

Table 23

#### *Table of Themes from Case Study of Barbara*

---

##### *Fear of dying from cancer*

- Possibility of death from cancer
- Fear of death and dying
- Fear and uncertainty about cancer
- Thoughts about death

##### *Understanding cancer diagnosis and treatment*

- Understanding how cancer treatment works
- Understanding a cancer diagnosis
- Understanding the need for cancer treatment

##### *Changes in perspective because of cancer experience*

- Keeping a realistic perspective
- Unrealistic thoughts about cancer
- Changes in self-worth due to cancer treatment

##### *Importance of faith and prayer*

- Using faith to cope with illness
- Using prayer and faith to cope
- Using faith to cope with life's challenges

(Table 23 cont.)

- Belief in God to comfort and heal

*Love and support of family*

- Importance of support from family
- Impact cancer has on family relationships
- Impact of cancer on love and support from family
- Importance of love from family

---

***Summary of the Case Study of Barbara***

The overarching theme for Barbara involved thoughts of death from her medical conditions. Specifically, she believed that either diabetes or cancer would take her life. Throughout the interviews with Barbara, she talked about dying from cancer. Because of the nature of the subject, an existential exploration was conducted to arrive at the meaning for Barbara of her cancer experience. It was during this point in the initial interview that she told me, “The meaning is that I have cancer, but I think I’m going to survive it and that I’m going to be alright. It’s like they caught it in time and they’re able to treat it and cure it, and like I said, I’m going to be okay.”

The change in Barbara’s perspective really became apparent toward the end of the interview process. She indicated that talking about her thoughts and feelings regarding her cancer experience helped her begin to see it differently. As Barbara said, “I think my cancer experience is going to make me see that some of the health issues people have in life can be treated. There are medicines and treatments that will make you better so you

can live a healthy normal life. I didn't really think that before being diagnosed with cancer."

### **Case Study of Susan**

Susan became a participant in this research study through a referral from the nurse of her medical oncologist. After making three attempts to interview Susan for this study, I met with her during her second chemotherapy treatment. I found her to be very forthcoming and more than willing to share intimate details of her cancer experience. Susan had received a diagnosis of Stage I breast cancer that was initially treated with surgery. Prior to being diagnosed, Susan reported having a premonition about cancer as evidenced by the statement, "Before I was diagnosed with cancer, for some reason in the back of my mind I kept thinking that something was going to happen. I just wasn't sure what would happen. At 49 years old, something was going to happen. I thought that I was going to get sick with something just like my mom did. And it happened just like I thought it would."

Because of an early diagnosis, Susan did not consider her disease to be life-threatening. As such, she talked about survival, coping, love, support, and faith. During the interviews, Susan spoke at length about topics that resonated with her positive outlook on her cancer experience as evidenced by her comment, "But my diagnosis is not a death sentence like hers was. My mom has been dead for 17 years. Back then, when a person was diagnosed with cancer, you automatically knew they were going to die from it. Now, that's not the case. There are more people surviving cancer than dying from it today. Things have changed a lot. Cancer is not a death sentence. It's not a death sentence like most people think it is."

### *Emerging Themes*

The transcripts of the interviews with Susan revealed 46 individual themes. These themes came from the perspective of a woman diagnosed with Stage I breast cancer treated with surgery, chemotherapy, and radiation therapy. The themes that emerged represent Susan's views on her cancer experience and the impact this event has had on her life. Of particular importance to Susan appeared to be the support she received from family and friends as well as from cancer survivors. In addition, Susan spoke at length about such topics as maintaining control and gaining strength from spiritual faith.

Table 24

#### *List of Emerging Themes from Case Study of Susan*

---

- Adjusting to cancer diagnosis
- Emotional impact of cancer
- Learning to cope with adversity
- Using thought to solve problems
- Support from cancer survivors
- Support from strangers
- Learning from others about cancer
- Maintaining control over life
- Adopting a positive outlook about surviving cancer
- Emotional impact of cancer treatment
- Being strong in the face of adversity
- Normal expression of emotions
- Coping with emotions due to diagnosis of cancer
- Maintaining control over emotions
- Using thought to maintain control
- Feeling out of control

(Table 24 cont.)

- Maintaining control after a diagnosis of cancer
  - Impact of cancer treatment on ability to work
  - Coping with events in life
  - Using leisure activities to cope with cancer diagnosis
  - Coping with cancer through distractions
  - Using leisure to reduce stress
  - Change in perspective due to cancer
  - Gaining strength through faith
  - Appreciation for life through faith
  - Strong faith in God
  - Importance of spiritual faith to coping with cancer
  - Financial support from family and friends
  - Emotional support from friends
  - Support from friends
  - Doubts about surviving cancer
  - Impact of cancer treatments
  - Using humor to cope with cancer treatment
  - Apply thinking to cope
  - Coping with stress caused by cancer
  - Relying on faith to cope
  - Keeping a low level of stress
  - Impact of cancer on self-worth
  - Love from family
  - Love and support from friends
  - Change in perspective regarding self-care due to cancer
  - Importance of self-care
  - Change in exercise habits due to cancer treatment
  - Changes in eating habits due to cancer treatment
  - Importance of eating healthy
-

### *Connecting the Themes*

The primary aim of this step of the interpretative process is to organize the data gathered from the interviews with Susan and make a connection between individual themes. The clustering of themes produced seven major themes grouped around concepts such as support, love, coping, control, faith, and self-care. Each of these major themes represents a significant topic discussed in detail during the interviews with Susan. In Table 25, a list of major themes that emerged from the transcribed interviews with Susan is presented.

Table 25

#### *Clusters of Themes from Case Study of Susan*

---

##### *Major Theme #1*

- Emotional impact of cancer diagnosis
- Emotional impact of cancer treatment
- Normal expression of emotions
- Maintaining control over emotions
- Coping with emotions caused by cancer

##### *Major Theme #2*

- Using prayer to relieve stress
- Coping with stress caused by cancer
- Using leisure activities to reduce stress
- Keeping a low level of stress

##### *Major Theme #3*

- Maintaining control over life
- Using thought to maintain control
- Maintaining control after cancer diagnosis

(Table 25 cont.)

- Feeling out of control

*Major Theme #4*

- Support from cancer survivors
- Support from strangers
- Learning about cancer from the experiences of others

*Major Theme #5*

- Importance of spiritual faith to coping with cancer
- Relying on faith to cope
- Appreciation for life through faith
- Gaining strength through faith
- Strong faith in God

*Major Theme #6*

- Financial support from family and friends
- Love from family
- Emotional support from friends
- Love and support from family and friends

*Major Theme #7*

- Change in perspective regarding self-care due to cancer
- Important of self-care
- Importance of eating healthy
- Change in exercise habits due to cancer treatment
- Changes in eating habits due to cancer treatment

---

An in-depth examination of the transcribed interviews with Susan resulted in the assignment of names to the seven major themes that surfaced from the data. A quote was selected from Susan's transcribed comments to support each of the major themes presented in Table 26. Susan's positive outlook on her cancer experience provided me

with a perspective from which to interpret her statements. The major themes that emerged from the interviews with Susan focused on emotions, coping, control, love, support, faith, and self-care. She shared her deeply personal thoughts throughout the interview process that gave me some insight into how she perceives herself and the world in which she lives.

Table 26

*Connection between Themes and Transcribed Statements from Case Study of Susan*

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*Major Theme #1—Emotional impact of cancer*

“When I was first told that I have cancer, I became very emotional. I sat in the parking lot at the doctor’s office for thirty minutes crying. And I haven’t cried since.”

*Major Theme #2—Coping with stress caused by cancer*

“Prayer helps me to keep my stress level down. Prayer is a good way for me to do that. My faith in God is a big influence on me and it’s something I rely on when I’m feeling stress.”

*Major Theme #3—Maintaining control*

“Things that have happened in my life like the death of close family members, my mother and my brother, and that’s how I learned to deal with things and stay in control when problems come my way.”

*Major Theme #4—Support from cancer survivors*

“People came into my life when I was diagnosed—strangers that I don’t even know that went through the same thing that I’m going through—that gave me a more positive outlook about it. They check on me on a regular basis, and just

(Table 26 cont.)

give me that support when I need it. I think that's the thing that has helped me out the most right now."

*Major Theme #5—Strength from faith*

"I think my faith makes me a stronger person because I know the strength that I have and that I get on a daily basis doesn't come from me, it's not from my friends, and it's not from my family. It's something that a person just can't give you. It comes from God."

*Major Theme #6—Love and support of family and friends*

"I probably love too much from what my children say. And I feel loved a lot."

*Major Theme #7—Changing eating and exercise habits*

"My view of my physical self has changed. I know I need to take better care of me instead of taking care of everybody else. That's what I've always done. Now it's time for me to take care of me."

---

***Table of Themes***

The process of multiple reviews of the transcriptions of the interviews with Susan resulted in three of the initial seven major themes being eliminated from the final table. I concluded that Susan's transcribed statements supported the four major themes presented in Table 27. The topics she emphasized focused on control, faith, love, and support. Susan viewed support from others as critical to helping her cope with her cancer experience. Love and support from family, friends, and complete strangers was a theme

that surfaced throughout the interviews with Susan and appeared to be significant to understanding how she copes with cancer.

Table 27

*Table of Themes from Case Study of Susan*

---

*Maintaining control*

- Maintaining control over life
- Maintaining control over emotions
- Using thought to maintain control

*Support from cancer survivors*

- Support from cancer survivors
- Support from strangers
- Learning about cancer from the experiences of others

*Strength from faith*

- Relying on faith to cope
- Gaining strength through faith
- Strong faith in God

*Love and support of family and friends*

- Financial support from family and friends
  - Emotional support from friends
  - Love and support from family and friends
- 

***Summary of the Case Study of Susan***

The dominant theme that surfaced from the transcribed interviews with Susan involved the support she received from other people in her life. Specifically, she reported

getting love and support from her children and other family members, close friends, and complete strangers who had survived cancer. Susan stated that this support made a real difference in the way she has coped with her cancer experience. She told me, “Had it not been for all the love and support I received from so many people, I’m not sure I could have dealt with this illness. I know I wouldn’t have dealt with it as well as I have.”

Susan demonstrated a positive approach to coping with cancer treatment. She seemed to be able to see it as a part of the process of dealing with a difficult situation and using the resources she has available to manage her cancer experience. The final list of themes that emerged from the transcripts is representative of a person who possessed resilience in the face of a significant life event and applied such resources as love, support, and faith to help cope with cancer.

### **Cross-case Analysis of Participants**

Adhering to Interpretative Phenomenological Analysis, I completed each of the individual case studies on all six participants before attempting a cross-case analysis. While IPA allows for flexibility in the cross-case analytical procedure, I decided to remain true to the initial intent of this approach and treat the participants as separate cases, and thus study them individually. I believed this method would result in an interpretative process that minimized the potential for researcher bias and produced a more accurate accounting of the participants’ perception of their cancer experience.

A summary of the case studies indicates the following number of individual themes that emerged from the interviews with participants: John – 49; Cheryl—66; Karen—41; Rachel—42; Barbara—51; and Susan—46. These six individual case studies resulted in a total of 295 themes. In keeping with the IPA process, the individual

themes were grouped together based on commonality that resulted in the following number of clusters for each participant: John – 9; Cheryl—13; Karen—9; Rachel—10; Barbara—8; and Susan—7. The total number of groups of themes present in the six case studies is 56. The next step in IPA involved the creation of major themes. For the participants in this study, the number of major themes that resulted includes: John – 5; Cheryl—7; Karen—5; Rachel—4; Barbara—5; and Susan—4. The total number of major themes that emerged from the six case studies is 30. The last step in IPA resulted in eight themes that comprise the master list of themes for all cases.

### *Analysis across Cases*

This study followed an individual case-study approach that started the interpretative process anew with each case. The first three steps of IPA were used to analyze the transcribed data from each participant to produce a final list of major themes. The list of major themes for each case study were blended together to form a consolidated list of themes for all cases. This process of analyzing transcribed interview data across six cases resulted in the list of major themes as represented in Table 28.

Table 28

#### *List of Major Themes from All Cases*

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##### *Case Study of John*

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Reflecting on life</li> <li>• Coping strategies</li> <li>• Self-care</li> </ul> | <ul style="list-style-type: none"> <li>• Survival, mortality, and death</li> <li>• Spirituality and existential meaning</li> </ul> |
|--|--|

##### *Case Study of Cheryl*

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li>• Mortality and death</li> </ul> | <ul style="list-style-type: none"> <li>• Maintaining control</li> </ul> |
|---|---|

(Table 28 cont.)

- Spirituality and faith
- Sexuality and cancer
- Normalcy and routine
- Physical impact of cancer
- Support from family and friends

*Case Study of Karen*

- Uncertainty in life due to cancer
- Maintaining and giving up control
- Faith and God
- Learning from cancer
- Love and support from family and friends

*Case Study of Rachel*

- Control and lack of control
- Faith in God
- Love of work
- Support from others

*Case Study of Barbara*

- Fear of dying from cancer
- Understanding cancer diagnosis and treatment
- Love and support of family
- Changes in perspective because of cancer experience
- Importance of faith and prayer

*Case Study of Susan*

- Maintaining control
- Love and support of family and friends
- Strength from faith
- Support from cancer survivors

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The major themes presented in Table 28 support a conclusion that the stage of disease has a significant influence on how individuals experience cancer. People with

advanced stage of cancer like John, Cheryl, and Barbara tend to focus on topics related to death, mortality, and survival. Individuals who have received an early cancer diagnosis like Karen, Rachel, and Susan seem to concentrate on support, control, and coping. It could be considered natural for anyone diagnosed with an advanced stage of cancer to become consumed with thoughts of death and dying. In this study, despite having Stage IV cancer, both John and Cheryl appeared to have accepted the fact that they might not survive their illness. They demonstrated an ability to remain positive about their lives at a time when they could be coming to an end.

Participants in this study reported relying on their spiritual faith to help cope with their cancer experience. This theme was discussed at length with all six participants and their comments reinforced the benefit of faith when confronted with a life-threatening event. Another theme stressed by all the participants involved the love and support they received from family and friends. Discussion of this topic with each of the participants in this study aroused strong emotions which emphasized just how important it was to have other people in their life to help them cope with the diagnosis and treatment of cancer.

#### ***Master List of Themes for All Cases***

Using the list of themes from all cases, I next created a master list. To determine which themes should be selected for the final list, I relied on the richness of the text to guide the decision-making process. Specifically, it was important that the themes were described in detail by the participants in their interviews. In addition, I placed value on how a particular theme helped to illuminate other aspects of the story. It was of particular importance that the themes were cited by more than one participant.

In Table 29, each of the master themes represents a significant topic in the cancer experiences of many of the participants in this study. Inclusion in the final list was not based solely on the number of participants reporting a particular theme; instead, a master theme designation was based on the importance I placed on a theme within the context of the overall cancer experience as reported by the study's participants. These master themes offer a perspective of how people collectively experience cancer diagnosis and treatment and the important topics that emerge.

Table 29

*Master List of Themes*

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- Facing mortality and possibility of death
  - Uncertainty about the future
  - Understanding cancer diagnosis and treatment
  - Reliance on faith and God
  - Maintaining and giving up control
  - Love and support from family
  - Physical impact of cancer
  - Importance of self-care
- 

Participants supported each of the themes presented in Table 29 with their statements during the interviews conducted in this study. In reviewing the data, I evaluated the level of importance placed by participants on the themes that emerged. With regard to mortality and the possibility of death, each participant recognized cancer

as a life-threatening illness; however, John, Cheryl, and Barbara emphasized this topic the most in their statements. These same participants regarded uncertainty about the future as critical to the coping process. For all the study's participants, understanding their diagnosis and treatment regimen was viewed as important. This topic was specifically cited by Barbara as being important to dealing with her cancer experience.

Reliance on a spiritual faith in God was emphasized by each of the participants in this study. Additionally, all six participants reported the love and support of family and friends as being important to helping them adjust to the cancer experience. Maintaining and/or giving up control was a topic cited by Cheryl, Karen, Rachel, and Susan as a major theme. The physical impact of cancer and cancer treatment and the importance of self-care were recognized by all the participants; however, John and Cheryl emphasized these themes more than the others.

In summary, themes in the master list represent topics commonly discussed by individuals following a cancer diagnosis. The life-threatening aspect of a disease such as cancer explains why people face mortality and death during cancer treatment. The possibility of recurrence of disease following treatment leads many people to report uncertainty about the future. An initial diagnosis of cancer represents a new experience that facilitates a need for greater understanding about the disease. For many people, cancer is a challenge that is best dealt with through a reliance on spiritual faith. Maintaining control of thoughts and emotions is another theme commonly expressed. Love and support of family and friends is seen as important to coping with the diagnosis and treatment of cancer. Physical demands of cancer are apparent as individuals seek to find ways to deal with the symptoms of their disease and the side effects of treatment.

The physical impact of cancer leads many people to realize the importance of self-care through proper nutrition and exercise. Collectively, the themes in the final table present a picture of how people cope with cancer and the lasting impact of their experiences.

