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TREATMENT DECISION-MAKING IN OLDER ADULTS WITH CANCER

by

Maribeth McCullough Hercinger

A DISSERTATION

Presented to the Faculty of

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TREATMENT DECISION-MAKING IN OLDER ADULTS WITH CANCER

Maribeth McCullough Hercinger, Ph.D.

University of Nebraska, 2007

Advisor: James A. Thorson

Decision-making for cancer treatment is becoming more and more complex and individuals are expected to be active participants in this process. As the diagnosis of cancer occurs more frequently among adults, health care professionals must be accountable to place a greater emphasis on assisting individuals with the difficult treatment decisions.

This study explored the experiences of older adults when making decisions for cancer treatment using a phenomenological approach. Thirteen in-depth, face-to-face interviews were completed with individuals who experienced a new diagnosis of cancer. Participants of the study included eight females and five males ages 51-83 years of age. Five major themes emerged in the present study: (1) importance of relationships, (2) communication, (3) spirituality, (3) positive coping, and (5) powerlessness. Powerlessness or lack of control was highlighted as one of the strongest themes. Psychosocial influences of the treatment decision-making process were voiced most frequently. The treatment decision-making process came into view as an ongoing, non sequential, interactive process that is complex with many influencing factors.

The implications of the present study are presented in relationship to the health care professionals' role with an emphasis on nursing. An understanding of the individual's unique perspective, including an assessment of the cancer patient's social, physical, psychological and spiritual needs and desires should be at the base of all nursing care. The results from the present study may add to the limited knowledge of the individual's perspective of the treatment decision-making process. Acknowledging the uniqueness of the older adult cancer patient's experience of treatment decision-making may assist health care providers to provide appropriate supportive care and improve their quality of life during this difficult process.

Treatment Decision-making in the Older Adult with Cancer

“You are not protecting me from anything; it’s a matter of including me...” Andrew

Chapter 1

Introduction to the Study

Decision-making for cancer treatment is becoming more and more complex, and individuals are expected to be active participants in this process. Consumers demand that health care professionals communicate and collaborate with them on decisions that will affect their lives. The number of older adults with cancer is rising, and health-related costs will continue to increase. The American Cancer Society (ACS) (2005) estimates approximately 1.4 million new cancer cases in the U. S. population for 2005 and an estimated five year survival rate of 85%. Cancer in older adults is a growing concern because of the burden it places on individuals and families. Cancer incidence and cancer-related mortality are higher in older populations (ACS, 2005). It is estimated that 60% of all cancers occur in those over the age of 65 (Ries et al., 2000 as cited in Oncology Nursing Society and Geriatric Oncology Consortium Joint Position on Cancer Care in the Older Adult, 2004). It is estimated that in the U. S. the population over the age of 65 is expected to double to 70 million by the year 2030, and this group will be racially and ethnically diverse (Center for Disease Control [CDC], 2000). This population’s health care expenditures will approach \$400 billion annually (CDC). Only recently has there been a focus on older adults with cancer in research studies. However, most of these studies concentrate on those who are undergoing treatment or who have survived cancer.

We know little about the specific experiences of older adults during the time they are making decisions for cancer treatment.

After the individual has been informed of treatment options, it is often the nurse who is the one who plays a vital role in the understanding and interpretation of the complexities patients have laid out before them. Therefore, nursing professionals must place a great emphasis on helping the adult work through all phases of care including the initial diagnosis. Comprehensive appreciation of the decision-making process may improve the quality of care for this vulnerable population.

This qualitative, phenomenological study was completed to understand the experience of the older adult with cancer when making treatment decisions. A review of the significance of cancer to the older adult, a description of this population and issues related to quality of life (QOL), the issues of decision-making in treatment for cancer, and the role of the nursing professional in the care of the older adult with a diagnosis of cancer are addressed in this paper.

Purpose Statement

The primary purpose of this study was to understand the experience of the older adult during cancer treatment decisions. The phenomenon of treatment decision-making from the individual's perspective was investigated. Qualitative research is an inquiry process that explores a human problem (Creswell, 1998). This study examined the fundamental nature of the older adults' cancer treatment decision-making processes from a personal perspective. The results of this study contribute to the evidence of the lived experience of this difficult process and ultimately may improve the individual's quality of life (QOL).

Significance of this Study

Cancer is often considered to be a disease of the elderly, and it has an overwhelming impact on the quality of life of those individuals who are diagnosed with this disease. When confronted with the making of decisions for cancer treatment the individual with cancer has his or her life turned upside down. Complex treatment decisions are required under very challenging circumstances. Decisions are influenced by chronological age, knowledge of the treatments themselves, family perceptions and beliefs, potential biases of ageism, comorbid diseases, cognitive function, and functional status (Monfardini, 1996). This terrifying ordeal is made more difficult because large amounts of information bombard the cancer patient, and these decisions must be made in a short period of time. It is imperative that health care professionals develop insight into the older adult's treatment decision-making process to improve quality of health care. When faced with a decision for cancer treatment, older adults are challenged with difficult choices. Having just heard the devastating news of a new diagnosis of cancer, these individuals must make decisions under stressful situations.

A qualitative approach was chosen for this study for it seeks to uncover pertinent issues involved in the decision-making process for the older adult. This inductive method to collect data seeks to uncover new understandings of this very personal decision-making process for cancer treatment.

When diagnosed with cancer, many consider it to be a disease with "both medical and emotional" impacts (Lenhard, Lawrence, & McKenna, 1995, p. 64). The cancer diagnosis creates anxiety throughout all phases of the cancer experience and impacts the individual, the family, and also the health care provider. A fear of death may be a primary

concern of a newly diagnosed cancer patient, and this fear is rooted in feelings of uncertainty (Shell & Kirsh, 2001). The person may feel overwhelmed by all the information, the anxiety of the situation and the complex treatment decisions that must be undertaken.

The oncology nurse is in a position to assist the patient to cope with the diagnoses and assist with the decision-making process. If nurses have a better understanding of the cancer treatment decision-making process, these patients can be provided with the support that they need and deserve. All health care professionals must understand the experience of treatment decision making from the cancer patient's perspective to be able to plan strategies to individualize care.

Age is no longer considered a primary standard for treatment of cancer, and health care professionals must make an effort to reduce age bias by patients, families, and health care professionals (Coleman, Hutchins, Goodwin, 2004). However, the current push to include the older adult in treatment regimens and research trials may put tremendous demands on them. Stressors on the older adult may be compounded and possibly lead to hasty treatment decisions. Empirical evidence demonstrates that the older person with cancer has unique needs (Oncology Nursing Society, 2004). An improved understanding of the decision-making process by the older adult will assist the health care professional to enhance the quality of care for cancer patients.

Research Questions

The grand tour question for this study was as follows:

“What is the experience of the older adult when making decisions for cancer treatment?”

This qualitative study was guided by the following research questions:

1. From the perspective of the person with cancer, what is the process of the treatment decision?
2. What or who are the influences in the decision-making process when older adults decide on treatment for a new diagnosis of cancer?

Conceptual Framework, Definitions, and Phenomenological Philosophy

Although individuals with cancer and their families make difficult decisions throughout their journey with cancer, there currently is no accepted theoretical framework for assisting patients with decision-making, and a dearth of research on the older adult and decision-making exists. The intent of the present research study was to increase an understanding of the older adult's treatment decision-making process when confronted with a new diagnosis of cancer. The tradition of inquiry proposed for this research is phenomenological. The philosophical assumption for this study is ontological, for the researcher feels that the reality is subjective and multi-factorial and is best seen from an individual's perspective (Creswell, 1998).

The chosen philosophy for this phenomenological research study is derived from Maurice Merleau-Ponty. This philosophy includes "both a philosophy of essences (Husserl) and a philosophy of existences (Heidegger)" (Macann, 1993, p.161). Merleau-Ponty's inclusion of both a world view and a scientific view provides a perspective that matches this research study. Cancer treatment is a very scientific perspective, but the individual with cancer can perceive the world in a unique way due to individual experiences. The perceptions of the individuals will provide meaning of the experience and includes the relational and cultural contexts (Thomas, 2005). Therefore, this

philosophy complements the experience of the cancer treatment decision-making process for it is believed to include these contexts.

Definitions were used to guide the study by bracketing the data to the naturalistic setting in which the decision for cancer treatment was made and provides a basis for the criterion sample used for the study. In this research study, the following definitions were used:

1. Decision-making: The process by which an older cancer patient decides whether to accept or decline treatment.
2. Process: “a series of related events that follow in sequence from a particular state or condition to a conclusion or resolution” (Mosby, 1994, p. 1278).
3. Older Adult Cancer Patient: Older Adult Cancer Patient: A person 50 years of age or older who is confronted with a new diagnosis of cancer.
4. New Cancer Diagnosis: A new cancer diagnosis is considered to be the first cancer diagnosis or a new primary cancer diagnosis and not a metastasis of a previous cancer.
5. Treatment: Treatment for cancer is the accepted treatment for cancer including surgery, chemotherapy, radiation, and/or biological response modifiers for the goal of cure or palliation.
6. Quality of Life: is “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to goals, expectations, standards, and concerns...affected in a complex way by the person’s physical health,

psychological state, level of independence, social relationships, and relationships to salient features of their environment” (World Health Organization [WHO], 2006).

These definitions provide a background to guide the study. The definitions were purposively broad to capture the individual’s personal point of view. For example, the WHO definition includes a perspective that can be used to describe the personal impact of the cancer experience.

Assumptions, Limitations, and Delimitations of the Study

Assumptions

This study had the following assumptions:

1. The participants in the study will report their honest perceptions and feelings about the treatment decision-making process.
2. The older adults will be able to recall the influences of their treatment decision-making processes retrospectively.
3. Although no treatment decision-making experiences will be exactly the same, it will be assumed that the respondent will describe an essential process that can be described verbally in an interview

Limitations

This study has the following limitations:

1. Because this is a qualitative study, the results may not be generalized beyond the sample itself.
2. The older adult population is heterogeneous, and therefore the sample will be unable to include all possible characteristics of the older adult with cancer.

3. Although personal experiences will be attempted to be set aside in the analysis, the individual researcher's perspective may impact the data interpretation.

Delimitations

The following are delimitations of this study:

1. This study was delimited by older adults over age 50 years. Although the age of 65 is considered to be the age of retirement in our society, individuals are retiring earlier. The older middle aged adult (50-65 years old) may bring an important perspective in this process and was included in this study.
2. This study was delimited by adults with a new diagnosis of cancer and a decision for a cancer treatment was accepted or rejected in the last 6 months to enhance accuracy and completeness of the experience's description.
3. The data from the study was analyzed from a perspective of an experienced nursing professional.