### **Findings by Research Question**

The process of collecting and analyzing data was conducted with the purpose of answering primary and secondary research questions. This research study focused on how people experience cancer treatment by comprehensively exploring the question, “What are the perceived supportive care needs of patients during cancer treatment?”

Additional research questions investigated in this study were:

1. How do patients perceive their supportive care needs after at least one month of cancer treatment?
2. What instrument and/or strategy can be developed for use in outpatient cancer clinics to holistically assess the perceived supportive care needs of patients entering treatment?
3. How can the wellness model used by counselors be applied to help individuals diagnosed with cancer?

Each of the research questions were answered with data collected from the interviews. As previously noted, transcriptions of interviews were interpreted to specifically address the primary and secondary questions of this study.

#### ***Primary Research Question: What Are the Perceived Supportive Care Needs of Patients during Cancer Treatment?***

To answer this question, I holistically assessed the full range of needs by interpreting the transcribed words of the participants from the initial interviews. Based

on the transcriptions, participants reported their perceived supportive care needs as indicated in Table 30. Specifically, participants all reported having physical needs; however, they stated the degree of need differed according to the amount of treatment they received. Given that they are confronted with a medical condition, this would obviously be a concern for the participants.

Another supportive care need reported by a majority of participants in this study involved psychosocial distress. The domain of psychosocial need includes a combination of psychological, emotional, and social support needs. Four of the participants indicated experiencing psychosocial concerns following the diagnosis of cancer that was manifested in a number of ways including depression, anxiety, emotional stress, and physical symptoms. According to what was reported by each, their psychosocial concerns continued as they entered treatment representing a significant need that required assessment and intervention.

Three out of the six participants expressed having a supportive care need that involved one of the following domains: communication/information, occupation/work-related, finances, and spiritual faith. Participants who had limited resources and who were unemployed before treatment expressed having financial needs. Individuals who had worked before being diagnosed with cancer reported having an occupational/work-related need.

Participants concerned with the manner in which important information was communicated to them expressed having a supportive care need that involved communication and/or information. The participants who were diagnosed with advanced stage of disease indicated having a supportive care need that is spiritual or existential.

One person reported a sexual/intimacy need. None of the participants indicated having cultural or gender-based needs.

Table 30

*Domains of Supportive Care Needs Reported by Participants during Initial Interview*

Supportive Care Needs	John	Cheryl	Karen	Rachel	Barbara	Susan
Physical	X	X	X	X	X	X
Psychosocial		X	X	X	X	
Communication/Information	X		X		X	
Occupational/Work-Related		X	X	X		
Financial	X				X	X
Sexual/Intimacy		X				
Cultural/Gender						
Spiritual/Existential	X	X			X	

In answering the primary question of this research study, it is important to note that people experience cancer in their own unique way. Because people respond to cancer treatment individualistically, the supportive care needs of patients as reported by the participants in this study represent their perceptions only. However, conclusions can be drawn from participant statements as being indicative of individuals undergoing cancer treatment. A further explanation of the participants' perceptions on each domain of supportive care need follows.

### *Physical Needs*

The physical needs reported by the study's participants varied in type and scope. Namely, the participants were impacted in different ways by the physical symptoms of cancer itself and the side effects of cancer treatment. John reported having concerns with pain and the way in which it had been managed by his doctor during treatment. He stated in his initial interview, "I can handle it [cancer treatment] until the point when I get in pain. When I get into pain, it's a totally different thing. I really want my doctor to make me pain free so I can take my treatments."

Fatigue was another side effect of cancer treatment reported by the study's participants. Rachel told me during her treatment: "Cancer has altered one aspect of control in my life. My physical ability and stamina has been affected by the cancer treatment. This has taken a lot out of me. Physically and emotionally, I am drained." The other participants made similar statements finding pain and/or fatigue to be significant challenges for them to overcome.

All participants in this study stated having some level of physical need during treatment. The primary difference was the degree of need that was present. For Karen, her physical need involved recovery from surgery. She reported during the initial interview: "Following surgery, I felt like my body was very fragile because I couldn't do normal things. After awhile, I got better physically and could function normally again."

The findings of this study with regard to physical need seem to coincide with the conclusions reached in previous research by Newell et. al. (1999) that found pain, fatigue, nausea, and hair loss were the most frequently reported symptoms of cancer treatment. Each of the study's participants indicated possessing at least one of these common

symptoms at some point in the first month of treatment. In every case except with John, the physical need was addressed and resolved either by the medical team's efforts or through the attitude of the patient. As Susan stated, "It's physically challenging to get through the treatments, but I know I must. Even though I'm worn down at times, I've learned how to deal with it and do the best I can."

### ***Psychosocial Needs***

The psychosocial needs of cancer patients are divided into three separate but interrelated needs—psychological, emotional, and social support—that can have a significant impact on how individuals experience cancer. In this study, psychosocial concerns were reported by five of the six participants with the type and degree of need unique to each person. Psychosocial needs were manifested in a number of ways including psychological disorders such as depression and anxiety, emotional disturbances, and interpersonal relationships with family and friends. All participants reported having some degree of psychosocial distress following their cancer diagnosis. Two individuals—John and Susan—indicated their psychological and/or emotional challenges did not rise to the level of an actual "need" and they reported being able to find ways to cope with this aspect of their cancer experience.

The other four participants in this study presented with psychosocial concerns that they considered to be a need and required outside intervention in the form of medication and/or talk therapy to enable them to cope. The psychosocial distress felt by several of the study's participants seemed to relate to the psychological and emotional challenge of dealing with a life-threatening illness. During the interviews with Karen, she addressed

this topic in an emotional manner: “I have been extremely afraid of the unknown, scared of surgery, terrified of dying, sad thinking about not seeing my daughter grow up.”

Barbara expressed in the initial interview having a reoccurring fear of dying that seemed real to her. She further reported having difficulty controlling her thoughts and emotions related to death and the possibility of dying from cancer. Her reaction to being diagnosed with cancer was extreme as demonstrated by her comment:

My doctor told me she got all the cancer out. But back in the back of my mind, I still have that thought about dying. The thought of dying has just stuck in my mind. Even though they said they caught mine when it was very small, I still think the cancer might spread to some other place on my body. Cancer has always been one of my worst fears. I’ve always feared cancer. That’s one of the things that I’ve asked the Lord, please don’t let me have cancer.

Despite having been trained in treating patients with cancer, Rachel acknowledged her psychosocial needs and periodically relied on prescription medication to relieve situational anxiety. Shortly after being diagnosed with Stage IV ovarian cancer, Cheryl began to question whether she was going to die from cancer which led to her developing a psychosocial need. During the initial interview, she told me, “Not all the time do I feel like I’m going to survive cancer. Some days I just have this overwhelming feeling that maybe I won’t make it. I struggle everyday with these doubts.”

The need for social support is important to coping with the demands of cancer treatment. The participants in this study agreed that family and friends played a big role

in helping them with their cancer experience. Participants reported relying on the love and support of family after they were diagnosed and continued to depend on that support as they underwent cancer treatment. All participants expressed having some degree of social support need; however, none of the participants were able to quantify the amount of need present. As Karen put it, “I depend on my family for support during my cancer treatment. I cannot tell you how much, but it’s a lot. I guess you could say I need the support I receive from my family and friends to cope with what I’m going through. I just couldn’t begin to say how much.”

### ***Communication and Informational Needs***

With regard to information, the participants in this study differed in the type and amount they needed to make treatment decisions and to feel comfortable with their care. Additionally, participants reported acquiring information from a variety of sources including medical professionals, cancer survivors, written materials, and the Internet. Participants who recognized the value of fulfilling an informational need were John and Karen. When John was initially interviewed, he discussed the need to be informed about his cancer diagnosis and treatment options. John reported, “With regard to cancer, I’m still trying to get enough information on my illness specifically before I’ll be comfortable knowing what I need to know.” John indicated he struggled with learning everything he could to make the best treatment decisions.

During the first interview, Karen stated, “When I first learned about my cancer everything the doctor was saying to me was foreign and very frightening. Becoming knowledgeable [about cancer] gave me a feeling of control over the situation.” Rachel affirmed what John and Karen reported regarding the importance of information. As a

physician, she realized the need to share information with her patients. As a cancer patient, Rachel stated, “When I don’t have enough information at hand to understand what I’m dealing with, then I have trouble. As long as I get the information I need, then I’m okay.”

According to the study’s participants, the manner in which their doctor conveyed information on critical topics such as diagnosis, disease staging, and treatment planning was instrumental in addressing their communication needs. Except for John, all the participants reported being satisfied with the level of communication they received from their cancer care team at the research site. John indicated that cultural differences made it difficult for him to communicate with his medical oncologist who was from a foreign country. Barbara discussed the benefit of communicating with other individuals who have experienced cancer. She stated, “It’s helpful to talk with someone who’s been through what you’re going through.” The communication needs of this study’s participants were fulfilled in a variety of ways. This study showed that every person is unique in how much information is appropriate and in how that information should be communicated.

### ***Financial Needs***

Financial needs can arise from the high cost of medical treatment, prescription medication, and other health support needs that are not covered by insurance and/or go beyond an individual’s income level. The financial needs of the participants in this study were directly influenced by their socioeconomic status prior to being diagnosed with cancer. The three participants—John, Barbara, and Susan—who reported an annual income at or below the poverty level indicated having a significant financial need.

According to all three, having to undergo cancer treatment made it difficult to work which further exacerbated an already difficult financial situation. Each of them reported that the loss of their ability to earn income made their financial outlook seem uncertain. Susan stated in the first interview, “I depend on my family and friends for a lot of things. Right now, they help me financially with my bills which takes some of the stress off of me.” The stress caused by unmet financial needs had additional repercussions on the overall well being of John, Barbara, and Susan as they experienced cancer treatment.

### ***Occupational and Work-related Needs***

The need to remain connected to work and co-workers was cited as important by three participants in this study—Cheryl, Karen, and Rachel—who reported having extensive careers in their chosen fields. Each participant reported having different needs with regard to work. Cheryl indicated her self-worth was tied to closely to the work she did as a marketing executive. She stated, “I lost my work. That was a big part of my life before becoming ill.” Because of cancer Cheryl can no longer work; however, she reported, “I’ve had to find other ways to keep myself busy.”

Karen indicated that she decided not to go back to work after her cancer treatment to remain at home to raise her child. She reported missing the connection she had with co-workers, “I miss the interaction with other people. That’s a loss for me in that I was very close to many of the people I worked with. I really miss those people.”

Rachel planned to return to her career as a physician once she completed cancer treatment. She reported being away from work had made her miss everything about it: “I miss my work. I miss interacting with my patients and taking care of them. I miss it terribly.” The findings of this study followed a logical progression in that individuals

who were closely connected to their occupations were more likely to experience a work-related need.

### *Sexual and Intimacy Needs*

The three married women—Cheryl, Karen, and Rachel—interviewed for this study reported some degree of sexual and/or intimacy need. Cheryl had difficulty coping with the changes to her sexual health because of the treatments she received for ovarian cancer. She stated during the first interview, “I miss being able to have normal sex. It’s hard at times to deal with this aspect of our marriage.”

Karen received surgery to treat her cervical cancer and discussed the loss to her sexual health tied to an inability to get pregnant, “After surgery, I didn’t feel much like a woman. I felt an important part of my sexuality—my ability to have a child—had been removed.” Rachel talked about the changes in her appearance because of the side effects of the surgery and chemotherapy used to treat her breast cancer. She reported, “I have a wonderful husband and our sex life is good. Even so, I did get stressed out about the changes in my appearance. I still want to be attractive to him, and I want to feel attractive. I don’t want cancer to have an effect on our relationship and our intimacy. That part is too important.”

The symptoms and side effects of cancer treatment resulting in sexual and intimacy needs can be devastating especially to women. Participants in this study reported physical changes because of cancer that impacted their sexuality ranged from disfigurement from surgery to self-consciousness associated with changes in appearance caused by chemotherapy.

Sexual and intimacy needs expressed by participants varied from extreme psychosocial distress connected to an inability to have sexual intercourse to moderate grief due to the loss of the ability to conceive children to mild stress associated with learning to live with changes in appearance. Three female participants discussed needs that involved their sexual health. Each person emphasized the importance of finding resolution to their sexual and intimacy concerns as a way of regaining a sense of normalcy in their life and helping them to once again feel like a woman. John, the only male participant in this study, did not report having a sexual or intimacy concern and made no comment on this domain of need.

### ***Cultural and Gender Needs***

Cultural and gender needs were discussed with the participants of this study; however, they all responded that this domain of need was not relevant to their current situation. The African American participants in this study all reported that culture was important to them in their daily lives but that it did not seem relevant to their experience as cancer patients. As John stated, “My culture as a black man is important to me, but I don’t think culture has anything to do with cancer. As far as I’m concerned, we’re all in this together. And I think my doctors recognize this too.”

Barbara reported, “I don’t think I have a cultural need as a person with cancer. I feel my doctor and nurse and everyone else have been sensitive to who I am as an African American woman. I’m sure I would feel different if that wasn’t the case.”

During their cancer experience, none of the participants in this study reported having supportive care needs that they believed to be directly related to their gender. Cheryl stated, “I have had difficulty feeling much like a woman after all my treatments.

The surgery and then all the chemo treatments have made it hard to identify with being a woman. But I still don't see it as a particular need.”

Karen, another participant who felt a significant loss associated with her cancer treatment, reported, “I lost my chance of having another child; however, that didn't make me feel less of a woman. I suppose someone else might feel differently. I just didn't see it as a need that's gender-related.”

### *Spiritual and Existential Needs*

This study found spirituality and existential awareness is important to cancer patients, particularly those individuals with a late stage diagnosis. The three participants in this study with advanced disease—John, Cheryl, and Barbara—reported having spiritual and/or existential needs as they began their cancer treatment. John seemed to find some existential insight by discussing the possibility his cancer could result in death when he stated, “I used to have the attitude that I would live forever. I think I believed that I'd never die. Cancer made me think about life differently. I realize now I'm going to die one day.” Barbara, another participant with advanced stage of disease, observed, “It [cancer] seems as though it took a part of my life away from me. It took the part of me that believed I would live a long life.”

During the interviews, Cheryl reported her diagnosis of Stage IV ovarian cancer made her rethink her relationship with God calling into question her spiritual faith. She told me, “Whatever it is about cancer, it seems a person's faith in God is either strengthened or challenged because of their experience with cancer. For me, I questioned God's purpose for allowing me to be diagnosed with cancer. I still struggle at times trying to find the answer.”

***Research Subquestion #1: How Do Patients Perceive Their Supportive Care Needs  
after at Least One Month of Cancer Treatment?***

To answer this question, the participants were interviewed for a second time after they completed one month of cancer treatment. The interview followed a structured format (see Appendix L) as a way of standardizing the results. An assessment instrument (see Appendix K) was developed specifically for this study and administered to participants prior to conducting the interview. Results of the assessment and interview process were interpreted with a comparison of similarities and differences made among participants to arrive at the answer to this research question.

Table 31

*Domains of Supportive Care Needs Reported by Participants during Follow-up Interview*

Supportive Care Needs	John	Cheryl	Karen	Rachel	Barbara	Susan
Physical	X	X		X	X	X
Psychosocial		X			X	
(Table 29 cont.)						
Communication/Information	X					
Occupational/Work-Related						
Financial	X				X	X
Sexual/Intimacy		X				
Cultural/Gender						
Spiritual/Existential	X	X			X	

Table 31 presents a summary of supportive care needs reported by the study's participants through the follow-up interview and written assessment. Compared to the results of the initial interview presented in Table 30, the supportive care needs perceived by the participants is reduced; however, a significant number of needs remained. The physical demands of cancer continued to be present one month into treatment for five of the six participants in this study. The only person not to report a physical need was treated with surgery only and did not receive chemotherapy. This study found that physical needs are present in individuals as long as they are actively receiving treatment.

Psychosocial needs were reported by five of the participants during the initial interview. Over the course of the first month of treatment, psychosocial distress was addressed by applying the appropriate intervention strategy—psychotropic medication, talk therapy, support group therapy, or some combination. The reduction in the number of participants reporting a psychosocial indicates a lower level of anxiety due in part to a familiarity with the treatment process. Several participants reported after one month of treatment they were less anxious because they knew what to expect. This is seen as a natural part of the process that cancer patients experience during treatment.

Other domains of need were addressed over the first month of treatment. Specifically, a number of the participants' supportive care needs reported when they entered cancer treatment were met. Communication and information needs were fulfilled as participants gained experience receiving treatments for their cancer. All participants reported getting their treatment-related questions answered by their medical oncologist. More important to the participants, the manner in which the information was delivered relieved their concerns and satisfied this particular domain of need.

According to the findings from the first interview with participants, occupational/work-related needs were most relevant to persons who are employed when entering their cancer experience and intend to return to their job once they complete active treatment and are physically able to work. Only one participant in this study—Rachel—reported a desire to return to work following the completion of treatment. One month into treatment, Rachel reported her work-related need fulfilled due largely to the realization that she will be able to return to her position as a physician and once again be able to help her patients.

Participants who believed they had sufficient financial resources when entering treatment continued reporting having no financial need present. For participants who came into cancer treatment unemployed and/or with limited resources, financial needs remained unmet. This result indicates that financial concerns are not resolved in one month and likely continue throughout cancer treatment and beyond. With limited financial resources available, people undergoing cancer treatment have few short-term options for addressing this domain of need. For people actively receiving cancer treatment and trying to adjust to changes in their physical wellbeing, the prospect of resolving financial needs is further complicated by an inability to earn income through work. As a result, financial needs are not easily addressed for those experiencing cancer treatments.

For the three participants who reported a spiritual and/or existential need during the initial interview, this need continued one month into treatment. The spiritual/existential need remaining unfulfilled is likely a result of the life-threatening nature of a late stage diagnosis. For participants in this study, finding answers to spiritual

and existential questions was difficult as these are complex needs that require introspective examination—a process that is not easy to undertake given the physical, psychological, and emotional demands of cancer treatment.

Cultural and gender needs was a domain of need that was not reported by any of the participants during the initial interview. This continued in the follow up interview as none of the participants reported having a cultural or gender-related need. This finding likely means that culture and gender needs are viewed by the study's participants as being either irrelevant or unimportant to individuals diagnosed and treated for cancer.

In conclusion, the first month of cancer treatment is a time when uncertainty is reduced as people develop some knowledge about what to expect. Several commonly reported domains of supportive care need involving information and psychosocial distress seem to naturally be resolved through the course of treatment. Other supportive care needs centered on the physical, financial, or spiritual are not as easily addressed because of the complexity of the situation. Physical needs are directly related to the extensiveness of the treatment regimen. Patients who undergo more involved treatments with a variety of modalities report having significant physical needs. People who lack employment and/or financial resources when entering cancer treatment have a higher frequency of reporting a financial need. These individuals report difficulty in finding a suitable resolution to their financial situation leading to an increased potential for psychosocial distress to be present over the course of treatment. Spiritual and existential concerns are most prevalent in individuals diagnosed with late-stage cancer. These needs do not subside after one month of treatment as people often struggle to find meaning to their experience and seek ways to use faith to help them cope with cancer.

***Research Subquestion #2: What Instrument and/or Strategy Can Be Developed for Use in Outpatient Cancer Clinics to Holistically Assess the Perceived Supportive Care***

***Needs of Patients Entering Treatment?***

The development of an assessment strategy designed to holistically examine the perceived supportive care needs of cancer patients early in the treatment process is critical for outpatient clinics if they are to provide a high quality of cancer care. For this study, I created an assessment instrument (see Appendix K) and a structured interview protocol (see Appendix L) based on the initial interviews with participants. I included in the assessment process eight domains of need that were reported as important by the participants in this study. The participants were asked to respond to each of the items included on the assessment instrument by indicating the appropriate answer on a scale from one to ten. Each domain of supportive care need had three questions. Chart 4 represents an example of one of needs included in the assessment instrument.

Chart 4

***A Domain of Need on the Supportive Care Needs Assessment***

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**Psychosocial needs:** Psychological and emotional concerns are a common and prevalent aspect of cancer diagnosis and treatment. Psychosocial needs are associated with degrees of emotional and psychological distress (e.g., depression, anxiety) or limitations on emotional functioning.

Rate your psychological and emotional needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your psychological and emotional needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your psychosocial needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

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the perceived supportive care needs of cancer patients. The downside to using this strategy is that it is harder to analyze the results among participants. By adhering to a structured approach—as was followed in the second round of interviews—the questions are standardized resulting in data that is more easily interpreted and analyzed across cases. The strategy that was used in this study promoted the discovery of new insights into the cancer experience; however, the lack of a standardized approach to data collection made it difficult to interpret findings that are conclusive.

For the purpose of answering this research question, it is important to acknowledge that everyone is unique in how they experience an event, especially one that involves the diagnosis of a life-threatening disease such as cancer. The development of a strategy and/or instrument for use in an outpatient cancer clinic to holistically assess the perceived supportive care needs of patients entering treatment must take into account the individualistic nature of the cancer experience. A one-size-fits-all approach to assessment could reduce effectiveness. Instead, an assessment strategy that can be adapted to the individual needs of patients might produce better outcomes. Additionally, a number of factors should be considered in the design of an assessment strategy including barriers related to language, ethnic and cultural backgrounds, and educational level of patients.

***Research Subquestion #3: How Can the Wellness Model Used by Counselors Be Applied to Help Individuals Diagnosed with Cancer?***

This study sought to answer this research question by applying the wellness model to a situation in which individuals are attempting to cope with a life-threatening medical condition. The 17 factors of wellness from the *IS-Wel* (Witmer, et. al., 1998)

were used, generally, as a guide for discussing the cancer experience of the study's participants, and specifically, as a format for identifying the perceived supportive care needs of individuals diagnosed and treated for cancer.

Table 32

*Wellness Factors Reported by Participants as Important to Coping*

Wellness Factors	John	Cheryl	Karen	Rachel	Barbara	Susan
Thinking			X	X		X
Emotions	X	X			X	
Control		X	X	X	X	X
Work				X		
Positive Humor		X	X	X		X
Leisure			X	X		
Stress Management	X	X	X	X	X	X
Self-Worth		X				
Realistic Beliefs	X		X			
Friendship		X	X	X		X
Love	X	X	X	X		X
Spirituality	X	X	X	X	X	X
Gender/Cultural Identity						
Self-Care	X	X	X	X	X	X
Exercise			X	X	X	
Nutrition	X	X			X	

This study found that 15 of the 17 wellness factors had some degree relevance, and could be considered important to a person trying to cope with cancer. The two factors of the wellness model that did not seem to apply were gender and cultural identity. Based on transcribed statements, participants found these two factors lacking relevance to their cancer experience. The remaining 15 factors of wellness seemed to be well suited for examining how individuals cope with cancer diagnosis and treatment. Table 32 highlights the wellness factors that participants reported as important to the coping process.

The factors of wellness that most resonated with the study's participants were stress management, spirituality, and self-care. All six participants acknowledged the importance of these factors in helping them cope with cancer. Each of the participants viewed their cancer experience as stressful and therefore, they were consciously seeking out ways to manage stress during treatment. Because each of the participants reported having a strong faith in God prior to being diagnosed with cancer, it makes sense that they would acknowledge the importance of spirituality. Regarding self-care, the study's participants recognized that cancer was a challenge to their physical health and as such, reported having a strong desire to take better care of themselves during treatment and beyond.

Five out of the six participants reported the wellness factors of control and love as being important. For these individuals, cancer had taken away the sense of control they felt about their life prior to being diagnosed. Further, they stated that control was a critical element in their decision-making with regard to treatment planning. Each of these participants desired to maintain control over care-related decisions. Nearly every

participant indicated the wellness factor “love” was absolutely vital to overcoming the challenges they faced throughout their cancer experience. According to the participants, love from family members and close friends helped in easing the burdens of cancer and reminded them that they were not alone when experiencing cancer treatment.

Other wellness factors that were believed to be important to several of the study’s participants were friendship, positive humor, exercise, and nutrition. With regard to friendship, four of the participants indicated that close friends played a big role in helping them cope with cancer. Positive humor was reported by four participants as being beneficial to relieving stress and anxiety. Exercise and nutrition were seen as important; however, it is my belief that the participants considered these two wellness factors to be under the broader factor of self-care and therefore, did not report it separately. All the participants indicated that taking care of their bodies took on greater importance following a diagnosis of cancer.

The study’s participants considered “thinking” and “emotions” as separate approaches to dealing with a life event such as cancer diagnosis and treatment. Therefore, the participants reported one or the other as predominately their way of coping. Some of the other factors of wellness—leisure, realistic beliefs, work, and self-worth—were reported by only one or two of the participants which it could be concluded that they were seen as unimportant given the magnitude of the cancer experience. The last two factors—cultural identity and gender identity—were not reported by any of the participants possibly indicating a lack of relevance to the research topic.

Overall, the majority of wellness factors seemed relevant to someone experiencing diagnosis and treatment for cancer. Counselors and other clinical mental

health professionals can use the wellness model as a structured approach for assessing the coping skills of cancer patients. Through an interview and written assessment process, this model can be applied to help people gain insight into their ability to adjust to cancer and develop new ways for coping with a life-threatening illness. While some of the factors did not seem to resonate with the study's participants, overall the wellness model seemed an appropriate approach to follow for assessing the perceived supportive care needs of cancer patients as it relates to their ability to cope with their disease.

### *Thinking*

The manner in which cancer patients think seems to have a big influence on how they handle their cancer experience. In the case of the participants in this study, the cognitive processes varied from thoughts that helped with coping to obsessive thoughts about the possibility of death. For example, Barbara chose to use her thought processes to help her realize the benefits of chemotherapy treatment. She said to me during the second interview, "I was thinking that if it kills the cancer in my breast and the chemo travels all through the bloodstream so if some of the cancer cells spread the chemo would destroy those cells."

Thought control was another technique participants used to keep from dwelling on their illness. John reported, "With regard to my cancer, doing things that don't involve thinking about my condition helps divert my thinking so I don't dwell on it. As far as I'm concerned, since I was diagnosed with cancer, it's never that far from my mind." Additionally, Karen reported, "While cancer will always be something I think about, I don't dwell on it. I am fortunate to have had a treatable cancer caught in a very early stage." Cheryl relied on thinking to help her comply with cancer treatment. She

stated, “And then my thinking takes over; my logical self takes control and I’m able to go to my treatments.” Susan acknowledged the presence of cancer in her thought process when she stated, “I always think about what I’m going through with cancer. Lately, I’ve been thinking about it more. I don’t know why.” For individuals experiencing cancer diagnosis and treatment, it appears difficult for them not to think about it.

Given that people experience cancer in their own unique way, it is not surprising that they would think differently about it too. While all the participants reported using thinking, Karen, Rachel, and Susan expressed a reliance on cognition to help them deal with their cancer experience. The results of this study concur with previous research (Antoni et al., 2006; Arora et al., 2007) that found cancer patients who engage in positive thought processes better adapt to their cancer experience as evidence by an ability to engage in problem-solving behavior and maintain emotional control.

### ***Emotions***

While all the participants in this study demonstrated emotional responses during the interview process, John, Cheryl, and Barbara openly expressed their feelings. In talking about their cancer experience during the interview process, these participants seemed to use emotions to reduce stress and promote psychological adjustment. Barbara reported the expression of emotions was a stress-release. She stated, “When I cry I release some of my emotions and I feel better. It relieves some of my stress that I’m feeling. I feel better for awhile and it allows me to think about something else.” Cheryl discussed the valuable role family and friends play in facilitating emotional expression. “I get a lot of emotional support from my close friends. If I feel like I need to talk, I can call them anytime. Whether it is morning, noon, or night, I can call anyone of them and

talk about what I'm going through. It really helps to get my feelings out and not let it build up inside." Rachel recognized the importance of controlling emotions through the use of cognitions when she stated, "I'm a very emotional person normally. I maintain control over my emotions by balancing my thoughts and not focusing on anything negative."

The comments of the participants on the subject of emotions confirm the findings of other studies (Classen, Koopman, Angell, & Spiegel, 1996; Quartana, Laubmeier, & Zakowski, 2006) that concluded the positive expression of emotions appears to lower psychological distress and improve psychological adjustment. The research supports the conclusion that emotional expression is important to the adjustment process for individuals diagnosed with cancer. This study showed the participants with an advanced stage of disease—John, Cheryl, and Barbara—focused on their feelings more than individuals with an early-stage cancer diagnosis who relied on thoughts.

### ***Control***

When discussing this wellness factor, Barbara indicated that the diagnosis of a life-threatening disease like cancer altered her perspective on how much control she actually has in her life. She stated, "Cancer made me feel that I really don't have any control over my life." Karen shared similar thoughts when she said, "So while I believe I have much control [over my life], there will always be things out of my control. And for those events, I can only control how I handle them as well as my reaction to them." As previous research (McIllmurray et al., 2001) concluded, this study found that maintaining a sense of control was important for people with cancer.

The cancer experience for several of the participants seemed to promote a new perspective on control as it relates to life. John reported his view of control had changed because of cancer with his statement, “My way of coping with things is to first look at the situation, accepting it for what it is, and just taking things one by one, day by day.” Rachel cited both cancer and another major life event—Hurricane Katrina—as examples of what little control individuals have over their life. During the interview, she said to me, “Between Katrina and cancer, I guess I don’t have much control over what happens to me. But overall, I believe I have control over how I react to them.” For Susan, cancer changed her view of control: “Now I think about how I’m in control of how I feel and how I think about cancer. I think about cancer different than I used to think about cancer. So I try to be aware and stay in control of my moods more now than before I was diagnosed.” Control for Barbara involved confronting her thoughts about dying from cancer. She told me during the second interview, “I know this fear may never go away, but I’ve got to learn to control it though. I want to learn to control my fear of dying so that it doesn’t interfere with my daily life.”

### ***Work***

Work is a factor in the lives of many people and the ability to work is often compromised by the side effects of cancer treatment. In this study, all six participants did not work while receiving treatment. Of the participants, only one individual—Rachel—was employed prior to being diagnosed; the other participants were unemployed or, like Karen, chose not to return to work. Four participants in this study—John, Cheryl, Barbara, and Susan—were considered disabled at the time they were interviewed so they were not able to return to work.

The impact of the cancer experience with regard to work varied. John reported missing being at work because it made him feel productive. Karen stated, “I miss the interaction with other people. That’s a loss for me in that I was very close to many of the people I worked with. I really miss those people.” Susan reported cancer caused her to reconsider the type of work she had been doing. Susan decided to change jobs when she is once again able to work. Rachel discussed the important lessons she learned from her cancer experience that can be applied to her work as a physician. During the second interview, she told me, “Every experience I have in some way helps me in my work. I can now say to my patients that I’ve been there and I know what you’re going to go through and this is it.”

### ***Positive Humor***

Results of this study concurred with the findings of previous research (Christie & Moore, 2005; Erdman, 1991) that concluded humor and laughter have a positive benefit for people experiencing cancer. A common theme reported by most of the participants in this study was the difficulty of actually laughing again following the diagnosis of their disease. As Karen stated, “I didn’t find much to laugh about at all in the beginning, but after a few months humor really helped ease the tension that was in the air when I spoke to friends and family about my disease.”

Despite the fact that it was hard to find humor, all the participants recognized the value in laughter, especially when facing a challenging life event like cancer. Cheryl may have said it best when she told me, “It’s hard to describe and if you’ve never had cancer you likely wouldn’t understand but sometimes you just have to find the humor in it.”

### ***Leisure***

Leisure activities were reported by the participants in this study as being helpful in reducing the stress brought on by the diagnosis and treatment of cancer. While none of the participants cited leisure as critical to coping, each of them reported that it was important to “keep busy.” Karen and Rachel indicated participating in leisure activities served as a distraction from thinking about their medical condition. Karen emphasized the value of reading books as a way of taking her mind off cancer. During the interviews, she told me, “They [leisure activities] have distracted me when I might have sat around worrying.” Rachel agreed that leisure activities distracted her thinking, “My free time enables me to forget about all the other stuff that is heavy and on my mind. Leisure activities serve as distraction from everyday problems.” The responses of this study’s participants show the potential benefit for cancer patients of engaging in leisure activities as a way of reducing stress and promoting functional thinking.

### ***Stress Management***

According to previous research (Antoni et al., 2006), the diagnosis and treatment of cancer are stressful events. Managing stress was a topic that resonated with the participants in this study. Every participant reported stress management was important to coping with the cancer experience. Some of the participants, like Barbara, reported being able to deal well with stress. She told me during the interviews, “Before the cancer, I handled stress well. I always try to find the positive in things and not dwell on the negative. That’s the way I try to handle stress.” Karen indicated she learned from her cancer experience how to better manage stress: “[Following cancer] I am more aware now of the effects stress has on my health and I try not to let it get too out of hand.”

Several of the participants discussed the methods they use to reduce stress. Susan reported, "Reading reduces my stress. When I get a book that I'm really into, it's almost like I become the character in the book. You know, it's just stress free. I'm not thinking about anything else, especially cancer. Reading takes me away from my problems." Barbara mentioned, "When I talk to someone about what's bothering me, it kind of relieves some of the stress that I'm feeling." Karen espoused the benefits of physical exercise in managing stress when she stated, "I place a very high value on exercise especially as it relates to disease prevention and stress reduction." All of the participants in this study agreed that managing stress was important to helping them adjust to lifestyle changes during and after cancer treatment.

### ***Self-worth***

Most of the participants in this study indicated having a positive self-image which might explain why Cheryl was the only individual who reported self-worth as an important factor in coping with cancer. Some participants viewed their cancer experience as helpful in promoting a stronger sense of self. Rachel told me during the second interview, "I think the meaning of being diagnosed with a disease like cancer is to make me a better and stronger person." Karen reported, "The manner in which I handled the ordeal [her cancer experience] makes me feel good about myself."