Overview of the Study

A phenomenological study was conducted to gain insight into the treatment decision-making process of the older adult with cancer. The purpose, significance, research questions, assumptions and limitations were presented in the current chapter. Chapter Two reviews relevant literature. Chapter Three discusses the methodology of the study. Chapter Four reports the findings, and Chapter Five interprets those findings and discusses their implications.

Chapter 2

Literature Review

Introduction and Purpose of the Study

This qualitative, phenomenological study was completed to capture the experience of the older adult with cancer when making treatment decisions. The literature review encompasses cancer and the older adult, quality of life issues with cancer patients, and cancer treatment decision-making.

Cancer and the Older Adult

The Older Adult

The older cohort is considered to be one of the fastest growing groups in North America, and they are considered to be a dynamic and ever changing population (Thorson, 2000). Twenty percent of the U. S. population will be over age 65 by the year 2030 compared with 12.4% in the year 2000 (CDC, 2000). In the year 2000 there were 232,195 residents, or 13.6% of the population, who were age 65 or older in Nebraska (United States Census Bureau, 2000). Projecting at least a 20 percent increase by the year 2030, the population of Nebraska's older adults will be nearly 280,000. As the population is aging, it is also becoming more diverse. The US Census Bureau estimates that by the year 2050, Hispanics will be nearly 25% of the population and another 25% will be Blacks, Asian Americans, and Native Americans. Also, diversity exists within the older adult population. They are no longer thought of as just one group but three different groups. The first is the 'young old' group who is aged 65 to 74 years of age. Those over 75 years of age are considered to be the 'old, old' group. The third and fastest growing group includes the 'oldest old,' those individuals age 85 and older (Thorson). The

definition of age is not clear among older adults, for physiologic age does not always reflect the chronologic age (Balducci, 2000). Astute and comprehensive assessments must be used to establish aging effects, disease and disability. There is an increased incidence and prevalence of chronic diseases and of functional dependence in the older adults and those over 85 have an increased risk of frailty and a 50% greater risk of dementia (Balducci, 2000). These challenges dictate that health care professionals evaluate the care of this vulnerable population.

As age increases, so does cancer. The number of older adults with cancer will continue to increase and will ultimately require an even more substantial allocation of health care resources due to greater morbidity and mortality in this group (Ershler, 2003). Health care management of the older population needs to take into consideration existing physical impairments, polypharmacy with the possibility of drug interactions, risks with route of delivery of treatments, travel for treatments, treatment related functional and psychological impairments, and cognitive impairments (Ershler, 2003). Complications of cytotoxic chemotherapy are more common in patients over 65 and can complicate the treatment regimen (Repetto, 2003). The cause of these toxicities may be age-related physiological changes, a decline in organ function, existing comorbidities, pharmacological therapy interactions (existing medications plus chemotherapy), and greater severity of the effects of bone marrow suppression (Repetto, 2003). Less than desired outcomes will ensue if these clinical problems are not managed effectively in the older adult.

Poorer outcomes in older cancer patients may be partially due to under treatment of their cancer from a belief that the elderly cannot tolerate the toxicities of treatment

regimens (Dale, 2000). Under-representation in randomized controlled trials has led to limited data on the efficacy of treatment for the older adult cancer patient. This under treatment and under representation is considered to be from individual preferences, a lack of specific data on efficacy in this population and/or from a tendency for health care providers to treat according to chronological age and not physiological age. Data on efficacy in this population and treatment guideline development for the older adult and improved management of treatment toxicity can reduce the age bias (Dale, 2000).

The National Cancer Coalition Network (NCCN) (2004) has responded to the need of a reduction in ageism through development of a clinical practice guideline called “Senior Adult Oncology.” The NCCN is a network of 19 major cancer centers in the U.S. that have presented a series of cancer guidelines as consensus statements and are based on the current available evidence. The recent guideline on the older oncology patient presents the issues of geriatric screening and assessment with the Comprehensive Geriatric Assessment (CGA) tool, preventing or decreasing complications from therapy, accounting for disease-specific issues, and management of patients unfit for standard cancer treatment (NCCN). However, this guideline does not assist health care professionals in understanding the treatment decision-making process or the pertinent psychosocial issues that are encountered by the older adult with a new diagnosis of cancer. The process of treatment decision-making is complex and therefore a greater understanding is needed about the patient’s perspective.

Quality of Life Issues with Cancer Patients

Health care research has evolved from focusing on morbidity and mortality to quality of life aspects. Increased survival time of patients has occurred in today’s health

care arena due to improved treatment regimens and active participation in health care. This extended length of life has increased the demand for an emphasis on improved quality of life. The older cancer patient's life is impacted in many ways throughout the cancer experience and extends from the time just prior to diagnosis to the post treatment phase. With emphasis on quality of life in care and the acknowledgement that the initial diagnosis of cancer greatly affects the individual, a more detailed discussion on this phenomenon is warranted to support the proposed study.

In an extensive review, Haas (1999) noted that over 7,000 articles on quality of life were found in a search on this topic and 1,022 of 4,000 articles in a recent four year period were related to quality of life in cancer patients (King, et al., 1997). The activities of the Oncology Nursing Society and the Oncology Nursing Foundation have demonstrated evidence of support through funding of research studies, nationally funded workshops for clinical nurses, annual awards to recognize quality of life issues, and lectureships (King, et al.). The Oncology Nursing Society has continued to rank quality of life as a top research priority for this professional nursing organization (Berger, et. al., 2005). It is apparent that the issues of quality of life provide an overarching impact for all aspects of care of the cancer patient.

Definition and Dimensions of Quality of Life

Quality of life (QOL) is a term that is frequently used in professional health care literature, in practice discussions and in popular literature. However, the definition of QOL is not interpreted or defined in a consistent manner. This has lead to difficulty in measurement and evaluation. Strong clinical application and research interest in QOL

may be threatened by the current lack of agreement on how to define, describe, and validly measure QOL for individuals with cancer (King, et al., 1997).

Despite the variation in descriptive terms, some general themes in describing QOL were the feeling of satisfaction with one's life, the ability to evaluate one's life as satisfactory, and an acceptable state of physical, mental, social, and emotional health (King, et al., 1997). Most of the cancer literature supports QOL as a multidimensional concept (Cella, 1998; Grant, Padilla, Ferrell, & Rhinere, 1990; King, et al.; Winningham, et al., 1994), one that is dynamic (King, et al.), and one that is subjective and should be viewed from an individual's perspective (Cella & Tulksy, 1990; Ferrell, 1996; Haas, 1999; Nail & Jones, 1995).

Although the definition of QOL does not have consensus in the literature, this concept is considered multidimensional and complex (Zebrack, 2000). Domains are noted to be anywhere from three to seven categories. Ferrell and colleagues (1996) and Haas (1999) describe QOL as having four dimensions including physical, psychological, social, and spiritual. Factors influencing the lack of agreement in QOL definitions may be its many diverse indicators, the situational perspective, the abstract nature of the concept, and its multiple overlapping sub-concepts (Mast, 1995).

Ferrans and Powers (1985, p. 16) define QOL as "an individual's perceptions of well-being that stems from satisfaction or dissatisfaction with dimensions of life that are important to the individual. The dimensions are health and functioning, psychologic/spiritual, family, and social and economic. Although one global definition may not capture all of the status of the individual, this description provides a perspective that can

be used to describe the personal impact of the cancer experience, including the cancer experience of the older adult.

Quality of Life and Cancer

As health care professionals have come to realize the importance of caring for the total person including physical, psychological, social and spiritual aspects of care, outcome measures are including QOL along with mortality (Dolbeault, Szporn & Holland, 1999). Most studies on QOL in cancer have been descriptive in nature. These investigations have been primarily among the breast cancer population (Berger & Walker, 2001; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Longman, Braden, & Mishel, 1999).

Ferrell and colleagues (1998) surveyed 298 survivors of breast cancer (age 40-60 years of age). Their results indicated the symptoms of pain and fatigue had continued to be a burden even after treatment regimens were completed. Psychological burdens related to fear of recurrence of patient's cancer were also identified.

Longman and his colleagues (1999) completed a descriptive, experimental study of 53 women with breast cancer receiving treatment exploring the side-effects burden experienced over time using the Side Effects Checklist. Overall life quality was significantly associated negatively with overall severity of side-effects burden and the number of side effects at all three time points (Longman, et al.). Although not specifically in the older adult population, this research provides support to develop specific strategies to manage symptoms in this population.

Cancer-related fatigue (CRF) is a common and significant problem in the life of cancer patients (Nail, 2002; Ream & Richardson, 1999). Fatigue is being recognized as a

frequently occurring and problematic symptom for cancer patients, and its impact on the more global issues of quality of life is gaining interest in the literature. The view of fatigue in cancer patients from a holistic approach, including physical and psychological perspectives, acknowledges its interaction with other symptoms and the impact on QOL issues. The impact of CRF has consistently been reported as negative, and its incidence is greater than 50% (Andrykowski, 2000; Blesch et al., 1991; Cella, Davis, Breitbart, & Curt, 2001; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; and Vogelzang, et al., 1997). CRF has been reported to cause significant reduction in physical functioning (Mock, et al., 2001) and to be more disruptive to daily activities than pain (Vogelzang, et al.). The issues of functioning and pain are pertinent to the older adult cancer population. The treatments of cancer have been reported to be associated with the fatigue experience (Haylock & Hart, 1979; Irvine et al., 1994; Messias, Yeager, Dibble, & Dodd, 1997; Richardson, Ream, & Wilson-Barnett, 1998; Woo, et al., 1998). Fatigue has been found to fluctuate over the course of cancer treatment (Berger & Higginbotham, 2000; Irvine, 1998) and may persist after treatment is completed (Andrykowski, 1998; Winningham, et al., 1994).

In a longitudinal study, Irvine and colleagues (1994) used a modified version of the Associated Symptom Subscale of the Piper Fatigue Scale to measure symptom distress in 143 breast, prostate, lymphoma, and ovarian cancer patients. This scale was reported to assess the degree to which subjects experienced 13 symptoms common in patients receiving radiation therapy. Irvine and associates (1994) found fatigue to be significantly related to symptom distress and psychologic distress. The most frequently reported self-help strategies were to sit and sleep, with exercise the least reported strategy

except at three months after treatment. Fatigue significantly increased over the course of the treatment, was highest at the last week of treatment, and returned to pretreatment levels by three months post treatment (Irvine, et al.). Using the Sickness Impact Profile, these authors found significant alteration in functional activities during treatment.