Viewed from a different perspective, Barbara reported being negatively effected by her cancer experience. She stated, "Sometimes I feel I'm not really worth too much because of the cancer. I feel that cancer has taken a big part of my life away from me and now my life is not worth as much as it used to be to me." Overall, the participants sought to maintain a positive self-worth despite cancer. Susan exemplified this desire when she

stated, “Seeing myself as a strong person is important now. That’s who I want to be.”

### ***Realistic Beliefs***

There is no doubt that a diagnosis of cancer challenges a person’s core beliefs about all aspects of life. The study’s participants reported having realistic thoughts about their treatment plan and prognosis for recovery. When this topic was discussed in the interviews, the participants seemed to lack a willingness to test the reality of their beliefs. Instead, they appeared satisfied that they were being realistic in their approach to coping with cancer. John and Karen considered this wellness factor to be important. John told me during his second interview, “As a realistic person, I see cancer for what it is and don’t try to make it into something that it’s not. For me, being realistic about my chances helps me to prepare for what lies ahead.”

### ***Friendship***

The participants in this study who viewed friendship as being important also reported having a number of close friends they depend on for support. Karen summarized the feeling of most of the participants when she said, “I have been blessed to have so many people who love and care about me. This is especially important during this time as I need their support to help me deal with cancer. I have no idea how people get through this disease, or other difficulties in life, without the love of family and the support of friends.” The results of this study closely mirror the findings of a study by McIllmurray et al. (2001) which concluded that support from friends is important to the vast majority of cancer patients. The responses of the participants in this study underscored the value of friendship in emotionally supporting people throughout their cancer experience.

## *Love*

For many people, the concept of love is often associated with family. However, love is an important element in relationships with close friends, co-workers, and God. For the participants in this study, the connection between love and family, friends, and God appeared very strong. Cheryl reported, “I cannot express how much love I feel. It’s incredible how much love I receive.” Rachel shared similar sentiments, “The support that I receive from those people who I love and who love me helps. Just knowing that I have them in my life helps.”

Several of the study’s participants felt the diagnosis of cancer strengthened their perspective on love which helped them cope with their experience. Cheryl commented on the impact that cancer has had on her views regarding love when she stated, “I think maybe my disease makes me appreciate the love and support I receive that much more.” John had a similar awareness of the importance of love in helping him deal with his medical condition, “I believe it [love from family] helped me to become the type of person that I am today—someone who is able to deal with HIV and cancer, whereas many people couldn’t.” Karen’s cancer experience has had a significant impact on her view of love as she reported during the first interview:

I know now that love is really the only important, lasting thing in life. My love of God, God’s love for me, my love for my family and friends, and their love for me really means the world to me now. Before, I might have taken it for granted. After being diagnosed with a disease like cancer, I feel love is the most important thing I have in my life.

## *Spirituality*

Numerous studies have concluded that spiritual and religious beliefs represent an integral part of the coping process for people confronted with a life-threatening illness such as cancer (Koenig, 1997; Koenig, Pargament, & Kielsen, 1998; Ott, Ehman, Short, Ciampa, & Hansen-Flaschen, 1999). For all six of the participants in this study, spirituality was critical to coping with cancer diagnosis and treatment. They collectively reported that a strong spiritual faith helped them remain hopeful during a difficult time.

Each participant emphatically stated that faith was the difference in enabling them to stay positive despite having to deal with the effects of cancer diagnosis and treatment. The comments they shared with me during the interviews emphasized the importance of faith in coping with cancer:

- Karen told me, “My faith plays a big part in helping me deal with this. Without my faith, I don’t know if I would make it.”
- Rachel shared a similar comment, “The only other way that I’ve coped is to rely on my faith.”
- Faith for Susan was important to helping her cope with cancer as evidenced by her statement, “So without my spiritual faith, I know I wouldn’t be coping with cancer as well as I am.”
- Cheryl relied on her spiritual faith to help her cope with advanced disease. She reported, “I wonder what I would have done if I hadn’t had God in my life.”
- John acknowledged the effect cancer has had on his spiritual faith when he stated: For me, my disease hasn’t effected my spiritual belief. If anything, my faith has gotten stronger. It has helped me a lot at this time. It’s hard to put in

words as to how my faith has gotten stronger, but it's something that I can't see; it's just a feeling.

### *Self-care*

All six of the participants reported self-care as being important to coping with cancer. Specifically, the participants indicated that the diagnosis of a life-threatening illness made them more aware of what they are doing or not doing to take care of themselves. Rachel told me during the second interview, "I pay much more attention to what I'm doing to take care of myself now because of cancer." Barbara made a similar claim when she said, "I think dealing with this disease has made me even more aware of the need to take care of myself."

Susan concurred with the other participants through her admission, "My attitude about my physical health has changed since this has happened. Now, I'm going to take better care of myself." All the participants in this study stressed the need for regular exercise and the importance of eating a proper diet as changes in self-care that resulted from their cancer experience.

### *Nutrition*

Cancer has a significant effect on the eating habits of individuals during treatment. The responses of the participants suggested that changes in nutrition were an important lifestyle adjustment during cancer treatment. The three participants in this study—John, Cheryl, and Barbara—who have a late stage of cancer stressed the importance, as well as the difficulty with maintaining a proper diet. From the comments of these three participants, it seems apparent that the struggle to eat is a significant challenge for people with advanced disease. John confirmed this conclusion when he

told me in the first interview, “Not eating well has been a real problem for me and it’s the main reason I don’t want to take the chemotherapy. Nutrition is the barrier to me starting my chemo treatments.” Cheryl, another participant with Stage IV cancer, simply stated, “You know, if I don’t have good nutrition, then how am I going to cope with treatment well.”

A diagnosis of cancer seemed to prompt more reflective thinking by the participants. They shared with me some very insightful comments regarding the importance of nutrition. Karen told me, “When I eat right, I always feel better and when I don’t, I now consider what effect it may have on my possibility of cancer recurrence – or getting another type of disease.”

The learning point for Rachel was a simple message, “I know I have to eat the right foods to help me to keep my strength as I’m going through chemotherapy. That’s really important for me to do.” Barbara summarized her views on nutrition with the following statement, “Cancer has made me more aware of what I’m eating and what I need to eat.”

Susan’s comment during the initial interview conveyed an important message, “Cancer and the treatments have opened my eyes to how I was eating and how much food I was eating and I realize I need to eat better.” From the statements of the participants, this study supports the notion that proper nutrition is important for people to consider during and after cancer treatment.

### ***Exercise***

The previous research in this area focused on the connection between physical exercise and cancer recurrence (Holmes et al., 2005; Meyerhardt, Giovannucci et al.,

2006; Meyerhardt, Heseltine et al., 2006). These studies suggest that cancer survivors who regularly participate in physical activity have significantly lower risk of developing a recurrence of their disease compared to those who do not exercise. The findings are consistent with the comments of participants in this study who reported experiencing significant benefits from exercise. Because they were actively receiving treatment, the ability of the participants to perform physical activity was somewhat limited; however, three individuals—Cheryl, Karen, and Rachel—rated exercise as a critical factor to helping them cope with their cancer experience. Cheryl indicated her regular walking routine helped her in several important ways, “I think exercising has made me feel like a normal person. Because if I didn’t exercise I wouldn’t feel well and then, what would be the point of exercising. If I’m exercising, then it means that I’m doing well and feeling normal again.”

Cancer served as motivation for Karen who said, “Not exercising is not an option anymore. Because of cancer, I will always have to think of the long term benefits of exercise on my health.” The results of this study along with the findings of previous research support the physical and psychological benefits of regular exercise for people experiencing cancer treatment.

## **Conclusions**

In this chapter, a detailed description of the themes that were extrapolated from the individual case studies of the research participants was presented. A cross-case analysis was conducted to arrive at a master list of themes representative of topics emblematic of the experience of individuals recently diagnosed with cancer. Findings responded to the primary and secondary research questions of this study. Specifically,

this study sought to gain insight into the perceived supportive care needs of patients recently diagnosed with cancer as they began treatment and at a second point following the completion of one month of treatment. Additionally, this study explored the development of a holistic assessment strategy for use in an outpatient cancer clinic. Finally, this study questioned the applicability of the factors of wellness to an event that is centered on a medical illness.

The final list of themes that emerged from the transcribed words of the participants in this study presents a picture of what it is like to be diagnosed and treated for cancer. The life-threatening nature of this disease forces many people to confront their own mortality for the first time in their life. The potential for a recurrence of cancer following treatment leads to uncertainty about the future. For people newly diagnosed with cancer, there is a desire to learn about the disease and treatment options. Coping with cancer is a challenge that leads many individuals to rely on their spiritual faith for help. Staying in control of thoughts and emotions is important for people experiencing cancer. Another important coping mechanism involves the love and support of family and friends. The physical challenges presented by cancer are obvious as individuals attempt to deal with the symptoms of their disease and side effects of treatment. The physical demands of cancer lead to many people realizing the importance of self-care through proper nutrition and exercise. While the manner in which a person experiences cancer is unique to every person, the themes presented in the final table summarize how many people cope with cancer and the lasting impact of their experience.

Cancer is a disease that effects people in a broad ranging manner. As such, individuals diagnosed with cancer experience a variety of supportive care needs during

treatment including seven out of the eight domains of need assessed in this study.

Because cancer is first and foremost a medical condition, people naturally have physical needs as a result of disease symptoms and treatment side effects. Physical needs require people to learn to cope with a life that often includes pain, fatigue, nausea, and physical changes in appearance. The relevance of physical challenges is apparent as this domain of need was reported by every participant in this study.

Another supportive care need deemed important by the participants in this study involved the psychosocial domain. All the participants reported experiencing some level of psychosocial distress manifested either as the presence of depression or a heightened state of anxiety. From the literature, this finding is consistent with other studies (Carlson & Bultz, 2003; Fitch et al., 1999; Miller et al., 2003; Steginga and Dunn, 1997; Zabora et al., 2001) that found psychosocial disorders prevalent in a majority of cancer patients. With the exception of cultural and gender needs, the holistic assessment process was successful at identifying the full range of perceived supportive care needs people experience during cancer treatment.

After one month of cancer treatment, individuals develop some understanding about what to expect which had the effect of reducing anxiety; however, an uncertainty about the future that comes with cancer diagnosis and treatment can result in a continued presence of psychosocial distress in some individuals. Supportive care needs involving information and psychosocial distress are often addressed naturally through the process of undergoing treatment. Other supportive care needs that center on physical, financial, or spiritual wellbeing are not as easily addressed because of the complexity of these domains of need. Physical needs are directly related to the type and extent of treatment

individuals must endure. Patients who undergo more involved treatments with a variety of modalities report having significant physical needs. People who lack employment and/or financial resources when entering cancer treatment have a higher frequency of reporting a financial need. These individuals report a difficulty in finding a suitable resolution to their financial situation leading to an increased potential for psychosocial distress. Spiritual and existential concerns are most prevalent in individuals diagnosed with late-stage cancer. Based on the comments of the participants in this study, existential needs do not subside after one month of treatment as patients search to find meaning to their cancer experience.

Individuals experiencing cancer diagnosis and treatment seemed to relate to most of the factors of wellness. As an approach to assessing the coping skills of cancer patients, the wellness model is appropriate for use by clinical mental health counselors. Through an interview and written assessment process, this model can be applied to help people gain insight into their ability to adjust to cancer and develop new ways for coping with a life-threatening illness. While some factors such as gender identity and cultural identity did not resonate with the study's participants and other factors such as self-worth and work were reported by only one participant, the vast majority of the factors that comprise the wellness model seemed appropriate for assessing the perceived supportive care needs of cancer patients within the context of their ability to cope with their disease.

## **CHAPTER FIVE**

### **DISCUSSION**

#### **Introduction**

According to Adler (1927/1954) every individual is unique. This uniqueness becomes evident by the way in which people perceive lived experiences and events. A diagnosis of cancer is one such event that demonstrates the individualistic nature of the human experience. Adler (1927/1954) further believed that human beings cannot be broken down into parts, but instead must be viewed as a whole person. This holistic perspective is relevant to people undergoing cancer treatment as this disease affects all aspects of a person's being—body, mind, and spirit. The literature is clear that cancer patients come to treatment with a variety of perceived needs (Broadhead & Kaplan, 1991; Carlson & Bultz, 2004; Carlson & Bultz, 2003; Fitchett & Handzo, 1998; Girgis et al., 2000; Jenkins et al., 2001; Kornblith et al., 2001; Mallinger et al., 2005; McIllmurray et al., 2001; Moadel et al., 1999; Newell et al., 1999; O'Conner et al., 1990; Sellick & Crooks, 1999; Steginga & Dunn, 1997; Zabora et al., 2001). Further, research studies clearly indicate the supportive care needs of patients often go unmet during cancer treatment (Girgis et al.; Hack et al., 2005; Sanson-Fisher et al., 2000). The implications of supportive care needs not being addressed and satisfied can have a negative impact on cancer patients' recovery and long-term chances for survival. It is with this consideration that this research study was conducted.

## **Purpose of the Study**

The purpose of this qualitative study was to examine the essence of the personal experiences of patients being treated for cancer at an outpatient clinic. The study focused on understanding and describing the cancer experience by exploring the perceived supportive care needs of patients following a cancer diagnosis—a time when they are confronted with a life-threatening illness. Adhering to a holistic, wellness-based model, this study investigated the full range of supportive care needs that six newly diagnosed cancer patients encountered during treatment. Methods of inquiry followed Interpretative Phenomenological Analysis (Smith, 2004), a structured approach for building understanding and meaning of a phenomenon. This research study was an exhaustive, time-consuming examination of the transcribed words of the study's participants to arrive at the themes and meanings associated with the cancer experience.

## **Summary of Procedures**

In summarizing the procedures used to conduct this research, it is noteworthy to recognize the evolution that took place from the planning phase to actual implementation of this study. Specifically, a few procedures were altered from the original research proposal that involved such methodological components as the number of participants included in the study and the second interview process. The intent for making these changes was to improve the overall quality of the research being conducted with the goal in mind of answering the questions under study.

Some of the more significant differences between the proposed research and the study that was actually carried out include such changes as inclusion in this study individuals diagnosed with advanced stage of cancer; reduction in the number of

participants in the study from eight to six; evolution of the questions and protocol used in the initial interview with participants as the experience gained from interviewing one participant informed subsequent interviews; flexibility introduced into the interview process which allowed for more in-depth questioning of important topics; and development and utilization of an assessment instrument as part of the second interview process. All of these changes to the study's procedures became apparent at various times in the research process. Ultimately, the procedural changes served to strengthen the methodology of this study.

### **Summary of Results**

This study examined the experience of six individuals who had recently been diagnosed with cancer. This study captured the personal thoughts and emotions of people attempting to cope with a life-threatening illness. The results of this study are organized into four separate but related categories based on the primary and secondary research questions: (a) the perceived supportive care needs of the study's participants as they begin cancer treatment; (b) participants' perceptions of their supportive care needs after completing one month of cancer treatment; (c) a strategy for holistically assessing the supportive care needs of cancer patients entering treatment; and (d) applicability of the wellness model to individuals diagnosed and treated for cancer.

#### ***Supportive Care Needs at the Beginning of Treatment***

Based on participant responses on a written assessment instrument that was administered as well as answers to questions asked during two semi-structured interviews, I reached the following conclusions on the primary research question of this study, What are the perceived supportive care needs of patients during cancer treatment?

### ***Physical Need***

Many cancer patients have a physical supportive care need related to symptoms of their disease. This domain of need depends largely on the type and stage of cancer and the physical side effects of the treatment regimen used to cure or manage the disease. The result of this study was consistent with the findings of previous research (Institute of Medicine, 2007; Newell et al., 1999) that cancer has a significant physical impact on individuals following diagnosis and throughout treatment.

### ***Psychosocial Need***

A majority of cancer patients experience a moderate to high level of psychosocial distress. Psychosocial distress manifested as depression and/or anxiety is most prevalent during the period of time following diagnosis and before treatment begins. Left unmet, psychosocial needs can develop into significant problems that interfere with patients' ability to comply with cancer treatment. The results of this study were similar to what was found in past studies on the psychosocial needs of cancer patients (Carlson & Bultz, 2004; McIllmurray et al., 2001; Miller et al., 2003; Steginga & Dunn, 1997; Zabora et al., 2001). Steginga and Dunn conducted a study of 82 women with gynecological cancer who were disease-free and found that 81% of the participants reported having psychosocial needs with the most common problems being depression (49%), anxiety (37%), and fear of dying (35%). A study by Miller et al. of 95 gynecologic cancer patients found a majority of them reported needing help dealing with emotional problems related to their cancer experience. Zabora et al. conducted a study on the prevalence of psychological distress among a large sample of 4496 cancer patients and found depression and/or anxiety present in 35.1% of the patients. The prevalence of

psychosocial need found in these studies appeared to be consistent with the results of this study.