The simultaneous experience of symptoms of cancer has been reported by researchers (Dodd, Miakowski, & Paul, 2001; Given, Given, Azzouz, Kozachik, & Strommel, 2001). A recent research focus on evaluating the relationships among multiple symptoms is beginning to be seen in the literature and has been called symptom clusters (Dodd, Miakowski, & Paul, 2001 Sarna, 1998). Symptoms are thought to act synergistically (Dodd, et al, 2001).

Psychological factors are important when examining QOL and symptom distress. In a descriptive correlational secondary analysis of 263 cancer patients undergoing chemotherapy, positive correlations between insomnia, fatigue, depression, and anxiety were reported, and all were negatively correlated with QOL (Redeker, et al., 2000). Measurement tools included the FACT-G scale, the Profile of Mood States, and The Symptom Distress Scale. These authors also found that older age was associated with a higher QOL and lower insomnia, higher anxiety and depression. Hierarchical regression was used to further evaluate the variables in this study. Fatigue and insomnia explained 32% of the variance in QOL in the first equation. The variables explaining the greatest proportion of the variance in QOL were fatigue, depression, and anxiety. The single item measures of fatigue and insomnia and the relationships of other dimensions of symptoms to psychological factors and QOL may limit the usefulness of their findings (Redeker, et

al.). The absence of information on the clinical course of cancer progression, treatment and the presence of comorbid diseases may impact QOL.

Treatment for cancer in the older adult may be altered because of comorbid conditions experienced by older people (Green & Hacker, 2004). These conditions may confound the side effects of chemotherapy, and the multiple medications may increase their risk for complications (Green & Hacker). Investigations in the elderly have demonstrated that comorbidities had a negative impact on the cancer patient's functional status and ultimately their recovery (Hodgeson, & Given, 2004; Sammarco, 2003). Reduced level of function and longer recovery may influence the older adult's QOL.

Comorbid conditions were investigated in a large case comparison of 15,626 population-based incident cases of cancer examining the prevalence of comorbidity in patients, and its relationship with multiple demographic and clinical variables (Ogle, Swanson, Woods, & Azzouz, 2000). They found comorbidity in 68.7% of cancer patients. Greater than 32% of these individuals had more than two comorbid conditions. The elderly, African American ethnicity, smokers, and those with lower socioeconomic status had more comorbidity. The increased comorbidity of the individual may not only complicate the assessment and treatment of their symptoms, but also the person may have synergistic effects of the symptom experience.

Studies on colorectal cancer often include a higher percentage of participants over 50 years of age. One study investigated 173 colorectal carcinoma survivors (average age = 70.4 years) using the Functional Assessment of Cancer Therapy Scales for Colorectal Cancer (FACT-C) and the Health Utilities Index (HUI) (Ramsey, et al., 2000). The results of the study included a reported lower overall QOL in the first three years after

diagnosis, and a relatively uniform and high QOL for stages I to III CRC after three years of diagnosis. Pain, functional well-being, and social well-being were affected most substantially across all stages and times from diagnosis. Low income was associated with worse outcomes for pain, ambulation, and social and emotional well-being. Only emotional well-being scores improved significantly over time in both surveys. A limitation of the study included a potential exclusion of the most severely ill patients and therefore a potential bias.

Chang, Hwang, Feureman, and Kasmisis (2000) explored the relationships of symptom prevalence, symptom intensity and QOL of predominantly older men (240 patients; mean age of 65 years) on an oncology unit in a Veteran's Affairs Medical Center. In-patient and outpatients were included in this study. Symptoms of the cancer experience were measured by the Memorial Symptom Assessment Scale (MSAS), and other tools used were the Brief Pain Inventory Short Form and the Functional Assessment Cancer Therapy Scale for QOL. The results showed that patients had multiple symptoms of high intensity, and they were distressful. Symptoms included lack of energy (62%), pain (59%), dry mouth (54%), shortness of breath (50%), difficulty sleeping (45%), feeling drowsy (44%), worrying (40%), feeling nervous (37%), cough (33%), and weight loss (33%). The intensity of the symptoms varied, but the reported most severe distressing symptoms were lack of energy (60%) and pain (52%). The number of symptoms correlated with the sum QOL scores. This investigation supports the importance of comprehensive assessments in the older adult with cancer and supportive care to improve the QOL of the older adult with cancer.

An examination of the domains of QOL and its relation to innate host factors (i.e.; age, gender) and selected social and physical factors, was completed in 143 newly diagnosed Norwegian cancer patients (Rustoen, Moum, Wiklun, and Hanestad, 1999). Using the Ferrans and Powers Quality of Life Index (QLI) and the Cancer Rehabilitation Evaluation System Short Form (CARES-SF), patients were least satisfied with their health, functioning and sex life (Rustoen, et al., 1994). Age was significantly associated with QOL in only the socioeconomic sub-scale with older persons showing higher quality of life than younger ones. Older persons were more satisfied than the younger in the psychological and marital domains, but the younger group was more satisfied with the sexual domain. Gender was not associated with QOL in this study except in the psychological domain of the CARES-SF instrument, with men having a higher QOL than women. Patients who received chemotherapy reported lower QOL than those receiving radiation (Rustoen, et. al). This study provides some support for a difference in the QOL effects at different age groups.

Few QOL studies were found that investigated the older adult cancer patient exclusively (Gift, Jablonski, Stommel, & Given, 2004; Given, Given, Azzouz, Kozachik, & Stommel, 2001; Given, Given, Azzouz, & Stommel, 2001; Hodgson, & Given, 2004), and few have investigated the issues of survivorship (Deimling, Kahana, Bowman, & Schaefer, 2002; Sammarco, 2003). In a secondary analysis of data from a study of newly diagnosed cancer, elderly patients (mean age of 72 years) with lung cancer were examined (Gift, et al., 2004). The symptoms of fatigue, nausea, weakness, appetite loss, altered taste, and vomiting formed a symptom cluster when a factor analysis was completed. The predictors of the symptoms reported were the initial staging of cancer,

the number of comorbid conditions, and whether treated with chemotherapy. There was a correlation among the number of symptoms reported, symptom severity, and limitations attributed to symptoms.

Given and colleagues (2001) followed a cohort of 841 patients who were 65 years of age or older who had breast, colon, lung, or prostate cancer over four time periods up to 52 weeks. Pain and/or fatigue improved over the year. Stage, greater comorbidity, and lung cancer were related to both pain and fatigue. In another study, Given, Given, Azzouz, & Stommel (2001) explored the predictors of functional limitations prior to diagnosis of cancer and if symptom cluster of pain, fatigue, and insomnia explain changes in physical function between three months prior to and eight weeks following diagnosis. Physical functioning was measured by the Medical Outcomes Study 36-item Short Form (SF-36), and comparison of function with national norms was completed. Symptom assessment and comorbid conditions were identified through patient interview. Patients with more extensive or combination treatments (as surgery plus chemotherapy) reported greater loss in functioning. They showed higher level of functioning prior to diagnosis but were comparable to norms after initial treatment. Cancer site and stage of disease did not predict the differences in levels of functioning. Pain, fatigue, and insomnia had a consistent and significant effect on functioning and were unrelated to treatment or comorbid conditions.

Older adults with cancer were examined post-operatively for psychosocial and disease-specific factors in a recent descriptive study (Hodgeson, & Given, 2004). This study found that comorbidities and symptom severity were significantly associated with a

response of a decreased probability of recovery (Hodgeson, & Given). Pain and fatigue were the most common and most severe symptoms reported in all types of cancers.

In a study sponsored by the National Institute on Aging conducted at Duke, 4,162 individuals over age 65 were evaluated for self reported comorbidities, function by four scales including the Katz Activities of Daily Living (Garman, Pieper, Seo, & Cohen, 2003). There was no association between duration of cancer survivorship and functional status found. However, comorbidities were significantly correlated with the function of older cancer survivors (Garman, et al.). These studies highlight the need for health professionals to address the impact of comorbidities of the older cancer patient's QOL.

Using a posttraumatic stress disorder model (PTSD), a survey of 180 older long-term survivors was completed among those with breast, colorectal, and prostate cancer (Deimling, et al., 2002). In a multivariate analysis, the older adults did not demonstrate clinical levels of PTSD. However, 25% showed clinical levels of depression. Current cancer-related symptoms were the best predictor of depression even when other stressors and non-cancer illness symptoms were controlled. Depression was also predictive by the PTSD sub-dimension of hyper-arousal. PTSD was correlated with traditional measures of psychological distress (anxiety and hostility). Many survivors displayed symptoms of psychological distress related to the continuing effects of cancer and cancer treatment. This unique view of the stressors of cancer survival may help health care professionals understand patient's perspectives and assist in designing psychological supports of the older cancer patients.

Sammarco (2003) also investigated the psychosocial dimensions of cancer in older adults. This descriptive correlational study used the Ferrans and Powers Quality-of-

Life Index-Cancer Version, the Social Support Questionnaire, and the Mishel Uncertainty in Illness-Community to study the relation among perceived social support, uncertainty, and QOL in 103 older survivors (age over 50) with breast cancer. The results found significant negative correlations between age and social support and uncertainty and total QOL. The findings indicated that the level of uncertainty increased with the presence of other diseases, which were associated with a poorer QOL. Positive correlations between perceived social support and QOL were found in this study. The influences of physical symptoms, fear of death or disability were negatively affecting the older breast cancer patient's QOL.

Summary of QOL and Cancer

All of the studies reviewed indicate that the older adult with cancer may experience many of the same issues related to their disease as do younger adults. However, differences do exist and further study is needed to improve the individualized care for older adults with cancer. Acknowledging that nurses play an important role in enhancing the QOL in cancer patients, health care professionals must work together to address the many unique challenges that exist in this population. An excellent starting place for this collaboration is at the point of the initial diagnosis and when treatment decision-making occurs.

Decision-Making

Health care decisions are multi-dimensional and dynamic (Noone, 2002). Decision-making in health care is becoming more and more complex as advancement of technology has led to innovative diagnostics, new medications and novel, progressive treatment regimens. Today's health care arena is placing patients and their families in

challenging roles of decision-making. With an emphasis on outcomes, greater consumer involvement, and the more complex technologies, the best course of action has been affected by the “complex web of diagnostic and therapeutic uncertainties, patient preferences, values, and costs” (Hunink, et al., 2001).

The decision-making process is further complicated by personal beliefs, emotions, past experiences, social support, and environmental issues. Among older adults, issues of comorbid diseases such as diabetes mellitus, hypertension, and coronary heart disease may further impact decisions made for cancer treatment. All of these multifaceted influences need to be considered when assisting the older adult with treatment decision-making, and the person that they affect is the only one that can tell us their importance. Therefore, it is necessary to extend the treatment decision-making knowledge from the view of the older adult.