### ***Spiritual and Existential Need***

Previous studies (Balboni et al., 2007; Fitchett & Handzo, 1998; Miller et al., 2003; Moadel et al., 1999) on the spiritual and existential domains of need concluded a vast majority of patients with an advanced stage of cancer believed addressing these needs was important. Balboni et al. interviewed 230 cancer patients with advanced stage of disease and found a majority associate spiritual support with improved coping and quality of life. Further, the study indicated 72% of patients reported that their spiritual needs were not supported minimally or at all by the cancer care system (Balboni et al.). This study confirmed the findings of the previous research that spirituality and existential awareness are important to cancer patients with a late stage diagnosis.

From this study, a conclusion can be reached that spiritual and existential needs are most prevalent in patients with advanced stage of disease than in patients with a diagnosis of early stage cancer. Further, patients with advanced disease have spiritual and existential needs that are more severe than those patients with early stage of disease. The importance of the existential domain of need lies in patients finding meaning to their cancer experience which can lead to greater insight and ultimately, facilitate better coping. This result confirmed in findings of past research on the existential meaning of a cancer diagnosis (Moadel et al., 1999; O'Conner et al., 1990; Ramfelt et al., 2002; Taylor, 2001). Moadel et al. studied an ethnically-diverse sample of 248 cancer patients on their spiritual and existential needs and concluded spiritual beliefs and practices promote adjustment to cancer through a personal search for the meaning of life, death,

and hope. Additionally, they found unmet spiritual or existential needs reported by 25% to 51% of cancer patients (Moadel et al.).

### ***Work-related Need***

Work-related need is more likely to surface in patients who were employed prior to their cancer diagnosis, or in people who cannot return to work because they have become disabled from cancer. This study's finding was similar to the result of another study conducted by Ferrell Grant et al. (1997) on the work-related domain of need. Ferrell Grant et al. conducted a qualitative study that evaluated the quality of life of women who had survived breast cancer and found the ability to return to work following cancer treatment was seen as a sign of triumph and validation. Of the women in the study who were employed at the time of their cancer diagnosis, a majority cited returning to work as confirmation of their survival (Ferrell Grant et al.). For many people, work represents an important part of their life that can be negatively impacted by cancer diagnosis and treatment.

### ***Financial Need***

Financial need is most prevalent in patients with limited income and/or few resources available to pay for daily living expenses. The financial situation of cancer patients is made even more difficult by the costs associated with cancer treatment that often involve prescription co-pays, transportation expenses, and the cost of child-care. These findings are consistent with the results of a study conducted by Spelten et al. (2002) that found 70% of people who stop working or experience a change in employment (e.g., reduction in work hours, interruption of work, change in place of

employment) after being diagnosed or treated for cancer have significant implications on their financial condition, particularly for patients with limited resources.

### ***Cultural and Gender-related Need***

The participants in this study did not report cultural and gender needs as being significant to their cancer experience. This result is most likely explained by the participants prioritizing other domains of supportive care such as physical, psychosocial, and financial needs as being more important; however, further inquiry is needed to make a definitive conclusion regarding the importance cancer patients place on cultural or gender-related needs. The finding of this study does not exclude the presence of cultural and gender issues; instead the participants in this study failed to recognize these domains of supportive care need or did not fully comprehend culture or gender as being a viable area of need. The lack of research conducted specifically on culture and gender within the context of supportive care need seems to indicate one of the following possible conclusions: (a) from the patients' perspective, culture and gender are viewed as having little or no relevance to the cancer experience; (b) cancer patients do not believe culture and gender are as important as other concerns; or (c) cultural and gender-related needs simply are not reported or are underreported by cancer patients.

### ***Supportive Care Needs after One Month of Treatment***

After one month of cancer treatment, a written assessment was again administered in addition to a structured interview. Past studies assessed patients' perceptions of their supportive care needs as they entered cancer treatment or at a specific period in time following the completion of treatment. Because no previous research had specifically assessed the supportive care needs of cancer patients after one month of treatment, no

comparison can be made between the findings of this study with the results of previous research. The following conclusions are based on the responses and comments from participants and represent some of the principle findings of this study:

- Physical needs remain constant or actually increase following one month of treatment based largely on the increased side effects of cancer treatment.
- Information needs are reduced likely because patients have one month of experience undergoing treatment and as a result have a better understanding of what to expect
- Financial resource needs remain for patients who are unemployed and/or who lack sufficient finances to pay for basic living expenses. Patients who are in a lower socio-economic status (SES) have the most difficulty addressing financial needs. The costs associated with one month of cancer treatment presents an even greater financial burden for patients with few available resources.
- Needs that are spiritually or existentially based are most prevalent in patients with advanced disease. These needs are not easily resolved over the course of one month as patients seek to find answers to complex existential questions such as understanding the meaning of their cancer diagnosis.
- After one month of treatment, patients who have occupational/work-related needs generally associate this domain of need with loss; namely, the loss of a connection with co-workers, loss of a sense of purpose because of work, or the permanent loss of the ability to work.

### *Holistic Assessment Strategy*

A review of the assessment strategy used in this study led to the following conclusions regarding the relevance of taking a holistic approach to identify the supportive care needs of individuals entering cancer treatment. It is important to note that no previous research had followed an approach similar to the one used in this study that holistically assessed the supportive care needs of cancer patients entering treatment. Therefore, it was difficult to compare the findings of this study to specific results in the literature.

- A comprehensive approach to assessing the supportive care needs of cancer patients is viable.
- An assessment strategy should be developed that addresses all areas of need including a common set of domains that standardizes the practice of needs assessment.
- A holistic assessment strategy based on many of the factors included in the wellness model has potential. Further research is needed to determine the validity and reliability of such a holistic approach to assessing the supportive care needs of cancer patients.

### *Wellness Model in Cancer Care*

One of the primary questions asked in this study involved the suitability of applying a wellness model to a situation in which individuals are attempting to cope with a life-threatening illness. The following conclusions were reached on the applicability of the factors of wellness to cancer patients undergoing treatment:

### ***Thinking and Emotions***

The factors of thinking and emotions are seen as mutually exclusive in that patients use one or the other as their predominant way of coping with cancer. Some patients use thought to process their cancer experience while others rely on their emotions. Arora et al. (2007) studied women who were newly diagnosed with breast cancer and found they adapted to their illness by engaging in a cognitive process that promoted solution-focused coping and emotional control. The connection between thinking and emotions was emphasized by participants in this study who viewed the positive expression of emotions as reducing intrusive thoughts and lowering psychological distress. This finding was consistent with studies conducted by Quartana et al. (2006) and Classen et al. (1996) that concluded emotional expressiveness is associated with improved psychological adjustment to the demands of cancer treatment. In research with 93 individuals treated for cancer, Quartana et al. found the positive expression of emotions reduces the frequency of intrusive thoughts and lower psychological distress. A study by Classen et al. of 101 women diagnosed with metastatic or recurrent breast cancer found emotional expressiveness to be connected to improved psychological adjustment. The findings of these studies highlight the importance emotions play in helping individuals adjust to cancer diagnosis and treatment.

### ***Control***

The uncertainty that comes with a cancer diagnosis challenges the ability of people to maintain a sense of control in their life (Holland, 2002). The vast majority of cancer patients, including all the participants in this study, believe control is important to coping with a life-threatening disease. This study's participants saw control from two

different perspectives; namely, maintaining control over thoughts and/or emotions, and giving up control to God or a higher being/spirit. This finding was similar to what was concluded by McIllmurray et al. (2001) in a study that surveyed 1000 adult cancer patients. McIllmurray et al. found that a majority of cancer patients expressed a need to maintain a sense of control in their lives. For participants in the study by McIllmurray et al. as well as in this study, control was seen as especially important to coping with the challenges posed by a diagnosis of cancer.

### ***Work***

The importance of work is directly related to patients' employment status when diagnosed with cancer. Further, the ability to work during treatment affects patients' perspective on the importance of this factor. Patients who are either unemployed or unable to work after diagnosis emphasize this factor of wellness less than those who are actively employed or who plan to return to work at the end of treatment. Previous research by Spelten et al. (2002) focused on the financial impact of the loss of work on individuals who survived cancer. Spelten et al. concluded nearly three-fourths of all cancer survivors who stop working or have a change in employment status (e.g., reduction in work hours, interruption of work, and change in place of employment) because of disease symptoms or treatment side effects experience financial difficulties. The financial repercussions of work-related changes have serious implications on an individual's ability to cope with cancer. Despite the evidence that cancer treatment negatively affects a person's ability to work while increasing financial concerns, no research has been conducted that specifically explores the psychological and emotional impact on individuals who cannot work because of cancer.

### ***Positive Humor***

Positive humor is used by patients to reduce the anxiety often associated with the diagnosis and treatment of a serious illness such as cancer. Laughter is seen as one way of reducing stress and anxiety when undergoing cancer treatment. The use of positive humor has the side effect for patients of keeping a sense of normalcy in their lives despite the seriousness of cancer. With regard to positive humor, the finding of this study is consistent with the conclusions reached by Erdman (1991) that laughter eases the mind, reduces tension, and has positive effects on the mental capacity of cancer patients. Christie and Moore (2005) conducted an extensive review of the literature and found a positive correlation between humor and comfort levels in patients with cancer. Additionally, they found in the literature an indication that humor frequently was used in cancer care to elicit relaxation and reduce anxiety and discomfort, which enabled patients to openly discuss their fears and concerns (Christie & Moore). Christie and Moore concluded from previous quantitative research that humor has a positive effect on the immune system, improved physical stress responses, and promoted feelings of well-being. The findings of this study agree with the previous research on this subject that a positive correlation exists between positive humor and feelings of well-being in patients with cancer.

### ***Spirituality***

For the participants in this study, the life-threatening aspect of cancer highlighted the importance of spirituality in coping with diagnosis and treatment. This study concluded that patients apply their spiritual and religious beliefs to help them cope with the many and varied challenges brought on by a diagnosis of cancer. A number of

previous studies had similar results concluding that religious and spiritual beliefs are integral to coping for some patients when confronted with a serious illness such as cancer (Koenig, 1997; Koenig et al., 1998; Ott et al., 1999). Of particular note, the study's participants reported using spirituality to address existential concerns involving meaning and death. These findings are consistent with the results of a study by Lauver et al. (2007) that found cancer patients experienced positive changes in their perceptions of life following the completion of cancer treatment. Lauver et al. concluded from their study that spirituality is especially relevant for cancer patients once treatment has ended—a time when they are often retrospective and use their spiritual beliefs to assign meaning to their cancer experience. Studies by Koenig (1997) and Koenig et al. (1999) explored the impact of spirituality on health and concluded that for some patients, religious and spiritual beliefs are integral to coping with a life-threatening illness such as cancer.

### ***Stress Management***

For all patients, managing the stress that comes with the diagnosis and treatment of a life threatening disease is an important part of coping with the cancer experience. Cancer patients use stress management intervention strategies to facilitate adjustment during and after treatment (Antoni et al., 2006). Because cancer affects people differently, the manner in which stress is managed differs from one person to another. Some of the ways participants in this study reported relieving stress included leisure activities, exercise, meditation and visualization, deep breathing, laughter, and prayer.

### ***Love***

When confronted with any major event in life, people use the support they gain from the love of others to help them overcome adversity. For people living with cancer,

love takes on even greater importance largely because of the life threatening nature of the disease. While love specifically has not been studied within the context of the cancer experience, the importance of family has been researched. A study conducted by McIllmurray et al. (2001) surveyed 380 cancer patients on various categories of psychosocial need and found that family support was reported as being important or very important by 89% of participants. The finding by McIllmurray et al. indicated that patients perceive love and support from family as valuable to coping with the diagnosis and treatment of cancer. The participants in this study held a similar view as five out of six reported love was very important to helping them cope with their cancer experience.

### ***Friendship***

The importance of friendship to facilitate coping is seen as important to those patients who, prior to cancer diagnosis, relied on their friends for help overcoming adversity. Some patients develop friendships with other patients during cancer treatment that fosters coping skills development. A study conducted by Arora et al. (2007) found that friends played a predominant role in providing emotional support for individuals during the diagnosis and treatment of cancer.

### ***Self-care***

Self-care is very important to patients experiencing cancer treatment (Williams et al., 2006). The participants in this study recognized the physical changes associated with the symptoms and treatment side effects of cancer necessitate a greater emphasis on self-care. The findings of this study suggest that self-care helps individuals undergoing cancer treatment feel more in control over their cancer experience. Participants in this study associated self-care with eating a proper diet and participating in regular exercise.

As such, the separate wellness factors of nutrition and exercise duplicate the broader factor, self-care. Studies had been conducted on nutrition and diet as related to cancer. Blanchard et al. (2003) found patients reported improvement in their nutritional habits indicating that a cancer diagnosis may have a positive influence on diet. The results of this study support the notion that proper nutrition is important during and after cancer treatment. With regard to exercise, studies conducted by Holmes et al. (2005), Meyerhardt, Giovannucci, et al. (2006), and Meyerhardt, Heseltine, et al. (2006) suggest that individuals who regularly participate in physical activity have significantly lower risk of being diagnosed with cancer compared to those who do not exercise. Further, the authors of these studies concluded that regular exercise lowers the risk of reoccurrence of disease for individuals who have completed cancer treatment and are considered to be in remission. While the scope of this study differed from previous research on the subject of self-care, the study's participants acknowledged the importance of exercise and nutrition in promoting physical well-being and good long-term health.

### ***Nutrition and Exercise***

Both exercise and nutrition are recognized as important to the participants in this study while they were undergoing cancer treatment. The emphasis placed on these two factors of wellness varies among cancer patients depending on individualistic needs and circumstances involved. For most patients, cancer serves as a reminder of the importance of regular exercise and proper nutrition. With regard to physical activity and diet, cancer is commonly seen as a life-changing experience and a motivating event for making lifestyle changes.

## *Leisure*

The participants in this study reported using leisure activities such as reading, gardening, meditation, and walking to facilitate relaxation and reduce anxiety and depression. These types of activities distract patients from thinking about cancer while helping them maintain a sense of routine and normalcy in their life. The result of a study by Abrahamson et al. (2006) supported the view that leisure activity can have a positive effect on individuals experiencing cancer diagnosis and treatment.

### **Theoretical Implications**

For counselors working in the field of psycho-oncology, the findings of this study have implications for the development of a theoretical approach to counseling cancer patients that is based on the wellness model. Specifically, the results of this study showed the applicability of Adlerian theory, holism, humanistic psychology, existentialism, and the wellness model to the development of an approach that holistically addresses the supportive care needs of people with cancer. By combining select tenets of established theories into one model, a theoretical approach could be created that assesses the full range of supportive care needs of cancer patients. In addition, this new theory could serve as the foundation for the development of a holistic intervention strategy designed to satisfy the identified needs of patients throughout the cancer experience. Key elements of existing theories that could be included in a holistic assessment model are:

- *Holism*. Holism represents the view that it is possible to learn more about something and better understand its nature and purpose if it is examined in totality (Smuts, 1926/1999). With regard to assessing individuals with cancer, this study supported taking a holistic approach to facilitate a more

comprehensive examination of the cancer experience from diagnosis through treatment into survivorship.

- *Phenomenological perspective.* Adler's emphasis on the importance of the internal and subjective. He stressed a person's perception of reality is what really matters. Adler (1927) saw each person as a unique individual and only by understanding the person's perceptions of the world can that person truly be known. Consistent with Adler's view, this study found that individuals experience cancer from their own unique, phenomenological perspective.
- *Uniqueness of the individual.* Adler (1927) held strong beliefs in the uniqueness of every individual. He believed in the importance of having a comprehensive understanding of the whole individual. This study provided support for the uniqueness of the individual as each of the participants experienced cancer differently.
- *Lifestyle assessment.* Adler believed it is necessary to gain a holistic understanding of people through a comprehensive and informative lifestyle assessment that focuses on evaluating the level of satisfaction people have with themselves, their relationships, and their lives (Ansbacher & Ansbacher, 1956). The results of this study demonstrate the value in holistically assessing an individual's lifestyle as a way of better understanding that person in an effort to improve the overall quality of cancer care provided.
- *Psychosocial emphasis.* Adler's theory stressed the psychosocial aspect of human development that includes the life tasks of love, work, and friendship (Ansbacher & Ansbacher, 1956). The results of this study showed the

importance cancer patients place on social connectedness manifested as love from family, support from friends, and loss from an inability to work.

- *Making meaning.* According to Rollo May (1969), people make meaning of their lives through the will to love and to live. Adler believed individuals find meaning in life through their unique philosophy of life (Ansbacher & Ansbacher, 1956). Meaning gives purpose to life which is challenged when a person is diagnosed with a life-threatening illness such as cancer. For many people experiencing cancer, including some of the participants in this study, there is real purpose in addressing the existential question, “What is the meaning of my cancer diagnosis?”
- *Inevitability of death.* The life threatening aspect of cancer forces many people to confront on some level their mortality often for the first time in their life. Assessing people’s perspective on this difficult topic can be important to understanding how well equipped they are to cope with cancer. Victor Frankl’s (1963) experience as a prisoner in a concentration camp during World War II and Irvin Yalom’s (1980) work with cancer patients illustrate how individuals confront and learn to cope with the inevitability of death.
- *Awareness.* From an existential perspective, the capacity for awareness is important for individuals to understand themselves and their world (Yalom, 1980). In assessing people with cancer, focusing on how aware they are of their limitations in relation to coping with life’s challenges can generate important insight into how they might handle cancer treatment.

- *Wellness.* This study found that many of the factors of wellness as conceived by Myers and Sweeney (2005a) can be incorporated into an approach for assessing the supportive care needs of cancer patients. Just as Adler (1927) focused on life tasks, this theoretical model could assess cancer patients on the wellness factors of control, stress management, spirituality, and self-care, among others.

### **Practical Implications**

The findings of this study have ramifications for the counseling profession as more licensed professional counselors practice in the field of psycho-oncology. In a recently released report, the Institute of Medicine (2007) acknowledged that licensed mental health counselors, if properly trained, are well suited to provide psychosocial services to cancer patients. The findings of this study have implications for the clinical practice of counseling as it relates to serving cancer patients. Some of the practical implications related to the findings of this study include: (a) development of better needs assessment instruments; (b) utilization of the factors of wellness in identifying the full range of supportive care needs through screening procedures; and (c) use of a holistic approach based on wellness to develop appropriate needs-based intervention strategies.

Professional counselors, trained in a CACREP counseling program, are prepared to address many of the issues that surfaced in this study. Some of the most important topics reported by the study's participants that have practical implications for the delivery of counseling services to individuals experiencing cancer include:

- *Uniqueness of the cancer experience.* The participants in this study experienced cancer in their own unique way. The uniqueness of the cancer

experience should be taken into consideration when counseling cancer patients.

As a guiding principle in providing counseling services, meeting clients where they are is appropriate to addressing the individualistic aspect of the cancer experience.

- *Life-threatening aspect of cancer.* Confronting the possibility of death is a real and present concern for many people experiencing cancer, especially those individuals diagnosed with an advanced stage of disease. From an existential perspective, death is inevitable and that realization gives purpose to life. For counselors working with cancer patients, exploring the life-threatening aspect of this disease can help facilitate conversations on death, a subject that is uncomfortable for many people and often times is avoided.
- *The meaning of cancer.* Based on the findings of this study, exploring the existential question, “What is the meaning of my cancer experience?” is a relevant and suitable approach to take when counseling individuals facing diagnosis and treatment of cancer. Examining such a difficult question with cancer patients has the potential to promote understanding and insight that can lead to an improved ability to cope with cancer.

### **Implications for Counselor Education**

Findings from this study have implications for the curriculum and instruction used in counseling programs. Counselor educators train graduate students to provide mental health counseling services to individuals with a broad range of issues in a variety of settings. Cancer counseling is a specialty area where counseling programs could focus attention and provide specific instruction designed to prepare masters and doctoral level

counselors to work with this patient/client population.

The mental health providers normally associated with psycho-oncology are psychiatrists, psychologists, and psychiatric nurses. These disciplines have a history of providing instruction and practice that prepare graduates to work with patients in traditional mental health settings. Recently, graduate programs in psychology have begun offering training in health psychology as an effort to broaden the scope of the discipline from a mental health to a health profession. Adhering to a similar, mental health counseling programs could offer training and practice guidelines to expand into the field of cancer care. Based on the findings of this study, a holistic model foundationally structured in wellness is well suited to helping individuals experiencing cancer and the supportive care needs that often come with the disease.

Clinical health psychology was formally recognized by the American Psychology Association (APA) as a specialty in the professional practice of psychology in 1997. Currently, there are 68 clinical or counseling psychology doctoral programs with an emphasis in health or medically related areas (APA, 2006). Additionally, predoctoral internships and postdoctoral fellowships with a major rotation in health psychology are available. Increasingly, academic medical institutions are providing clinical practice and research opportunities in psycho-oncology for health psychology interns and fellows. Over the past decade, clinical health psychology has been a major area of growth in psychology.

The counseling profession could learn from what has taken place in psychology and begin moving in a similar direction. Counselor education programs could expand the boundaries of the profession into psycho-oncology by providing a separate certification

or concentration in cancer counseling. A curriculum in cancer counseling could be offered in CACREP counselor education programs in any of four distinctly different ways: (a) as elective courses in cancer counseling with no specific certification or degree concentration; (b) as a concentration area for masters level graduate students; (c) as a certification for post-masters practitioners; and (d) as an area of concentration for doctoral students.

A cancer counseling curriculum could consist of four required courses plus a one year clinical practice internship in a cancer center setting. The list of courses for a degree concentration or certification in cancer counseling should include:

- *Introduction to Cancer.* The course focuses on the basics of cancer, cancer diagnosis and staging, treatment modalities, psychosocial distress, common DSM-IV diagnoses in cancer care, psychopharmacology, palliative care, and other topics related to an introduction to cancer.
- *Theory and Practice in Cancer Counseling.* The course covers counseling theories applied to counseling cancer patients, family theories applied to counseling caregivers of cancer patients, group work principles for cancer support groups, counseling in a clinical setting, and the application of theory to the practice of cancer counseling.
- *Ethics and Professional Identity in Cancer Counseling.* The course covers counseling ethics applied in a clinical/medical setting, maintaining a professional identity in a multidisciplinary setting, HIPAA requirements, writing progress notes, writing clinical notes, and other topics related to the ethical behavior of a cancer counselor.

- *Issues in Cancer Counseling.* The course focuses on a wide range of issues in cancer counseling including grief and loss, spirituality, death and dying, supportive care needs, quality-of-life, end-of-life, cancer survivorship, and other issues related to counseling cancer patients, survivors, and their caregivers/family members in an individual, couple, family, or group format.
- *Practicum and Internship in Cancer Counseling.* This course involves one year of clinical practice in an outpatient cancer center setting providing individual, couple, family, and group support services.

While offering a separate concentration and/or courses in cancer counseling might not be possible for some counseling programs, counselor educators could encourage masters and doctoral counseling students to enter into the field of psycho-oncology by providing internship opportunities in clinical outpatient settings. Through clinical practice, counselor interns could gain valuable experience that could lead to paid positions following graduation.

As previously indicated, approximately 1.4 million people in the United States are diagnosed with cancer annually. Recent studies found that 35% to 50% of cancer patients experience a clinically significant level of psychological distress (Carlson & Bultz, 2003), which translates into 450,000 to 700,000 cancer patients each year who have a clinically diagnosable psychological disorder. Additionally, a chronic and life-threatening illness such as cancer affects not only the person diagnosed with the disease but also family members and loved ones. The resulting impact is an even larger number of individuals who could benefit from psychosocial support throughout their experience with cancer. Given the extreme need for mental health services, counselors who are

properly trained and prepared to practice in psycho-oncology should find ample opportunities to work and succeed in this field.

The report by the Institute of Medicine (2007) recognized that mental health counselors who receive the proper training have a role in providing psychosocial services to cancer patients:

Psychosocial health services are provided by licensed mental health providers, such as psychologists and counselors, who address psychological health as the primary purpose of their intervention. Their services are by definition “psychological,” their education and training can reasonably be expected to address psychosocial health care. For these practitioners, as for psychiatrists and social workers, the issue is how well prepared they are to serve those with acute and chronic health problems (especially when these problems can be life-threatening) and how well they are prepared to carry out key psychosocial interventions such as assessing social issues affecting the patient, coordinating care, and working with an interdisciplinary team (p. 251).

Based on the findings of the IOM (2007) report, there is an opportunity for the counseling profession to expand into psychosocial health care, as has happened in the field of psychology. For counselor educators, the question is how to train and properly prepare counseling graduate students to serve individuals with serious, life-threatening illnesses such as cancer. According to IOM, “Ultimately, the delivery of cancer care that addresses psychosocial needs depends on having a health care workforce with the attitudes, knowledge, and

skills needed to deliver such care” (p. 12). A conclusion that could be reached from the results of this study is that the wellness model—an approach used by professional counselors—is well suited to deliver psychosocial care to individuals with cancer. What many counselors seem to lack is the formal training in psycho-oncology that focuses on the knowledge and clinical skills necessary to successfully practice in this field.

### **Limitations**

In spite of the fact that medical research traditionally has been a quantitative inquiry, a growing interest has developed since the mid-1990s in qualitative methodology (Borreani et al., 2004). Even though qualitative inquiry is gaining increased acceptance within the medical field, according to Borreani et al. the validity of phenomenologically-based research remains largely unproven. Given the subjective nature of IPA research, it should be noted that the findings can be interpreted in a variety of ways.

With regard to this research study, one of the limitations of this research involved the modest number of participants in the study. A sample size of six participants is not sufficient to represent the study’s findings to the larger population of all cancer patients. The diverse characteristics and various cancer diagnoses and treatment regimens of the study’s participants further limit the applicability of the findings.

As the primary investigator for this study, it was my responsibility to make every effort to remain unbiased throughout the entire research process. Maintaining impartiality was especially important given the hermeneutic nature of the inquiry undertaken in this study. For the findings of this research to have relevance, it was critical that I remain unencumbered in my effort to understand the study’s participants as

they tried to comprehend the meaning of their cancer experience. Keeping an unbiased posture was certainly difficult at times as the stories I heard from the six participants sometimes touched my emotions.

During the interviews, I sometimes found myself thinking as a mental health counselor and wanting to provide supportive counseling services to the participants yet all the while knowing that my purpose for being there was to gather research data. This conflict challenged me to remain mentally aware of my role and the purpose of this research study as I interpreted the meaning of the participants' words. Despite my best attempts to maintain an unbiased perspective throughout the interpretative process, I likely made errors in understanding the true intent of participants' statements leading to false conclusions. Specifically, at times I relied on my professional experience as a cancer counselor to interpret the meaning of the participants' statements. At other times, I recalled on my personal experience as a caregiver for my mother and wife and applied that knowledge to understand how the study's participants experienced cancer. I believe my professional and personal experiences influenced my ability to remain unbiased resulting in a fundamental limitation of this study as the findings of a phenomenological inquiry rely largely on the interpretative skill of a single researcher.

It is important to note that the transcribed data in this study were not reviewed nor were the findings confirmed by other researchers. Had a peer review been conducted, researcher biases could have been checked and the accuracy of the interpretative process could have been confirmed. A peer review of the data was not undertaken in this study as I believed the research procedures followed throughout were consistent with the intent of IPA that relies on the interpretative skill of one researcher. It is my belief that the

inclusion of additional researchers in the interpretation of the data would be counter to the IPA process. However, it should be noted that the lack of peer review could be considered a limitation of this study.

### **Suggestions for Future Research**

The findings of this study highlight the potential that exists for further exploration of the cancer experience from a holistic perspective. Based on the results of this study, I believe future researchers could develop an instrument that holistically assesses the full range of supportive care needs. The instrument could be administered at specific times during the treatment regimen to quantitatively measure the changes that occur in patients' perceptions throughout the course of treatment. Additionally, a structured interview protocol could be developed that promotes a holistic, qualitative examination of the cancer experience at specific points of time during the treatment regimen. The combination of an assessment instrument and a structured interview into a mixed method design is the evidence-based approach needed to truly answer the research questions addressed in this study.

Specific domains of supportive care needs could be explored in greater detail as a way of holistically assessing cancer patients. In this study, cultural and gender related needs were not viewed by participants as having relevance to their experience coping with cancer diagnosis and treatment. The dearth of clinical research on the influence of culture and gender on individuals' ability to cope with cancer indicates that opportunities exist to study this domain of need to further the knowledge base. The emphasis in multicultural and gender-based training and practice in CACREP counselor education

programs makes licensed professional counselors well qualified to conduct research in this area.

Comprehensive wellness programs have been found to be effective in improving patient knowledge, coping skills, and confidence in managing a number of chronic illnesses, such as diabetes, heart disease, and arthritis (IOM, 2007). While some of these programs have been found to be effective in improving health outcomes, health self-management programs based on wellness similar to those that exist for individuals with other chronic illnesses have not been studied in individuals diagnosed and treated for cancer. Research in this area is needed to develop a comprehensive wellness program appropriate for people living with cancer at diagnosis, treatment, and survival.

The factors of wellness that comprise the *IS-Wel* (Witmer et al., 1998) could be further evaluated individually for applicability to coping with a chronic disease such as cancer. This study showed the potential value for cancer patients of such wellness factors as control, stress management, love, spirituality, and self-care. Future research into these factors could lead to the development of a coping model for cancer patients that is based on the concept of wellness. Such a model could be used to help individuals at various points in the disease continuum. Additionally, research on the application of wellness principles to coping with cancer could be separated by the primary disease site—for example, breast, prostate, lung, colon, blood—and by the stage of the initial diagnosis.

Another area that could be researched involves the theoretical differences between the various mental health professionals working in the field of psycho-oncology. Specifically, a study could be conducted on the approaches typically used by psychiatrists, clinical psychologists, social workers (i.e., licensed clinical social workers),

and mental health counselors (i.e., licensed professional counselors) to help individuals who are experiencing cancer. Research in this area could compare the efficacy of the wellness model traditionally used by counselors to the medical model, an approach commonly followed in psychiatry and psychology.

While four research questions were answered in this study, the very nature of inquiry opens the door to potentially many more questions that could be addressed by future research. Some possible research questions for future studies could include:

- What role does culture play in individuals coping with the diagnosis and treatment of cancer?
- What influence does culture have on the way African Americans cope with cancer?
- How does gender influence the manner in which women experience cancer diagnosis and treatment?
- What is the psychological and emotional impact of individuals losing their ability to work due to symptoms and/or treatment side effects of cancer?
- What is the efficacy of the wellness model in assessing the supportive care needs of cancer patients during treatment?
- How can a coping model based on the factors of wellness be developed for cancer patients?

### **Researcher's Personal Reflection**

Reflecting on my experience as a researcher, I was honored to have had the opportunity to hear the very real and personal stories of the participants. These are people attempting to deal with a terrible disease for which they had little preparation. For

each of them, their cancer diagnosis became a life-changing experience. From the moment their cancer experience began, these individuals searched for ways to understand and cope with the knowledge they have cancer. I had the utmost respect and all the empathy in the world for this study's participants as they fight to survive their disease.

My responsibility as a researcher was to remain unbiased as much as that is conceivably possible and to adhere to the established procedures for collecting and interpreting data. Within the context of this study, I made every effort to conduct myself in an ethical and professional manner. As a participant observer in this study, I acknowledge that I was profoundly affected by the research process. Specifically, reading and rereading the transcribed words of the participants made their stories seem more real to me. I was challenged to maintain objectivity when reading the participants' statements about the struggle to survive, the physical toll of cancer treatment, and the emotions associated with confronting a disease like cancer. For some reason, reading the words of the participants several times was more difficult than hearing them spoken during the interviews.

I will be forever grateful to John, Cheryl, Karen, Rachel, Barbara, and Susan for allowing me to come into their lives and for sharing their personal stories for the purpose of this study. Their honesty and courage to open themselves up to questions during a very difficult time is greatly appreciated. Their contribution in the name of research goes beyond the scope of this study as I will never forget my experience with them.

## POSTSCRIPT

At the time of this writing, it has been approximately five months since I conducted the last participant interview. During that time, the participants in this study have continued their experience with cancer. Some of them have completed their treatment regimen while others continue receiving chemotherapy or radiation therapy. For all the people in this study, cancer interrupted their life and seemed to change their perspective and view of the world in a real and meaningful way. What follows is the latest update on each of the participants in this study.

Following the final interview with John, he began receiving chemotherapy to reduce the size of the tumors in his lungs. Unfortunately, these treatments did not work as intended. Recently, John's physician told him that no other treatments are available to control the spread of his disease. As a result, John was referred to an inpatient hospice facility where he was admitted. Shortly after he arrived at the hospice facility, I visited with John to offer some support during this difficult time. We discussed a variety of topics including his perceptions of death and issues associated with the quality of his life at the end of life. As John expressed to me, "I've had a good life. At this point, all I want is a pain free end to it." John reported that his pain was being managed. He did not appear to suffer during his final days and, according to the hospice nurse, died peacefully in his sleep.

Cheryl received some good news recently when she got the results of her latest diagnostic test. She reported to me by email, "My PET scan turned out great and my doctor says the tumors are 'insignificant'. The nodules in my pelvis haven't gotten any

bigger. Just a few more, in my stomach lining and in my left lung, but so small that she is not worried. So we are sticking with the same chemo. So she is happy and so am I. I am rejuvenated to keep going!” I continue to receive periodic updates from Cheryl as she strives to maintain a normal life despite the lifestyle interruptions associated with cancer.

I recently spoke with Karen during her clinic visit and she told me she is doing fine with no lasting effects of her surgery. Karen indicated she sometimes feels down when she is reminded that she cannot have another child. The result of her most recent clinic exam indicated there is no cancer present. Her oncologist continues to tell her she is cured. Karen told me she only thinks about cancer on the days immediately before she returns for a clinic visit. She said, “I no longer think about cancer except when I have a check-up. Otherwise, I’ve moved on and consider that chapter of my life as being closed.”