In order to better understand the process of decision-making and establish a starting point for discussion, it is necessary first to define terms. *The Oxford American Dictionary and Language Guide* (1999) defines decision as “the act or process of deciding; a conclusion or resolution reached especially as to future action after consideration; the settlement of a question; a formal judgment; tendency to decide firmly; resoluteness” (p. 245). With this definition, the older cancer patient could be thought of as making treatment decisions by formulating value judgments on the course of action. The value judgments are very personal and individual.

Formulating and finalizing decisions is a process that involves more than one event, time, or person. Mosby defines a process to be a “series of related events that follow in sequence from a particular state or condition to a conclusion or resolution”

(1994, p. 1278). The decision-making process involves not only older cancer patients but also their personal experiences, family and significant others, real or anticipated expectations, and understanding of their situation. Even with a greater prominence of patient-centered care, common language or an accepted theoretical decision-making framework from the patient's perspective is not accessible to assist the older adult in this process.

One systematic approach for decision analysis was described in detail in a recent book by Hunink and colleagues (2001). This framework, named "PROACTIVE," was developed "to deal with the uncertainties associated with the decision problem," and, "to find the best available evidence to support or refute your assumptions" (Hunink, et al., p. 5). Each letter of this description stands for the suggested action in the process. This mnemonic (PROACTIVE) is a step-by-step way to deal with difficult decisions in a systematic manner and was described as "problem: define the problem; reframe: reframe from multiple perspectives; objective: focus on the objective; alternatives: consider all relevant alternatives; consequences and changes: model the consequences and estimate the changes; trade-offs: identify and estimate the value trade-offs; integrate: integrate the evidence and values; value: optimize expected value; and explore and evaluate: explore the assumptions and evaluate uncertainty" (Hunink, et al., p. 26). This tool was reported to be useful in clinical practice (Hunink, et al.). No research was found on the use of this tool for clinical decisions by professionals or for use by patients in treatment decision-making. However, this model seems to integrate many components of other decision-making models and may be useful for the data analysis of the present study.

Janis and Mann's Conflict Model of Decision-making is another paradigm and was used to examine 172 patients to determine why patients choose or decline participation in clinical trials (Verheggen, Nieman, & Jonkers, 1998). This model, from the discipline of psychology, views decision-making from a stress perspective and sees the process as a balance sheet of risk appraisal, success assessment and availability of time (Janis & Mann, 1977, as cited in Noone, 2002). Patients in that study were found to make decisions by looking at a balance sheet comprised of physical and emotional gains with risk and negative aspects. This type of risk appraisal tool may be useful for health care professionals to assist patients with their treatment decisions.

Patterson and Thorne (2000) completed interviews assessing 22 patients with diabetes mellitus to evaluate decisions about unanticipated glucose levels. They identified assessment of risk, comparative analysis, diagnosis, choice of action and evaluation as components of the decision-making process. Familiar situations were compared to previous situations, and unfamiliar situations were based on experimentation or seeking help to problem solve. Although not in the cancer population, this analysis of the decision-making process may be applicable for looking at treatment decisions.

In a study of 57 older adults, Roberto, Weeks, and Matheis-Kraft (2001) studied decision-making in hypothetical health care scenarios using a mixed methods design. They identified five primary reasons of guidance for older adults when making decisions for health care: (1) medical considerations, (2) personal relationships, (3) past experiences, (4) quality of life, and (3) age. This study may offer possible influences to explore in the older oncology patient when making treatment decisions.

In a qualitative study using focus groups, Verhoef and White (2002) investigated the decision to forgo conventional cancer treatments for alternative treatments. Their exploration found most of the participants (22 of 31) wanted to make the final treatment decisions, nine wanted to make the decision with the physician, and none wanted to have the physician make the decision alone. Some of the things identified as reasons to forgo conventional cancer treatment included having someone close die of conventional cancer treatment, personal experience of their cancer diagnosis, and other factors (beliefs of mind and body connection, control needs, treatment side effects, and physician communication). The patients offered recommendations on how health care providers can be supportive including: communicate clearly, honestly, and be informative; refrain use of fear strategies; listen well; and be open to alternative therapy (Verhoef & White). Although this study is small, it reflects the importance of providing an environment of openness and honesty when assisting patients with their treatment decisions.

Decision-making in Cancer

Making health care decisions when the patient has heard the devastating news of a cancer diagnosis may be complicated. The present state of investigation of patients' cancer treatment decision-making is inadequate and has really only begun to be researched. Most studies have been done among the breast cancer population and there have been limited investigations in older adults.

In interviews to evaluate decision-making among 48 breast cancer patients, Pierce (1993) identified three processes: (1) deferring to an attractive choice often recommended by the physician; (2) delaying or vacillating among choices; or (3) purposely using a plan and seeking information. In this investigator's further research, Pierce (1996) recognized

that a naturalistic or unaided decision-making process is supported by the literature.

However, she recommends a structure to evaluate the decision-making process in order to identify strategies that patients use, be able to identify when to interview, and evaluate decisions when outcomes are known.

Based on earlier work, Pierce and Hicks (2001) presented a framework for patient decision-making that involved a decision problem, the patient, and the context. This framework provided a systematic approach to study patient decision-making and to ultimately assist patients with the appraisal of their potential choices. This model states that a “decision worthy of explication” has four parts: (1) initial options, (2) values, (3) uncertainties, and (4) possible outcomes (Pierce & Hicks, p. 268). It is proposed to advance the limited knowledge of how health-related contexts influence decision behavior.

Schaefer and colleagues (2001) investigated decision-making among 26 women (44-67 years of age) with breast cancer when considering participation in a prevention trial. Using a grounded theory approach, their in-depth interviews revealed a nonlinear process of thinking. The authors called this process “backing and forthing” which includes life review, desire to be sure by obtaining information, risk taking and decision-making that is dynamic in nature (Schaefer, et al., 2001, p. 706). The women’s complex situations were highlighted by the data and included a concern for those around them and the need for trusting and supportive relationships in their health care providers. Although this was in a younger cancer population and related specifically to prevention trials, it increases the understanding of the decision-making process.

In a phenomenological study, Lacey (2002) identified six themes when investigating the lived experience of 12 women (ages 38-68) with breast cancer. Major themes were: (1) being stressed and overwhelmed, (2) feelings of intense urgency, (3) trusting the physician, (4) the importance of family and friends, (5) nurses' lack of involvement in the initial decision, and (6) the lack of a multidisciplinary approach (Lacey, 2003). Although this study had a small sample size, had a wide age span, and did not look primarily at the treatment decision-making process, the study adds to the evidence of the cancer experience after diagnosis.

Patient participation is an expected part of today's health care setting. However, the manner of patients' preference for participation in the decision-making process is somewhat unclear. Some studies report that patients do not want to make decisions for treatment (Lauri & Sainio, 1998; Beaver, Kuker, Owens, Leinster, Degner, & Sloan, 1996). In a study of 25 cancer patients with breast cancer, Sainio, Eriksson, and Lauri (2001) explored patients' perceptions in decision-making and factors that facilitate or restrict participation. In focus group interviews, these authors found that promoters of patient participation in decision-making were the patient's activity of being involved in the process, the treatment of the patient as an equal and taking time for the patient. The factors that were considered barriers to participation were patient ignorance, physical and mental imbalance and shyness of the patient (Sainio, et al.). Health care professionals must create an environment of support for decision-making and evaluate a patient's view of what this environment would look like.

A sample of 377 Australian women's pre-diagnostic decision-making styles for breast cancer treatment was surveyed by Budden, Pierce, Hayes, and Buettner (2003).

This quantitative study used the Pre-Decision Portfolio Questionnaire and found that 19.9% were deferring responsibility style, 0.3% avoidance style, 32.7% information seeking style, and 63% deliberator style. The style was affected by age, education, occupation, and employment status. This study was limited in that it examined the women's prediction of their decision-making process for treatment during cancer screening.

A qualitative study exploring treatment decisions (Henman, Butow, Brown, Boyle, & Tattersall, 2002) reported similar results as Sainio and colleagues (2001). They did telephone interviews with 20 women with breast cancer. Their results identified the issue of having a good personal relationship with the specialist as important. Time and acknowledgement that these patients were listened to were cited as being factors that influenced their decision for treatment. Other factors in decision-making were the risk of recurrence, life expectancy, side-effects, and quality of life. The authors concluded that patient priorities and concerns should be dealt with prior to treatment discussions.

Decision-making in Older Cancer Patients

Limited studies were found for decision-making among older adults with cancer; subsequently, the age-related aspects of decision-making need to be studied (Noone, 2002). As noted earlier, most studies found were in the breast cancer population. More recently there has been information in the literature on treatment decision-making related to prostate cancer. Studies of the older adult with cancer include a wide range of subjects from the young adult to the older adult. One study reported that older patients use more of a passive role in the decision-making process (Degner & Sloan, 1992). Age was also

identified as a predictor for deferring treatment decisions for older breast cancer patients (Budden, et al., 2003).

In a qualitative study of ten interviews with oncology patients and three interviews with oncology surgeons, Ferrell, Chu, and their colleagues (2003) looked at decision-making for palliative surgery. The researchers used a decision-making model adapted from a QOL model to describe how the process is influenced by patients, family and the health care team. This model involves goal identification, values, acknowledgement of alternatives, and the weighing of risk and burdens of the situation. This model also looks at the treatment choice in relationship to the impact on QOL, including four dimensions of physical, psychological, social, and spiritual well being. The findings indicate that uncontrolled symptoms are the primary factors in considering palliative surgery. Although this study was not related to treatment decision-making for a new diagnosis of cancer, it did show a QOL model can be used to conceptualize the process.

One cross-sectional mailed survey of patients 65 and older looked at patient and physician factors influencing the decision to use adjuvant chemotherapy for stage III colon cancer (Kutner, Vu, Prindiville, & Byers, 2000). A total of 92 physicians and 67 patients completed the survey. Physicians identified comorbid conditions, the medical literature, and patient preference as important factors in making decisions. Patients identified the physician's opinion, family preference, and family burden as the important factors. Older patients were more likely than younger patients to identify age, life expectancy and tumor characteristics as affecting their decision for treatment. The authors concluded that patient priorities should be considered in treatment decisions.

Individualized information to assist in treatment decision-making was examined in a quasi-experimental study of 74 men and their partners (Davison, Goldenberg, Gleave, & Degner, 2003). The study used a computerized version of the Control Preferences Scale by Degner and Sloan (1992) to assess preferences for control for treatment decision-making, a paper and pencil survey questionnaire administered after four months, as well as the Spielberger State Anxiety Inventory to assess current psychological state. The Center for Epidemiologic Studies Depression Scale for depression measurement also was used. All showed a greater than anticipated active role in treatment decision-making, and all had lower psychological distress at the four-month evaluation. Although this is not a randomized trial, it gives support for providing individualized instructions to enhance treatment decision-making to ultimately improve QOL. Most of the patients wanted to be actively involved in decision-making (51% active and 42% collaborative role). The men with partners wanted to share the decision-making 54% of the time with the partner, 37% wanted to seriously consider their partner's opinions and only 10% wished to make the decision alone. Most of the partners wanted to play a collaborative role (55%) rather than a passive role (2%). As the mean age of the patients was 62.2 years, this study offered some insight into decision-making processes among older individuals and in a cancer group besides breast and included partners in their analysis.

A systematic review of selected literature on the perceptions of older people with cancer related to information, decision-making and treatment was recently completed (Chouliara, Kearney, Stott, Molassiotis, & Miller, 2004). These researchers found 18 studies that met their criteria for inclusion. The information received by the older adult

was primarily viewed as acceptable. However, they were not satisfied with care and contact in these studies for their needs were not met in many cases. They desired information on cancer diagnosis and treatment progress but not on the progression of illness or survival time. Methodological limitations of the quality of the information were presented in detail and included interview issues, small sample size, selection bias, indirect obtaining and lack of in-depth analysis of perceptions, physical and cognitive disabilities, and lack of a clear framework. These authors highlighted the need for more studies to provide strong evidence for using less structured and in- depth interviews to better understand the treatment decision-making process in the older adult cancer patient.

Summary

Some of the literature has been reviewed on issues of cancer and the older adult, quality of life issues with cancer patients, and treatment decision-making. Limited research on treatment decision-making processes was found for the older adult with cancer. A better understanding of the process for the treatment decision-making process for the older cancer patient is needed to provide quality care for these individuals. The oncology nurse's commitment to improve the QOL of the older adult will be enhanced by examining this process from the individual's perspective.

Chapter 3

Research Methods

Introduction

A phenomenological approach was used in this qualitative study. The present investigation involves an inquiry process that explored a human problem (Creswell, 1998). The purpose of this study was to understand the experiences of older adults making cancer treatment decisions. Health care professionals have a limited understanding of how the older adult makes treatment decisions. This chapter discusses the research methodology, including the design specifics.

Qualitative Design Rationale

The qualitative approach was deemed appropriate in the present research study of older adult cancer patients because the treatment decision-making process is very subjective and almost impossible to quantify. The decision-making process is complex and includes cognitive, perceptual, and affective activities that are not directly observable (Pierce and Hicks, 2001). A quantitative approach would necessarily limit the responses of the participants to only the standardized measures (Patton, 2002). Therefore, statistical methods would not necessarily be acceptable for exploration of older adult's perspectives for the decision-making processes for cancer treatment. Qualitative methods on the other hand provide a way to study the issue of patient decision-making "in depth and detail" (Patton, 2002). It is this 'depth and detail' that will allow a broader view and understanding of this multi-factorial process.

With the treatment decision-making process of the adult cancer patient involving the family, other health care professionals, previous life experiences, and personal values,

this process is considered to be very complex and multi-faceted. Qualitative research is appropriate for study of complex and dynamic phenomena and that cannot be “reduced to a few discrete variables and linear, cause-effect relationships” (Patton, 2002, p. 41). Therefore, quantitative analysis might be too limited and ultimately be less meaningful in studying the very multifaceted and personal issue of making treatment decisions for cancer.

Increasing knowledge of the individual’s perspective of treatment decision can assist nurses to develop strategies and provide appropriate support for adults with cancer. Ultimately, it is hoped that improvement in the QOL during this difficult experience may be possible.

Methodology

This exploratory study uses the qualitative tradition of phenomenology to better understand the experience of the treatment decision-making process in older adults with cancer. As described by Straus and Corbin (1998), it will “provide a sense of vision, where it is that the analyst wants to go with the research” (p. 8). A more intimate understanding of the treatment decision-making process will enhance the quality of care provided to cancer patients.

Phenomenology

Qualitative research may be viewed as an intricate quilt that has many pieces that fit together to provide a beautiful piece of art (Denzlin & Lincoln, 2000). The meaning of treatment decision-making is a complex and sensitive issue and warrants research that can uncover the whole and the parts from a human perspective. The decision-making process can be envisioned as a quilt of many small pieces, and this type of research will

assist in exposing the many parts that encompass this complex process. The tradition of phenomenology was chosen because it conveys insight from the cancer patient's very personal perspective.

The purpose of phenomenological research is "to describe the meaning of the lived experiences for several individuals about a concept" (Creswell, 1998, p. 51). The study will be completed to uncover the meaning of the cancer treatment decision-making process and will seek to draw attention to the external and internal view of this experience. Creswell (1998) identifies this understanding as the "intentionality of consciousness" (p. 52).

Cancer treatment decision-making can be viewed from many perspectives and has a very personal quality influencing this process. An ontological view was adopted for this study because it is "the nature of reality for the qualitative researcher; reality is constructed by individuals involved in the research situation" (Creswell, 1998, p. 76). The ontological view indicates that there are multiple realities including the individual, the researcher and those who read the study (Creswell, 1998). This view is one that reports these 'realities' from the individuals and those who interpret the findings. Therefore, the findings were presented in the participant's words through quotes and identify themes as interpreted by this researcher.

The phenomenological philosophy that guided the study is Merleau-Ponty. This approach emphasizes the concepts of perception, intentionality and embodiment (Thomas, 2005). These concepts acknowledge aspects of the cancer treatment decision-making process and will strive to assist in better understanding this complex phenomenon. Perception of the patient takes into account the cancer patient's previous

experiences, relationships, and contexts such as culture. Intentionality acknowledges the “interconnectedness between humans and the lifework” (Thomas & Pollio, 2002 as cited in Thomas, 2005, p. 70). Embodiment reflects the belief that the body is part of our human existence (Thomas, 2005). These concepts correspond with the belief that quality of life is multi-dimensional and is impacted by the body’s response to cancer treatment, the relationships during the treatment decision-making process, and the therapeutic responses of health care professionals.

The study included in-depth individual interviews to uncover the meanings of decision-making by adult cancer patients. The data were analyzed using the procedures detailed later in this paper.

Research Questions

The grand tour question for this study was “What is the experience of the older adult when making decisions for cancer treatment?”

This qualitative study was guided by the following research questions:

1. From the perspective of the person with cancer, what is the process of the treatment decision?
2. What or who are the influences in the decision-making process when older adults decide on treatment for a new diagnosis of cancer?

Definitions

The following definitions were used to guide the study:

1. Decision-making: The process by which an older cancer patient decides whether to accept or decline treatment.

2. Process: “a series of related events that follow in sequence from a particular state or condition to a conclusion or resolution” (Mosby, 1994, p. 1278).
3. Older Adult Cancer Patient: A person 50 years of age or older who is confronted with a new diagnosis of cancer.
4. New Cancer Diagnosis: A new cancer diagnosis is considered to be the first cancer diagnosis or a new primary cancer diagnosis and not a metastasis of a previous cancer.
5. Treatment: Treatment for cancer was the accepted treatment for cancer including surgery, chemotherapy, radiation, and/or biological response modifiers for the goal of cure or palliation.
6. Quality of Life: is “an individual’s perception of his/her life in the context of culture and values, as well as objectives, expectations, standards, and interests.... A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (World Health Organization [WHO], 2006).

Sources of Methodology

There are three kinds of qualitative data: interviews, observations, and documents (Patton, 2002). In-depth interviews were selected for this study as they provide direct quotations from the older adult’s experience with cancer treatment decision-making for analysis. Also, interviews were used because they are anticipated to communicate feelings, opinions, and knowledge and consisted of the verbatim responses of the participants (Patton). A broad guide provided the format for the interview. The interviews

were audio taped and then professionally transcribed. A detailed protocol for this research study was developed and is included in Appendix A.

Observations were utilized this study. For example, the researchers observed the subject's nonverbal response to the questions and these were recorded in brief notes taken during the interview. It is felt that accuracy in recording aspects of the experience is important and was emphasized throughout data collection. Although the interview was recorded, note taking allowed for the interviewer to formulate new questions as appropriate, allow seeing the identifying themes of the interview, facilitating later analysis of the data, or possibly being a backup for a tape's data (Patton, 2002). Since each case was considered unique, details were considered to be important, and every attempt was made to capture the specific information from the individual's decision-making process. The in-depth interviews and attention to details provide rich, descriptive data to appreciate the experience of the cancer patient during treatment decision-making.

The study participants completed a background data form to provide descriptive data of the sample. The form included age, gender, marital status, employment status, other roles, ethnicity, education, income, cancer diagnosis, and length of time since treatment decision, length of time from diagnosis to treatment decision and the treatment decision that they chose (see Appendix B).

Documents such as patient charts and diagnostic information were not used in this phenomenological study. The decision-making process for cancer treatment is a very personal and subjective experience. Therefore, these sources were not considered to contain information relevant to the study's purpose.

Role of the Researcher

In qualitative research, the researcher is considered an instrument, and the credibility will depend on the “skill, competence, and rigor of the person doing the fieldwork” (Patton, 2002, p.14). The researcher made every attempt to look at the data objectively and systematically. This included attempting to recognize potential bias, thinking abstractly, being open and flexible, being sensitive to respondents and displaying a devotion to the work of the research (Straus & Corbin, 1998).

This researcher has had over 30 years of experience in adult medical surgical clinical nursing with the most recent 10 years focused in the oncology area. This knowledge provided a base to complete the interviews with the older adult patients. Concurrent experience of teaching in a school of nursing also provided background for analyzing pertinent themes in the data. Current doctoral studies in gerontology provided a solid base to complete this study of older adults.

Because of the nature of nursing, it may be difficult to stand back and not intervene in situations. The researchers were cognizant of this potential behavior and made attempts to listen instead of act when these issues arose.

The researchers may have another potential bias in regard to treatment decisions. There may be times when the researcher may not agree with the patient’s decision for treatment. This opinion was not shared verbally or nonverbally. In all cases, every effort was made to reduce any personal bias with a focus on allowing the patient to tell his or her personal story about the decision-making for cancer treatment.