Rachel returned to her medical practice and is once again helping the patients that she loves. While she reported feeling tired at times, she said her strength is coming back a little more every week. Rachel said her cancer experience has rejuvenated her to care for her patients in a holistic manner by focusing on all their needs. She was excited when she told me, “I was given so much care when I needed it, and it was care that addressed all my needs. I have a real appreciation for just what it takes to help someone with everything they are experiencing. Looking back on it, my experience with cancer has made me a better physician. More importantly, I believe I am a better wife, a better mother, and a better person.”

Since I last interviewed Barbara, she completed chemotherapy. She reported having some significant physical difficulties due to her chemotherapy treatments and

continued to be bothered by the loss of her hair. She told me, “I still have trouble looking at the bald person in the mirror and realizing that person is me.” Barbara mentioned she is beginning to laugh more about it which she said means, “I’m learning to live with cancer.” When we met, Barbara told me she was about to begin six weeks of radiation treatments. She indicated being tired of all the medical procedures but still believes she will survive cancer. I agreed to support Barbara in any way necessary to help her better cope with the remainder of her treatment. I continue to meet with Barbara for supportive counseling whenever she feels the need to talk.

I recently saw Susan and she reported feeling pretty good despite continuing to undergo cancer treatments. She told me fatigue had been a problem throughout her chemotherapy regimen. Susan reported she has experienced more “down feelings” lately which she referred to as “depression.” I agreed to get her the help with the psychosocial distress she may be feeling. Susan reported she continues to get a lot of support from her family which has helped her better deal with her cancer experience.

## **Cancer Does Not Have Me**

*A poem written by Cheryl, a participant in this study*

I have cancer  
But cancer does not have me.

Numerous chemos, CT scans and blood draws later  
And still cancer does not have me.

Cancer teases me,  
A tumor here and a tumor there  
saying, "Catch me if you can."

I can and I will,  
because cancer does not have me.

Cancer will not and cannot take  
away my memories, my future,  
my laughter and my tears.

"Wow you're stubborn," cancer says.  
And I reply, "You are right,  
I'm not going anywhere."

For I tricked cancer.  
Love, hugs, and kind words  
are my medicine to share.

So for each additional chemo,  
CT scan, or blood draw I can rejoice  
and say, "See I may have cancer, but  
cancer does not have me."

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## **APPENDICES**

Appendix A: Tulane University IRB Letter of Approval

Appendix B: University of New Orleans IRB Letter of Approval

Appendix C: Recruitment Letter

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Appendix E: Personal Characteristics and Treatment Plan Questionnaire

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Appendix I: Initial Interview Protocol

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Appendix K: Supportive Care Needs Assessment

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**Appendix A**

**Tulane University IRB Approval Letter**



Tulane Office of Human Research Protection  
Institutional Review Boards  
Biomedical  
Social Behavioral  
FWA00002055

September 12, 2007

Robert B. Gardner  
1415 Tulane Ave.  
HC-62  
New Orleans, LA 70112

Re: IRB Study # **07-00155** At: Tulane University Health Sciences

Dear Mr. Gardner:

We have received the following study as of 8/31/2007:

**Protocol Title:**

A Holistic Assessment of the Perceived Supportive Care Needs of Cancer Patients During Treatment (07-00155)

This New Study has received expedited approval granted 9/10/07 in accordance with 45 CFR 46.110(b)(1). It will appear on our agenda for the 9/13/2007 meeting date. It has been recorded in our system under our internal # 13757.

Please note that the study expires on 9/09/2008. You will receive renewal instructions approximately two months before your expiration date. Should you have any questions, please do not hesitate to contact the office at (504) 988-2665.

<b>Status Grid:</b>
Our Internal # <b>13757</b>
Meeting Date: <b>9/13/2007</b>
Expedited: <b>Yes</b>
<b>Pre Meeting Action: Approved</b>
Expiration Date: <b>9/09/2008</b>

Mark A. James, Ph.D.  
Chair  
Committee on Use of Human Subjects

1430 Tulane Ave., TW-36, New Orleans, LA 70112 – 2699 tel 504.988.2665 fax 504.988.3892 www.irb.tulane.edu

**Appendix B**

**University of New Orleans IRB Approval Letter**

**University Committee for the Protection  
of Human Subjects in Research  
University of New Orleans**

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*Campus Correspondence*

Dr. Louis Paradise  
Robert Gardner  
ED 348-G

10/2/2007

RE: A holistic assessment of the perceived supportive care needs of cancer patients during treatment

IRB#: 01aug07

The IRB has deemed that the research and procedures are compliant with the University of New Orleans and federal guidelines. Your project has received expedited approval (45 CFR 46.110(b)(1)).

Please remember that approval is only valid for one year from the approval date, which is the date of this letter. Any changes to the procedures or protocols must be reviewed and approved by the IRB prior to implementation.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best of luck with your project!  
Sincerely,

Laura Scaramella, Ph.D.  
Chair, University Committee for the Protection of Human Subjects in Research

**Appendix C**  
**Recruitment Letter**

## Participation in a Research Study

A research study entitled *A Holistic Assessment of the Perceived Supportive Care Needs of Cancer Patients during Treatment* is currently recruiting people who have been recently diagnosed with cancer. The purpose of this study is to describe the lived experience of individuals entering cancer treatment in an outpatient clinic by examining their perceived supportive care needs. Your participation will involve being interviewed about your experience as someone recently diagnosed with cancer. The interview is anticipated to last between 60 and 90 minutes at which time you will be asked open-ended questions about your cancer experience and your perceived supportive care needs. A follow up interview will be conducted after you complete one month of cancer treatment. This second interview is expected to take 45 minutes to complete. On both occasions, you will be asked to complete a written self-assessment instrument prior to the start of the interview session.

The primary risk associated with this study is that you will be asked to share personal information regarding your cancer experience following your diagnosis. Most patients have no difficulty talking about their cancer experience, so you may not experience this risk. You do not have to answer any question that you do not wish to answer. Due to the length of the interview, you may become tired or fatigued. Should that happen, you may take a break or choose to discontinue this interview.

Your participation in this research study is voluntary and will not be compensated. The benefits of participating in this study for you personally are minimal; however, you will be contributing to the scholarly research about assessing the supportive care needs of patients entering cancer treatment with the purpose of better understanding what needs are most prevalent and important to address.

The results of this study will be published in my dissertation; however, your name, identity, or institution will not be revealed. You will be assigned a pseudonym and the pseudonym will be used in the reporting of your comments. Your name will only be known to the researchers and any transcriptions of this interview will be kept in a locked file cabinet accessible only to the researchers.

If you are recently diagnosed with cancer and have not yet begun receiving treatment at Tulane University Cancer Center, you will be considered for participation in this research study. If you are interested in participating or if you want more information regarding this study, please contact Robert Gardner at ...

(office) 504-988-0844  
(cell) 504-256-4259  
(email) rgardner@tulane.edu

Thank you for your interest in this study.

**Appendix D**  
**Informed Consent**

## **Informed Consent**

Research Project: *A Holistic Assessment of the Perceived Supportive Care Needs of Cancer Patients during Treatment*

1. Robert B. Gardner, M.Ed. (504.256.4259; rbgardne@uno.edu) doctoral student under the supervision of Louis V. Paradise, Ph.D. (504.280.6026; lparadis@uno.edu) and April Watley Bedford, Ph.D. (504.280.6607; awhatley@uno.edu), faculty at the University of New Orleans, are requesting your participation in a research study entitled *A Holistic Assessment of the Perceived Supportive Care Needs of Cancer Patients during Treatment*. The purpose of the study is to describe the personal experience of individuals undergoing cancer treatment in an outpatient clinic by examining their perceived supportive care needs. Your participation will involve being administered written assessments and being interviewed on two occasions. The first interview will take place as you begin your cancer treatment. A second interview will be conducted approximately one month after starting treatment. The interviews are anticipated to last between 60 and 90 minutes at which time you will be asked open-ended questions about your cancer experience, and your perceived supportive care needs. On both occasions, written self-assessment instruments will be administered to you for you to complete shortly before the start of the interviews.
2. One risk associated with this study is that you will be asked to share personal information regarding your cancer experience following your diagnosis and receiving treatment. You do not have to answer any question that you do not wish to answer. Due to the length of the interview (60 - 90 minutes), you may become tired or fatigued. Should that happen, you may take a break or choose to discontinue this interview. Most patients have no difficulty talking about their cancer experience, so you may not experience any of these risks.
3. The benefits of participating in this study for you personally are minimal; however, you will be contributing to the scholarly research about assessing the supportive care needs of patients during cancer treatment with the purpose of better understanding what needs are most prevalent and important to address with patient entering their cancer experience.
4. You do not have to participate and are free to stop the interview at any time without consequence. Additionally, you are free to withdraw from this study at any point.
5. The results of this study will be published in my dissertation; however, your name, identity, or institution will not be revealed. You and your institution will be assigned a pseudonym and the pseudonym will be used in any reporting of your comments. Your name will only be known to the researchers and any transcriptions of this interview will be kept in a locked file cabinet accessible only to the researchers in number 1 above.

6. Participants may become tired or have some discomfort talking about past experiences. You are free to request a break as needed or decline to respond to any question.
7. Any questions you have about the study should be addressed with the researchers listed in number 1 above. Any other questions regarding research subjects' rights should be addressed to Dr. Richard Speaker at 504.280.6607.
8. Your participation in this research study is voluntary and will not be compensated. Refusal to participate will involve no penalty. You may discontinue participation at any time.

By signing this document, the participant acknowledges having read the Informed Consent form and understand the conditions of participation in the research study.

Participant:

Researcher:

\_\_\_\_\_

Date

\_\_\_\_\_

Robert B. Gardner

\_\_\_\_\_

Date

## **Appendix E**

### **Personal Characteristics and Treatment Plan Questionnaire**

## Personal Characteristics and Treatment Plan Questionnaire

Please complete this questionnaire by checking the appropriate answer that applies to you. The information you provide will remain confidential and not be disclosed to any person not involved in the research study.

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### Personal Characteristics

Age (yrs.): _____	Education (highest completed)
Gender	____ Elementary/middle school
____ Male	____ High school/GED
____ Female	____ Some college
Ethnicity	____ College
____ White	____ Graduate/professional school
____ African-American	Religion
____ Hispanic/Latin American	____ Catholic
____ Asian	____ Protestant
____ Other _____	____ Jewish
Marital status:	____ Other _____
____ Never married/single	____ None
____ Married	Employment:
____ Divorced/separated	____ Employed/currently working
____ Widowed	____ Employed/currently on disability
Annual household income: \$ _____	____ Unemployed/unable to work
Number of children: _____	
If you have children, what are the age(s): _____	

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### Treatment Plan

Primary cancer site:	Disease Stage:
____ Breast	____ Stage I
____ Gynecological	____ Stage II
____ Colon and rectum	____ Stage III
____ Lung	____ Stage IV
____ Other	
Treatment planned or received to date:	
____ Surgical removal of cancer	____ Hormone treatment
____ Chemotherapy	____ Participate in a Clinical Trial
____ Radiation therapy	____ Other _____

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## **Appendix F**

### **Psychosocial Distress and Coping Skills Self-assessment**



## **Appendix G**

### **Self-assessment of Wellness Scale**

### Self-assessment of Wellness Scale

*Instructions: Assess yourself on the following wellness factors. Respond first to “How well do you feel?” Circle the appropriate number on a linear scale for each factor with 1 meaning “completely ill” and 10 representing “completely well.” Next, rate “How satisfied are you with your level of wellness in this area?” Circle the appropriate number on a linear scale for each factor with 1 representing “not satisfied at all” and 10 meaning “totally satisfied.”*

<b>Thinking</b>	"Being mentally active, open-minded; ... the capacity to change one's thinking in order to manage stress; the ability to apply problem solving strategies to resolving social conflicts" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to thinking and your satisfaction with your thinking.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Emotions</b>	"Being aware of or in touch with one's feelings; being able to express one's feelings appropriately; being able to enjoy positive emotions as well as being able to cope with negative emotions" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to emotions and your satisfaction with your emotions.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Control</b>	"Beliefs about your competence, confidence, and mastery (i.e., 'I can'); belief that you can usually achieve the goals you set out for yourself; being able to exercise individual; ... being able to be direct in expressing one's needs (assertive)" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to control and your satisfaction with your control.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Work</b>	"Being satisfied with one's work; ... feeling that one's skills are used appropriately; feeling that one can manage one's workload; feeling a sense of job security; feeling appreciated in the work one does; having satisfactory relationships with others on the job; ... the ability to cope with stress in the workplace" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to work and your satisfaction with your work.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Positive Humor</b>	"Being able to laugh at one's own mistakes and the unexpected things that happen; the ability to laugh appropriately with others; ... the ability to use humor to accomplish even serious tasks" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to positive humor and your satisfaction with your positive humor.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Leisure</b>	"Activities done in one's free time; satisfaction with one's leisure activities; ... having at least one activity in which 'I lose myself and time stands still'; having a balance between work and leisure activities" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to leisure and your satisfaction with your leisure.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Stress Management</b>	"General perception of one's own self-management or self-regulation; ... on-going self-monitoring and assessment of one's coping resources; the ability to organize and manage resources such as time, energy, setting limits, and need for structure" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to stress management and your satisfaction with your stress management.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Self-worth</b>	"Accepting who and what one is, positive qualities along with imperfections; acceptance of one's physical appearance; affirming the value of one's existence; valuing oneself as a unique individual" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to self-worth and your satisfaction with your self-worth.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Realistic Beliefs</b>	"... The ability to perceive reality accurately, not as one might want or desire it to be; separating that which is logical and rational from that which is distorted, irrational, or wishful thinking; ... avoiding unrealistic expectations or wishful thinking" (Myers & Sweeney, 2005, p. 10).									
	Circle the number that best reflects your overall wellness related to realistic beliefs and your satisfaction with your realistic beliefs.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Friendship</b>	"Social relationships that involve a connection with others; ... having friends in whom one can trust and who can provide emotional, material, or informational support when needed; ... having a capacity to trust others; having empathy for others; feeling understood by others; having relationships in which non-judgmental caring is experienced; ... being involved in one or more community groups" (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to friendship and your satisfaction with your friendship.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Love</b>	"The ability to be intimate, trusting, and self-disclosing with another person; the ability to give as well as express affection with significant others; ... having at least one relationship that is secure, lasting, and for which there is a mutual commitment; ... having a family or family-like support system characterized by sharing spiritual values, the ability to solve conflict in a mutually respectful way, the ability to solve problems together, commitment to on another, healthy communication styles, shared time together, the ability to cope with stress, and mutual appreciation" (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to love and your satisfaction with your love.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Spirituality</b>	"Personal belief ... in a higher power; hope and optimism, worship, prayer, and/or meditation; purpose in life, compassion for others; moral values; and transcendence, or a sense of oneness with the universe" (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to spirituality and your satisfaction with your spirituality.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Gender Identity</b>	"Satisfaction with one's gender; feeling supported in one's gender ..." (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to gender identity and your satisfaction with your gender identity.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Cultural Identity</b>	"Satisfaction with one's cultural identity; feeling supported in one's cultural identity ..." (Myers & Sweeney, 2005, p.11).									
	Circle the number that best reflects your overall wellness related to cultural identity and your satisfaction with your cultural identity.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Self-care</b>	"Taking responsibility for one's wellness through self-care and habits that ... include obtaining timely medical care, wearing a seat belt; limiting the use of prescribed drugs and avoiding the use of illegal drugs; avoiding the use of tobacco; abstaining from or very moderately using alcohol; getting adequate sleep ..." (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to self-care and your satisfaction with your self-care.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Nutrition</b>	"Eating a nutritionally balanced diet, three meals a day including breakfast, consuming fats, cholesterol, sweets and salt sparingly; maintaining a normal weight, ... and avoiding overeating" (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to nutrition and your satisfaction with your nutrition.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Exercise</b>	"Engaging in sufficient physical activity to keep in good physical condition; maintaining flexibility in the major muscles and joints of the body through work, recreation, or stretching exercises; regular exercise and not overdoing it are important guidelines" (Myers & Sweeney, 2005, p. 11).									
	Circle the number that best reflects your overall wellness related to exercise and your satisfaction with your exercise.									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

Source: Myers, & Sweeney (2005)

**Appendix H**  
**Self-assessment of Wellness Scale—Revised**

### Self-assessment of Wellness Scale—Revised

*Instructions: The 17 factors of this scale are commonly associated with the concept of wellness. Within the context of this study, please assess yourself on each of these wellness factors on how you use each of them to help you in your life both now and in the past. You may choose to consider your cancer diagnosis and how that event has influenced each factor.*

*Respond first to “How well do you feel?” Circle the appropriate number on a linear scale for each factor with 1 meaning “completely ill” and 10 representing “completely well.” Next, rate “How satisfied are you with your level of wellness in this area?” Circle the appropriate number on a linear scale for each factor with 1 representing “not satisfied at all” and 10 meaning “totally satisfied.”*