Research Design Specifics

Sample Population and Issues Related

To gather information on treatment decision making, a purposive, criterion sample was selected to enhance quality assurance (Creswell, 1998). A potential participant was eligible for recruitment if they were 50 years of age or older; had a new diagnosis of cancer (solid organ cancers or hematological cancers; melanoma); experienced the phenomena of making a cancer treatment decision in the last six months; and was English-speaking and mentally competent. The researchers made attempts to include cancer patients who have made the decision to undergo treatment and those who chose no treatment, those who were of both genders and of diverse races. It had been proposed to complete 10-15 interviews of adult cancer patients who have made a recent treatment decision for a new diagnosis of cancer or complete the study when theoretical data saturation was attained.

The informants were recruited from one academic university health care setting (oncology, internal medicine, family practice, and geriatric offices); cancer support groups in a large metropolitan area; one senior education group that was affiliated with the academic university health care system; a local senior publication, the *New Horizon*, produced by the Eastern Nebraska Office on Aging; and local church newsletters (the Catholic Voice newspaper from the Archdiocese of Omaha) and church bulletins. Recruitment techniques included flyers, newspaper advertisements, church bulletins, and letters to medical facilities (see Appendix D).

The sample was based on the study's purpose and was judged in the context of the experience of the older adult's experience of cancer treatment decision. "The validity,

meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (Patton, 2002, p. 245). The sample was sequential with the analysis guiding the data collection, as recommended by Straus and Corbin (1998). Sampling continued until saturation occurred (Straus & Corbin). Theoretical saturation occurs when “no new properties, dimensions, or relationships emerge during analysis” (Straus & Corbin, p. 143).

In this study sample, saturation was deemed to be met after Participant K or the 11th participant. No new themes seemed to emerge when completing this interview. However, a concern that participants of different races were not yet included in the study. Therefore, the decision to continue recruitment was done with an emphasis on obtaining at least one or two more participants who were not Caucasians.

Ethical Issues

The research proposal was approved by both the University of Nebraska at Lincoln (UNL) and Creighton University Medical Center’s (CUMC) Institutional Review Board (IRB) (See Appendix C). Working closely with physicians and nurses in the medical offices and following strict Health Information Portability and Accountability Act (HIPAA) guidelines, prospective participants were identified. The researcher worked with the oncology staff to screen whether the clinic patients met the eligibility criteria. A letter was placed describing the study in the chart on clinic patients who were to be eligible for the study when their physician gave permission to do so. These letters are also included in Appendix C.

The sites for the study were the medical offices and hospital at Creighton University Medical Center (oncology, internal medicine, family practice, and geriatric offices); cancer support groups in a large metropolitan area; cancer survivor education sessions; and senior education groups in this area. When using the medical offices, contact nurses at each office were provided with the necessary information on eligibility for the study. The patients were not contacted until the decision for treatment had been made by the patient. After the staff attained the patient's verbal acceptance to discuss the study, eligible patients were called. If a positive response from the patient was obtained, the researcher made arrangements for a personal meeting in the patient's home, the doctor's office or a mutually convenient place to obtain consent.

Recruitment from advertisements, community groups or bulletins included only those individuals who had made a decision for treatment. If the participant contacted the researcher and the treatment decision had not been made, participation in the project was delayed. The recruitment tools are included in Appendix D. The principles of informed consent were consistently followed throughout the project.

The potential participants were provided with written information about the study protocol, the purpose of the study, the length of time the study would take, the study procedure, and the risks and benefits of the study. They were allowed time for questions and verbalization of concerns. Interested participants needed to consent to participate in a formal written format. The consent forms followed guidelines directed by CUMC and UNL IRB committees (see Appendix E). These consent forms included the right to voluntarily withdraw from the study at any time; the purpose of the study and the data collection procedures; acknowledgment of the confidentiality of the respondents; a

statement of the known risks associated with participation in the study; the expected benefits to accrue to the participants in the study; and a place for the signature and dates of the participant and the researcher (Creswell, 1998). The location of the interview was established in a place that ensured privacy and included the individual's home, office, a secured meeting room or in a coffee house/restaurant.

Each participant that completed the background data form and the personal interview was given a small token of appreciation of their time. The subjects were offered a \$20 Target gift certificate as compensation. This small gift from the researchers was intended to provide a thank you with a gift that could be used for food or merchandise as they desire.

Individuals who made a decision not to participate were shown appreciation verbally and their explanation for refusal was recorded anonymously for future review. The researchers made every attempt to reduce burden of the interview. Some examples include: allowing adequate time for response to the questions; allowing the participant to set the day and time of the interview; and encouraging the participants to reschedule the interview if they were fatigued or not feeling well.

Data Collection Methods

Interview. The interviewer collected data using face-to-face individual interviews lasting approximately 60-90 minutes. The participants were asked broad, open-ended questions. Questions were meant to determine the individual's point of view, and the interview is thought to be a tool to discover the information from the participants (Patton, 2002). The interview provided direct quotations about the individual's perspective and experience of the treatment decision-making process.

The interviews were completed in less than six months and more than one month after the decision for treatment had been established by the patient. The rationale for this time frame was to reduce patient burden by not adding to their activities too soon after the treatment decision itself and to enhance recall by not allowing too much time to have lapsed. One participant made a treatment decision greater than six months prior but was included in the study. The rationale for inclusion of this individual was thought to be important for this study and will be discussed in detail in Chapter 4.

The interview process was planned and designed to elicit pertinent information from the older adult participants and subsequently understand the process of cancer treatment decision-making. A standardized open-ended interview was completed and consisted “of a set of questions carefully worded and arranged with the intention of taking each respondent through the same sequence and asking each respondent the same questions with essentially the same words” (Patton, 2002, p. 342). This type of interview allowed for a focus on the decision-making process in cancer treatment and enhanced the analysis for comparison of the participants.

Interview Questions. The personal interview form was used to guide the interview and presented in Appendix F. These open-ended interviews were thought to offer an “opportunity for an authentic gaze into the soul of another” (Weitzman, 2000, p. 823) and to uncover the meanings of decision-making of cancer treatment. They provided the tools to understand the reality of this challenging process.

A copied form of these questions was given to the participant in the study. The form and questions were developed using Creswell’s guidelines (1998). This format allowed brief note taking from the researcher during the interview. The interview

questions were memorized in order to enhance eye contact and enhance the confidence in the interviewer (Creswell, 1998).

When initiating the questions, an introductory statement was included as follows: “I am interested in knowing more about your experience with your cancer treatment decision-making process. Thinking back to when you made this decision, please answer the following questions.” The questions for the interview are listed below:

1. What were your feelings when you were first confronted with your diagnosis?
2. Tell me about when you made your decision to accept (or refuse) cancer treatment.
3. What was difficult/easy about making your decision to accept (or refuse) cancer treatment?
4. Did particular people influence your decision for treatment? Please explain how you are involved with these individuals.

Please explain how they were influences. If so, how did they influence your decision for treatment?

If no, then would you have liked someone to assist you with this decision?

5. How long did this decision for treatment take?
6. Can you describe how you made your decision for treatment?
7. Can you identify certain issues that affected your decision for treatment?

Can you prioritize these issues for me?

Did your age affect this decision? If so, how?

8. Did your physical or mental health influence your decision for treatment?
- If they did, please explain how they influenced your decision.

9. Did your spiritual values influence your decision for treatment?

If they did, please explain how they influenced your decision for treatment.

10. Did you feel that your treatment decision had any effect on other people in your life?

If yes, please explain who and please tell me about what you feel these effects were.

11. How did you feel when the decision for treatment had been made?

12. Is there anything else that you would like to share with me about your cancer treatment decision?

Probes were used throughout the interview to encourage interviewees to elaborate on their responses and keep talking. These probes were verbal and nonverbal. The verbal probes assisted with gathering further details of the “who,” “what,” “where,” “when,” and “how” (Patton, 2002). Probes were used by the interviewer to encourage the individual to expand his or her cancer treatment decision-making experience. Some examples of the probes included statements such as: “Tell me more about that...,” “Can you give me an example...,” or “Can you describe this in more detail (or depth)...” Clarification statements were made during the interview to enhance interpretation and may include statements such as: “I am not sure what you mean...,” or “I think that you are saying...” There was a conscious effort to limit any provision of descriptive words to influence meaning for the subject. The nonverbal probes were the basic attentive skills such as head nodding and good eye contact maintained during the interview.

The interview structure began with a discussion to allow for trust building and included a commitment to confidentiality and a review of the study’s goals. Throughout

the interview, the researcher demonstrated verbal acceptance and asked for clarification when needed. The end of the interview included an open-ended question to ask if there is anything else they would like to share and an acknowledgment of appreciation for their thoughts and time.

Patton (2002) described the importance of the qualitative researcher's voice as a tool to convey genuineness and trustworthiness. "Complete objectivity being impossible and pure subjectivity undermining credibility, the researcher's focus becomes balance-understanding and depicting the work authentically in all its complexity while being self-analytical, politically aware, and reflexive in consciousness" (Patton, p. 41). The researchers made every attempt to display a genuine approach to the questions and to remain objective.

The normal changes that are associated with the aging process were taken into consideration during the interview. Although the researchers acknowledged that this is a heterogeneous group, some of the issues that must be considered are visual changes, hearing deficits, and potential issues related to chronic illnesses and their subsequent symptoms. Fatigue from the cancer experience must also be considered and measures to reduce burden. Some examples of adaptation for this population include increasing the font of all written material to 14 point, reduction of environmental noise, appropriate lighting, normal voice speed and clarity of tone, and allowing adequate time for responses.

Each interview was audio taped and transcribed verbatim for analysis. Formal transcription was completed by Patty Marsh in the Creighton University Medical Center School of Medicine; an individual who has completed the ethical training for IRB and has

had experience in this skill. Field notes were transcribed immediately by the researchers and reviewed after each interview. Data was analyzed after every interview. The tape recordings were reviewed immediately by the researchers and any additional notes were added if appropriate.

The interviewer was the principal investigator for 10 participants and an assistant for three of the participants. This assistant, Tina Miller, has participated in previous research projects that included interviews with older adults. Both researchers were knowledgeable of the details described above and both practiced the interview form with colleagues to become familiar with the protocol.

Data Management

Data was secured in a separate and secure locked file in the Creighton University School of Nursing (Room 233) to maintain confidentiality of the responses. The tape recordings were erased when transcriptions are completed. Duplicates of the transcriptions were made and filed in the locked file. Anonymity was maintained through a coding system and names were not identified on the forms. A data collection matrix was used to locate and identify information in the study (Creswell, 1998).

Data Analysis

The background data form was analyzed using a statistical package, SPSS (version 11.5, LEAD Tools, 2002). This type of analysis provided participant characteristics in a form for easy retrieval and display. The researcher developed a coding worksheet and it is provided in Appendix G.

The data analysis for the present research study on the treatment decision-making process of older cancer patient was completed by data managing (organization), reading

and memoing, and classification (coding) (Creswell, 1998). The transcriptions were read and reread to begin the analysis procedures.

A computer software program was used to further facilitate the analysis of the interviews (Creswell, 1998). NVivo was the selected software for analysis of this research as this computer analysis was thought to offer an additional tool to organize and store the data (Student version 7, QSR International, Markham, ON, Canada). Transcripts, field notes, journal reflections, and any pertinent decision notes were imported into the program. The program also assisted in the search for themes, crossing of themes, diagramming and template creation (Creswell, 1998).

Some of the theme derivation was completed via paper and pencil in addition to the computer program analysis. Colaizzi's (1978) phenomenological method of inquiry was used to further analyze the data in this format. This method is a descriptive and inductive seven-step technique to search for the essence of the data. The steps included: (1) reading the transcripts; (2) rereading the transcripts and pulling significant phrases out; (3) making attempts to find the meanings that are hidden in the transcripts; (4) clustering and validating the themes; (5) combining all data findings into an exhaustive list that describes the phenomena; (6) formulating a statement of the essence of the phenomena; and (7) validating the exhaustive description with the research assistant and including new data that emerged (Calaizzi, 1978). This analysis provided this novice researcher with an opportunity to work more intimately with the data.

This inductive analysis is an "immersion in the details and specifics of the data to discover important patterns, themes, and interrelationships; begins by exploring, then confirming; guided by analytical principles rather than rules; ends with a creative

synthesis (Patton, 2002, p. 41). Meaningful statements were bracketed from the transcripts and then assigned to tables to formulate key themes and sub-themes. An attempt was made to exhaust the descriptions to ascertain the “essence” of the experience (Creswell, 1998).

The use of a journal to record the research experience was utilized as suggested by Straus and Corbin (1998). This technique was completed to assist in bracketing any personal beliefs of the researcher as well as to record personal thoughts during the data collection and analysis.

Verification of Interpretation

To increase the trustworthiness of the data, thick descriptive data and theoretical sampling was planned (Guba, 1981) and completed. Planned quality controls of the data included verbatim audio taping; raw data, field notes and memos were kept to allow for auditing; copies of the transcripts kept in a separate locked file cabinet; the interviewer compared the transcript with the tape for accuracy, and a notebook for an audit trail was maintained as records of decisions are made throughout the project. Confirmation of the results with the participants was completed during, immediately after or within one week of the interview. These controls augmented bias reduction, accuracy, consistency, and confidence that the data reveals the perceptions of the participants. The researcher reflected on potential biases to reduce the potential conflict (Dick, 1999). Active formal information seeking was accomplished to disconfirm personal assumptions and interpretations.

An external audit will further establish credibility and an examination of the process and the product will be completed (Creswell & Miller, 2000). A review of the

project by an expert in the phenomenological method was completed. This expert is Dr. Joan Norris, Professor and Associate Dean of Research from CUMC School of Nursing, who has completed, reviewed, and evaluated previous phenomenological studies. This audit was completed at the end of the study. The auditor did not have any formal connection to the study (Creswell, 1998). These procedures were thought to enhance consistency and reduce bias.

The purpose of the interview is to gather data and not to be a counseling session or make judgments (Patton, 2002). Therefore, the researchers focused on being neutral and not provide therapeutic support for the patient's decisions for treatment or make any attempts to change their decisions. The researcher made every effort to put her values and feelings aside during the interviews through constant focus on the purpose of the study. The patient was shown respect if he or she made choices not to share data or become uncomfortable with the questions or probes.

Summary

This chapter provided a description of the research methodology for this phenomenological study on treatment decision-making in the older adult with cancer. The design specifics were detailed including the phenomenological philosophy, the methodology used for the study, and the specifics of the research design.

Chapter 4

Findings

Introduction

The phenomenological analyses of interviews was completed and resulted in identification of themes that describe the experience of treatment decision-making in a sample of adults with cancer. The presentation of findings includes limitations, verification procedures completed, considerations, the sources of the findings, a discussion of the data analysis procedures that were completed, and presentation of the actual findings in tables, figures and narration. The interviews are individually discussed and a summary of the emerging themes is included. The practice participant data and lessons learned from the recruitment phase are then shared.

Results

Sources of the Findings

The researchers completed 13 in-depth interviews with individuals who experienced cancer. These interviews occurred during the months of January to March 2007. The sources of the data included the completed background data form, audio-taped and transcribed interview, a journal of reflective notes from the primary investigator, an audit trail for notes on the process of the research, and numerous memos from the interviews and data analyses.

The research assistant reviewed the transcripts to uncover themes not initially identified and provided verification of the identified themes of the primary researcher. Consensus was achieved between the two researchers' interpretations of the interviews.

Background Data

The criterion sample consisted of 13 individuals between the ages of 51 to 83 with a mean age of 63.62 years. There were four males and nine females. Most participants were Caucasian, with two of other races including an African American and one of a reported mixed race with African American features. Five of the participants worked or retired in health care related fields. Three worked or retired from government or civil service jobs and two had backgrounds in teaching. The remaining individuals had worked or were currently working in an office setting. Eight individuals were currently working full-time and five were retired. The reported family income was spread across several income levels with four individuals at the \$40,000-\$60,000 level. All but two individuals had graduated from high school. The roles outside of work that the participants remained active and included one to 11 types of home, social, or volunteer activities. Most individuals reported having at least three to five different roles, and nearly all of the participants completed volunteer work in their community. The demographic characteristics of the participants are detailed in Table 1.

The cancer characteristics of the individuals are presented in Table 2. There were six breast, two colorectal, one non Hodgkin's lymphoma, (NHL), one uterine, one ovarian, two prostate, one kidney, and one thyroid cancer patients in this study. Three individuals were diagnosed with two types of cancer. All but one participant had been diagnosed and made a decision for cancer treatment within the last six months. This participant's data were considered important and trustworthy, and his decisions were able to be recalled in detail from a log of the events and an in-depth reflective journal of personal thoughts during diagnosis and

treatment. The data presented were very rich and was different than most of the other

Table 1 Demographic Characteristics

Participant Characteristic	Frequency
Age	
	(X=63.62)
50-59	6
60-69	3
70-79	3
80-89	1
Gender	
Male	4
Female	9
Race	
Caucasian	12
African American	1
Other	1
Family Income	
Below \$20,000	2
\$20,000-\$40,000	2
\$40,000-\$60,000	4
Above \$60,000	2
Prefer not to answer	2
Marital Status	
Married	6
Divorced	2
Never Married	2
Widowed	0
Employment Status	
Full-time	8
Retired	5

participants. Therefore, this interview provided an additional perspective.

Table 2 Cancer Characteristics

Cancer Characteristics	Frequency
Cancer Type*	
Breast	6
Colorectal	3
Non Hodgkin's Lymphoma	1
Uterine	1
Prostate	2
Ovarian	1
Kidney	1
Thyroid	1
Length of Time from Treatment Decision	
< 6 months	12
>6 months*	1**
Treatment Decisions	
Conventional Treatment	13
Surgery	
Radiation	
Chemotherapy	
Hospice after conventional	1
Non conventional therapy	2

* Three participants had more than one cancer.

** Only one participant was included with > 6 months

Interviews

Each individual shared a unique story of cancer treatment decision-making process, and the stories are worthy of a detailed narrative description. The following descriptions of the interviews will help paint a picture of the participants of this research.

Fictitious names are given to personalize the data yet maintain confidentiality. A short summary table will conclude this narrative.

Andrew. The first interview developed into an inspiring experience for the primary researcher. Andrew, a 72 year old male with colon cancer, welcomed the interviewer into his home as if a family member had arrived. Just minutes after meeting Andrew, it was evident that he was a truly amazing individual. Although he shared that his cancer was advanced and “aggressive,” he stated that “it’s been a wonderful adventure.” His story was illuminated by his spirituality and his positive attitude. He talked of his strong faith in God and his Christian faith. The common phrase ‘Let go, let God’ was interwoven throughout the interview. Even when noted experiencing pain, he responded “my faith and my walk with the Lord...(are) carrying me through.”

A strong faith in God was noted throughout the interview. This commitment also brought an obligation to God and as noted in the statement “He (God) made it very clear to me that if he chooses to keep me on earth, that He says there is one thing that I want you to do, and that is share your story with as many people as possible.” Andrew reported surprise and happiness when sharing that friends and relatives recently have told him that his words and examples have inspired them to be led to God. Sharing his faith and his story with others was a common theme throughout the interview. This sharing was even extended to the researcher after the interview with a thank you card and an offer to talk to others such as students. A possible theme surfacing during this discussion may be the importance of leaving a legacy for others who are left behind. Also, an overall theme of relationships seemed to emerge as he discussed his relationship with God and with others.

Andrew valued the importance of open and honest communication. This expectation was encouraged for health care decisions as well as in other interactions with family and friends. "... for me, that's the way I have operated all my life, you know, I have to be able to trust people and I have to have total honesty between one and another, you know, in order to really have that trust relationship." Open communication was thought to be important to establish and maintain a trusting relationship, and Andrew expected this of himself and those around him. The interconnectedness of relationships and communication with the decision-making process seemed to be a basis of the interview with Andrew.

Involvement in the decision for cancer treatment was brief and limited for Andrew because of the immediate need to complete surgery and then chemotherapy. However, he did want to be informed, and the need for open and honest communication was again stressed. "I have always been one that wanted to know and understand something before I could agree to or, you know, be involved in a decision. To have the facts and to really have an understanding of what was being asked of me or whatever, so I think with that I'm really trying to say that more communication and the more togetherness there can be is very important, and I think it would add a lot to the care giving professions, to their...lot more satisfaction in their work and being part of really helping people make decisions and guide them as much as you can without having them feel it's being forced upon them." He shared that he did not want to be a person who passively allowed others to make decisions for him. A major underlying theme of open and honest communication came through even when the decision had to be made in a rapid manner

Past experiences influenced Andrew, as he had been exposed to many family and friends with cancer, including his mother. When his mother was diagnosed with cancer and he had to return to the Army, he shared: “I’ll always remember this, when I left that day, she said my name, she said that if we don’t see each other again on earth, she said we will see each other in heaven. So that was my send off, and it’s always stuck with me and I’m sure had a great impact on how I lived and that looking forward to coming back home to see her.” His mother did survive until he returned and then he was able to spend a year with her. During this last year and his care for her, he was led to a job as a health care administrator. “...she died in my arms. That was the greatest experience I could have had. There was no thought in my mind of ever getting into long-term healthcare but it wasn’t, I think, ten years later that I did. That (the care for his mother) had a great bearing on my philosophy too because, I had the opportunity to be a part of her care and observing how people cared for her and how she interacted with them and so on.” Past experiences of Andrew’s affected his decision-making process. Again, the importance of relationships emerged as a major theme.