<b>Thinking</b>	How much do you rely on your thinking to help you find answers to problems; your ability to think about problems to help you manage adversities in your life.									
	<i>Circle the number that best reflects your overall wellness related to thinking and your satisfaction with your thinking.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Emotions</b>	Being aware of and in touch with your feelings; being comfortable expressing your feelings when its appropriate									
	<i>Circle the number that best reflects your overall wellness related to emotions and your satisfaction with your emotions.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Control</b>	Your belief about having control over events in your life; setting goals and asserting yourself to achieve your goals.									
	<i>Circle the number that best reflects your overall wellness related to control and your satisfaction with your control.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Work</b>	Being satisfied with the work you currently do or have done in the past; how well have you been able to manage your work and balance work with other aspects of your life; feeling appreciated in the work you have done; your ability to cope with work-related stress									
	<i>Circle the number that best reflects your overall wellness related to work and your satisfaction with your work.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Positive Humor</b>	Being able to laugh at yourself when you make a mistake; using humor when unexpected things happen; laughing appropriately with others; using humor to help you cope with situations in your life even when they are serious									
	<i>Circle the number that best reflects your overall wellness related to positive humor and your satisfaction with your positive humor.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Leisure</b>	Placing importance on your free time; having at least one activity in which you can “get away from it all and forget about life”; having a balance between work and leisure activities									
	<i>Circle the number that best reflects your overall wellness related to leisure and your satisfaction with your leisure.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Stress Management</b>	Your perception of your ability to manage stress in your life; being able to monitor stress yourself without outside help; your ability to organize and manage resources such as time, energy, and setting limits in order to reduce stress									
	<i>Circle the number that best reflects your overall wellness related to stress management and your satisfaction with your stress management.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Self-worth</b>	Accepting yourself for who you are including your imperfections as well as your positive qualities; acceptance of your physical appearance; valuing your existence as a unique individual									
	<i>Circle the number that best reflects your overall wellness related to self-worth and your satisfaction with your self-worth.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Realistic Beliefs</b>	Your ability to perceive reality accurately, not as you might want or desire it to be; relying on logic and avoiding unrealistic expectations or wishful thinking									
	<i>Circle the number that best reflects your overall wellness related to realistic beliefs and your satisfaction with your realistic beliefs.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Friendship</b>	Having social relationships that involve interacting with other people; having friends in whom one can trust and who can provide emotional, material, or informational support when needed; having the capacity to trust other people; having empathy for others; feeling understood by others									
	<i>Circle the number that best reflects your overall wellness related to friendship and your satisfaction with your friendship.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Love</b>	The ability to be intimate, trusting, and self-disclosing with another person; the ability to give as well as express affection with significant others; having at least one relationship that is secure, lasting, and for which there is a mutual commitment									
	<i>Circle the number that best reflects your overall wellness related to love and your satisfaction with your love.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Spirituality</b>	Belief in a higher power; using worship, prayer, and/or meditation to help you during difficult times; having a compassion for others; relying on moral beliefs and values when making decisions about what to do									
	<i>Circle the number that best reflects your overall wellness related to spirituality and your satisfaction with your spirituality.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Gender Identity</b>	Your satisfaction with being a [man/woman]; identifying with and feeling supported by other people of your gender									
	<i>Circle the number that best reflects your overall wellness related to gender identity and your satisfaction with your gender identity.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Cultural Identity</b>	Your satisfaction with your culture; identifying with and feeling supported by other people with your cultural background									
	<i>Circle the number that best reflects your overall wellness related to cultural identity and your satisfaction with your cultural identity.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Self-care</b>	Taking responsibility for your health through your self-care and your personal habits that includes obtaining timely medical care; limiting the use of prescribed drugs and avoiding the use of illegal drugs; avoiding the use of tobacco; abstaining from or very moderately using alcohol; getting adequate sleep; wearing a seat belt when driving a car									
	<i>Circle the number that best reflects your overall wellness related to self-care and your satisfaction with your self-care.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Nutrition</b>	The importance of eating a balanced diet each day; your ability to actually eat a balanced diet everyday									
	<i>Circle the number that best reflects your overall wellness related to nutrition and your satisfaction with your nutrition.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

<b>Exercise</b>	How important is it for you to follow the recommended guidelines regarding exercise; you ability to actually exercise on a regular basis each week									
	<i>Circle the number that best reflects your overall wellness related to exercise and your satisfaction with your exercise.</i>									
Overall wellness	1	2	3	4	5	6	7	8	9	10
Satisfaction	1	2	3	4	5	6	7	8	9	10

Source: Myers, & Sweeney (2005)

**Appendix I**  
**Initial Interview Protocol**

## **Initial Interview Protocol**

### **Creative Self**

Global: *Describe your thoughts and feelings about your life at present.*

1. Probing: *How has your thinking helped you to solve problems that have come your way? (Thinking)*
2. Probing: *Describe the emotions you have had since being diagnosed with cancer. (Emotions)*
3. Probing: *What level of control do you believe you have over your life? (Control)*
4. Probing: *Describe your level of satisfaction with the work that you do now or have done in the past. (Work)*
5. Probing: *Describe how you use humor in a positive way to help deal with life's challenges. (Positive Humor)*

### **Coping Self**

Global: *How are you able to cope with life's challenges?*

1. Probing: *How do you like to spend your free time? (Leisure)*
2. Probing: *How are you normally able to handle stress? (Stress Management)*
3. Probing: *How has cancer affected your self-worth? (Self-worth)*
4. Probing: *How would you characterize your ability to perceive reality accurately? (Realistic Beliefs)*

### **Essential Self**

Global: *What do you think is the meaning of your cancer experience?*

1. Probing: *How has cancer affected your spiritual belief or faith? (Spirituality)*
2. Probing: *Describe how comfortable you are as a [man/woman]. (Gender Identity)*
3. Probing: *Describe how you see yourself from a cultural perspective. (Cultural Identity)*

### **Social Self**

Global: *Describe the support you receive from other people in your life.*

1. Probing: *Describe the social relationships that are important to you. (Friendship)*
2. Probing: *How much do you love and how much do you feel loved by others? (Love)*

### **Physical Self**

Global: *Describe your perception of your physical well-being in the past, present, and future.*

1. Probing: *Discuss the importance of taking care of yourself. (Self-care)*
2. Probing: *What value do you place on physical exercise? (Exercise)*
3. Probing: *Describe how important proper nutrition is to you in your everyday lifestyle. (Nutrition)*

**Appendix J**

**Initial Interview Protocol—Revised**

## **Initial Interview Protocol—Revised**

### **Creative Self**

*Global Question: Describe your thoughts and feelings about your life at present.*

*Probing Question: How did your cancer diagnosis alter your thoughts and feelings about your life?*

### **Factors of Creative Self**

#### **Thinking**

*Global Question: How has your thinking helped you to solve problems that have come your way?*

*Probing Question: In what way(s) have you used your thinking to help you cope with a cancer diagnosis?*

#### **Emotions**

*Global Question: Describe the emotions you have had since being diagnosed with cancer.*

*Probing Question: In what way(s) do you normally express your emotions?*

*Probing Question: How have your emotions helped you to cope or made coping more difficult following your cancer diagnosis?*

#### **Control**

*Global Question: What level of control do you believe you have over your life?*

*Probing Question: Was your view of control altered by being diagnosed with cancer? If so, how?*

#### **Work**

*Global Question: What type of work do you do, or have done in the past?*

*Probing Question: Describe your level of satisfaction with the work that you do now or have done in the past.*

*Probing Question: If you are not working at present, describe what you miss about work?*

*Probing Question: If you have had a change in your work status because of your cancer diagnosis/treatment, describe what you are now doing with the time you used to be dedicated for work.*

#### **Positive Humor**

*Global Question: Describe how you use humor in a positive way to help deal with life's challenges.*

*Probing Question: How have you used positive humor to help you cope with cancer?*

### **Coping Self**

*Global Question: How are you able to cope with life's challenges?*

*Probing Question: How have you been able to cope with cancer thus far?*

## **Factors of Coping Self**

### **Leisure**

*Global Question: How do you like to spend your free time?*

*Probing Question: How do leisure activities add to your life?*

*Probing Question: How has leisure activities helped you to cope with cancer?*

### **Stress Management**

*Global Question: How are you normally able to handle stress?*

*Probing Question: How has cancer affected your ability to manage stress?*

*Probing Question: In what way(s) have you learned to manage stress differently following a cancer diagnosis?*

### **Self-worth**

*Global Question: How has cancer affected your self-worth?*

*Probing Question: How important is it for you to see yourself in a positive manner?*

*Probing Question: How has cancer made it more difficult to maintain a positive self-image?*

### **Realistic Beliefs**

*Global Question: How would you characterize your ability to perceive reality accurately?*

*Probing Question: How has cancer affected your ability to maintain a realistic perspective?*

## **Essential Self**

*Global Question: What do you think is the meaning of your cancer experience?*

## **Factors of Essential Self**

### **Spirituality**

*Global Question: Describe your spiritual faith. How strong a faith do you believe you have?*

*Probing Question: When confronted with adversity in your life how have you used your faith to help you cope?*

*Probing Question: How has cancer affected your spiritual beliefs or faith?*

*Probing Question: How has your spiritual faith helped you to cope with cancer?*

### **Gender Identity**

*Global Question: Describe how comfortable you are as a woman.*

*Probing Question: In what way(s) has cancer affected your identity as a woman.*

### **Cultural Identity**

*Global Question: Describe how you see yourself from a cultural perspective.*

*Probing Question: How has cancer affected your cultural perspective?*

## **Social Self**

*Global Question: Describe the support you receive from other people in your life.*

*Probing Question: How has your social support (e.g., family, close friends, co-workers) helped you cope with cancer diagnosis and treatment?*

### **Factors of Social Self**

#### **Friendship**

*Global Question: Describe the social relationships that are important to you.*

*Probing Question: How have these friendships helped you since being diagnosed with cancer?*

#### **Love**

*Global Question: How much do you love and how much do you feel loved by others?*

*Probing Question: What role do you think love has played in helping you to cope with difficulties and challenges you have faced during your life?*

*Probing Question: How has your view of love changed since being diagnosed with cancer?*

## **Physical Self**

*Global Question: Describe your perception of your physical well-being in the past, present, and future.*

### **Factors of Physical Self**

#### **Self-care**

*Global Question: Discuss the importance of taking care of yourself.*

*Probing Question: How has a cancer diagnosis changed the way you care for yourself?*

#### **Exercise**

*Global Question: What value do you place on physical exercise?*

*Probing Question: How has being diagnosed with cancer altered your view of exercise?*

#### **Nutrition**

*Global Question: Describe how important proper nutrition is to you in your everyday lifestyle.*

*Probing Question: How has cancer changed your view of proper diet and nutrition?*

**THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY.**

**Appendix K**  
**Supportive Care Needs Assessment**

## Supportive Care Needs Assessment

### Supportive Care Needs

*Instructions: Circle the number that best describes your rating for each of the items listed below.*

**Physical needs:** Physical side effects of cancer treatment are commonly reported by patients following surgery, chemotherapy, and/or radiation therapy. Commonly reported physical symptoms of cancer treatment include fatigue, nausea, and hair loss. The treatment side effects along with symptoms related to the disease often results in patients developing a physical need.

Rate your physical needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your physical needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your physical needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Psychosocial needs:** Psychological and emotional concerns are a common and prevalent aspect of cancer diagnosis and treatment. Psychosocial needs are associated with degrees of emotional and psychological distress (e.g., depression, anxiety) or limitations on emotional functioning.

Rate your psychological and emotional needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your psychological and emotional needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your psychosocial needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Social support needs:** Social support need is often associated with activities related to family, friendships, and other relationships that exist at home, work, and elsewhere.

Rate your social support needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your social support needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your social support needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Communication and information needs:** Every person differs in the type and amount of information they need. The manner in which information is conveyed to patients by their physician and other medical professionals can lead to a need for better communication.

Rate your communication and information needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your communication and information needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your communication and information needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Sexual and intimacy needs:** Cancer treatments often cause physical and psychological changes that impact a person's sexual health. The threat that cancer poses to one's sexuality ranges from disfigurement, infertility, and impotence to fatigue, discomfort and hair loss.

Rate your sexual and intimacy needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your sexual and intimacy needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your sexual and intimacy needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Occupational/work-related needs:** The importance of employment for people with cancer goes beyond satisfying financial need. For many people, work represents an important part of their life and the loss of work, even temporarily can be difficult.

Rate your occupational/work-related needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your occupational/work-related needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your occupational/work-related needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Financial resource needs:** The impact of cancer is certainly felt in a person's ability to continue to earn income through work. Such a situation can cause cancer patients and their families to experience a financial crisis in which a resource need develops.

Rate your financial resource needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your financial resource needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your financial resource needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

**Spiritual and existential needs:** Spiritual need is based on the notion that a serious illness can strengthen faith or it can challenge spiritual beliefs thereby causing people to begin questioning their faith. Existential need is grounded in the belief that people strive to find value, meaning, and purpose in their lives. A life-threatening illness such as cancer is an experience that can often facilitate an existential search for meaning and purpose.

Rate your spiritual and existential needs before beginning cancer treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

Rate your spiritual and existential needs at the present time.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
low moderate high

During your cancer treatment, how important has it been for you to get help with your spiritual and existential needs.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not important moderately important very important

=====

**Coping Skills**

*Instructions: Circle the number that best describes your rating for each of the items listed below.*

Rate how well you believe you coped with cancer after your diagnosis but before beginning treatment.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not well moderately well very well

Rate how well you believe you have coped with cancer treatment thus far.

1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_ 5 \_\_\_\_\_ 6 \_\_\_\_\_ 7 \_\_\_\_\_ 8 \_\_\_\_\_ 9 \_\_\_\_\_ 10  
not well moderately well very well

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**Appendix L**  
**Follow-up Interview Protocol**

## Follow-up Interview Protocol

### Supportive Care Needs

1. *Ask participants to explain their responses to the supportive care needs assessment inventory on their supportive care needs. Ask participants to cite specific examples of how their needs have been met or what barriers exist that prevents their needs from being satisfied.*

- Physical needs**
- Psychosocial needs**
- Social support needs**
- Communication and information needs**
- Sexual and intimacy needs**
- Occupational/work-related needs**
- Financial resource needs**
- Spiritual and existential needs**

### Coping and Wellness

2. *Ask participants to explain their responses to the supportive care needs assessment inventory on coping and the factors of wellness. Ask participants to cite specific examples of how they have used these factors to help them cope with their cancer experience.*

- Thinking** – using your thoughts and analytical ability to help you understand your experience; not over-thinking what you are experiencing
- Emotions** – letting out your emotions when appropriate; not ignoring your feelings but embracing them in a positive way
- Friendships** – allowing friends to help you when you need the help; staying in contact with close friends and not shutting them out
- Work** – continuing to stay involved in work-related activities even though you are not working; maintaining contact with co-workers

- Leisure** – using leisure activities to distract you from your illness; trying some new hobby or activity that you have not tried before
- Stress Management** – being aware of the stress you are feeling and managing it in an appropriate way
- Self-worth** – maintaining a positive view of yourself in spite of the physical changes you may be experiencing
- Realistic Beliefs** – keeping realistic thoughts about what you are experiencing; checking unrealistic thoughts when they enter your mind
- Positive Humor** – using laughter to relieve stress; continuing to enjoy life even during a difficult experience
- Control** – staying in control of your thoughts and emotions by not letting them get control of you; giving up control to others when appropriate
- Self-care** – taking care of yourself in spite of your illness; maintaining a desire to be attractive
- Exercise** – remaining physically active as much as that is presently possible; acknowledging the importance of exercise to good health
- Nutrition** – eating a proper diet as much as that is presently possible; recognizing the importance of nutrition to good health
- Spirituality** – relying on your spiritual faith to get you through; putting into practice your spiritual beliefs when confronted with a big challenge
- Love** – allowing those around you to love you; loving others back for all the love and support they give you

## VITA

Robert Blanchard Gardner was born and raised in Memphis, Tennessee. In 1982, he earned a Bachelor of Science in Business Administration from Auburn University. More recently, in 2005, Robert completed the program requirements for a Masters of Education degree in Counseling with a focus in community counseling, and completed the requirements for the Doctor in Philosophy degree in Counselor Education at the University of New Orleans in August 2008.

Robert is a Licensed Professional Counselor (LPC) in the state of Louisiana and he is also a National Certified Counselor (NCC). Robert has provided supportive counseling to a variety of clients as a counseling intern at Tulane University Hospital and Clinic and Tulane University Cancer Center where he focused much of his clinical practice on counseling people diagnosed and receiving treatment for cancer. Since March 2006, Robert has been employed at Tulane University Cancer Center as a clinical mental health counselor and patient navigator where he began a cancer orientation program to help recently diagnosed patients and their families proactively identify their supportive care needs. Robert has presented at state and national conferences on a variety of topics related to the counseling profession and the field of psycho-oncology.

## **Glory, Glory**

*A poem written by Cheryl, a participant in this study*

Finally, today, I stand in front of the mirror

And I like what I see.

I look, really look.

I sing, I dance, and I'm free.

My face in the mirror, my bright eyes staring back at me.

My crows' feet, my laugh lines, and my freckles;

Just more evidence that I'm still here.

I smile and I can finally say;

I really love what I see.

My face in the mirror, my mouth opens, my toes move

And my heart sings.

Glory, Glory – I'm still here.