Care for and about others was unmistakable throughout the interview. He was concerned about his family, his friends, his nurses and his doctors. This care may have been impacted by his life roles but also led to what he determined as one of his most difficult experiences with his cancer. “The biggest adjustment I had to make and it really hit me hard emotionally. I’ve always enjoyed helping people and giving my best and my most to people and now all of a sudden I am on the other side...” Andrew reported that it took awhile and support from family and his pastor to “totally surrender” to be the “receiver of care.” Adjustment to changing roles had to be made in Andrew’s life, and it

may be the case that limitations demand much from the adult cancer patient could potentially lead to personal self-esteem issues. However, Andrew had a strong self-concept and was able to maintain his self-esteem even with his role changes within his family. He seemed to persevere even during his life changes. A theme of positive coping became apparent during the reading of his transcripts.

Portraying a positive outlook on life even when facing death, Andrew affirmed “So I just, enjoy life to its fullest, and my goal for many years has been to live each day to the fullest because that is the only day we’ve got a guarantee of and so that’s been my philosophy and my practice.” His positive attitude certainly impacted many facets of his life as well as others around him. This positive attitude affected the researcher by his remarks that he thought that the research was important to health care.

This participant had touched the heart of the researcher so much that tears of joy were shed when traveling from the interview and thinking about what had just transpired. It was evident that the interview became meaningful for both the participant and the researcher.

Barbara. Meeting at a local restaurant after her work at a local Catholic grade school, Barbara shared her story of breast cancer. This 59-year-old also told her decision for a lumpectomy with radiation in an open manner. The interview location did present some challenges to reduce noise and maintain confidentiality. However, it was adapted to meet privacy and comfort of the participant.

Barbara expressed a different picture than Andrew with her treatment decisions. She had to wait nearly a month before knowing it was cancer and expressed great frustration in the long wait. Having an unexpected final diagnosis of cancer and being

alone was the “scary” part. “And that was the first time he ever mentioned that word to me. So that was kind of a shock and I was by myself.” Barbara also noted a feeling of being overwhelmed by the information. “And then you know how your head spins and he is saying “well if you are going to go out and look in the internet don’t go to this site or this site, go towell I know nothing about that and I’m.....my head is just spinning, and I’m thinking my daughter needs to be here because she knows how to do something on the Internet, I don’t! So I had him write it all down, had him write all these words down. That’s when I went and found out from people that yes this is really a cancer, its just stage zero and it’s all contained.” These comments carry the themes of fear but also of shock and disbelief that she has cancer. The feelings of powerlessness also come across.

Although Barbara and her children were close, she reflected that “My children were the biggest problem, because they of course, heard the word cancer and they of course assumed you have to have a mastectomy, you have to have a mastectomy and I am trying to explain to them I don’t believe so. They are not telling me I have to. I think trying to convince my adult children that it is okay, that I don’t have a mastectomy.” Barbara was a single person who was very much in control of her life. At this point, her life was on shaky ground with her children trying to take control. She stated that they were very close but their views were different than hers. “But it was harder convincing them (about the treatment) than it was for me to make the decision for myself.” Again, powerlessness came through in Barbara’s interview.

Barbara reported having trust in the surgeon and the oncologist for having current information on what is standard practice. However, she expressed frustration at the lack

of knowledge of the radiation treatment regimen and its side effects. “I think understanding more when you don’t know anything about this and I went, like my initial treatments, you know when they do all the measuring and they make this board, knowing what they are doing, I, and they do give you a book. They give you a whole book about what radiation is about and all but I don’t think still it told you all the stuff that they were going to do or what to expect. I mean, the burning, the burn that you get from it. You know they say it will be like a bad sunburn, well, it didn’t happen, it didn’t happen, didn’t happen, and I thought maybe this thing isn’t working because I’m feeling no effects and then all of a sudden, WHAM, it happened big time. I just think you need more preparation for all that.” Barbara seemed to be saying that more patient education was needed regarding the effects of treatment and that a pamphlet is not enough. The desire for more information seems to come out as a theme enmeshed with communication.

Barbara expressed further concerns not knowing about all of the examinations that she would have and not knowing that she would have “permanent little marks all over me, until they did, well we are going to tattoo you, and I went ‘Oh really!’ I don’t know, it’s just, I feel like a little kid on their first day of school and you just don’t know what to expect.” This feeling of powerlessness became more apparent as Barbara gave an example from her life as a second grade teacher. It demonstrated her empathy to her pupils but expressed how out of control and fearful that she felt during the diagnostic and treatment process. This expression of powerlessness came across loud and clear.

Barbara shared that the knowledge cannot just come from pamphlets and the Internet. She suggested that “... maybe just having someone to walk you through it, who’s been through it and knows how, especially at the very beginning when they are

doing all those machines and measuring you doing all this stuff. Maybe it, you know, someone could just be there who has been through it...” This need for knowledge and connection to someone who “has been through it” suggests a need for a relationship or connection with someone with her type of cancer.

The interview ended with an expression of another frustration. She wanted to take the “newer drug” to prevent recurrence of the disease but “... couldn’t because of the bone density scan showed that my bones were not good enough for the newer drug...” She was concerned about the potential long-term side effects of the older drug. Again, the desire and need to know more information resurfaced in the interview.

An under-riding theme of communication became more evident in the interview with Barbara as she spoke of the need for better teaching, the need for someone to be with her when informed of the cancer, the delay in informing her that she had cancer and with her need to communicate her desires for treatment with her family. She stressed the importance of calling patients by their preferred name for this was frequently not adhered to in her care. She also shared that the radiation staff were genuinely “happy to see her.” This individualization of care is an important part of the communication process. Barbara’s impression of this situation highlights the relationship of health care providers and patients. These examples demonstrate respect of the person with cancer as a unique individual.

Catherine. The third interview took place in the home of an 83 year old, retired nurse who had been single all of her life. Although she was 83 chronological years, she was very healthy looking and this interviewer was surprised to think she was even over 70 years old. She was diagnosed with breast cancer and had two major decisions to deal

with---surgery and follow-up treatment. She did make the decision to have a mastectomy and follow-up chemotherapy and radiation.

Catherine remains very active in her community, especially in the political realm and in volunteer activities for the elderly. As a nurse in a military hospital she accomplished much during her education and career. Catherine was very proud of her independence and her community involvement. She was very willing to be part of this study and was very determined to provide complete information. These were demonstrated by the fact that she called me days after the interview to tell me about another role that she had forgotten to add to the background form. Also, it was interesting to note that she called after her surgery and prior to making the decision for follow-up treatment. The researcher responded by delaying the interview until after this second decision was made in order for the study not to influence her decision.

Although a nurse and highly educated individual, Catherine found herself in a “... sort of a shock.” She started the interview with “... you know, you hope something like that won’t happen to you. But from the time of the diagnosis to going into therapy was fast and I didn’t have to ponder...” The interview continued in a very matter-of-fact manner with her answers thorough, yet with little emotions exhibited.

Catherine reported feelings of being overwhelmed by all of the physician visits, and transportation concerns. She reported that driving was more difficult with the winter and it took much coordination with her sister’s schedule. Making the decision for surgery she shared that she did not feel that the decisions were difficult for “we all just had confidence in the doctors and just decided to go ahead.” About making the decision for follow-up chemotherapy and radiation therapy, she reported “I just decided to go ahead, I

don't think there was anything difficult about it, I thought well, that is what I needed to do and so I went ahead." This type of very straightforward answers about her treatment decisions was characteristic of the entire interview and led the researcher to believe that this 'just get moving' attitude was how she handled her life in the past. This approach may be reflective of her military and professional experiences.

Although the interview was very direct, subtle messages of spirituality became apparent to the researcher on review of the transcripts. Catherine stated "Well, I think you just hope for the best and you know, and you know you keep praying that things will be okay." She also noted that "I have another close friend, interestingly enough she had breast cancer forty years ago and she had a mastectomy and she has lived forty years, you know, so you think well there is hope, you know." She also noted that she received support from the positive attitude of the physicians with whom she has worked. The theme of prayer and hope came through, although she seemed to be very private on these issues.

Catherine indicated that her family has helped her emotionally and with transportation. Her support has health care background with her sister, a pharmacist and a niece a licensed practical nurse. She also remarked "I have a very, very close (friend), she's a classmate, and her daughter has breast cancer and so we talk too, you know. She is a younger person and she was diagnosed about ten years ago but she has a reoccurrence now so, we compare notes." She indicated that she gains support from these individuals. The theme of relationships came through during this interview.

Catherine shared that she has two masters degrees with one in education and that she explored much information about the cancer and its treatment prior to making the

decisions. She noted that individuals “need to explore everything, as I said and I told you I went to the Cancer Society and I’m going to a class on Monday at the hospital that in case I start losing my hair and things like that, you know, you prepare for, for hopefully for any changes that you can meet those okay and so I think you need to look at things that might help you, as time goes on here.” Her pamphlets, internet downloads and information from the American Cancer Society were placed in a notebook and filed according to topics. The desire for more information came out in the interview. Her self-initiative to find the information resulted in her reporting that she was able to find resources independently.

When asked about the influence of age, she responded “I did ask the oncologist, the chemotherapy oncologist, I said, at my age what he thought about going through chemotherapy and he said, well he said, interesting enough if you were my mother I would suggest it. And he said you know, anytime if I felt like I needed to stop, we could stop and that type of thing.” A theme of collaborative decision making was coming through this interview when noting the thorough information-gathering yet clearly letting the researcher know that she had a part in the decision. The underlying themes of open communication, involvement in the decision and also the respect for the physician emerged.

The importance of independence and fear of losing this came across when Catherine stated “Well you know you are concerned, you wonder how you are going to tolerate it and living alone and how that is going to work, you know, you don’t know.” No other statements were made but her nonverbal communication of looking down and facial grimacing indicated that becoming dependent on others was a concern to her.

Powerlessness surfaced as a theme related to potential physical limitations and role changes.

Dorothy. This interview took place at a respiratory therapist's outpatient office, and her interview was interrupted by phone calls and staff communications. Although the interview had to be put on hold at intervals, it became apparent that this setting allowed the researcher to see Dorothy exhibit her inherent compassion for others and commitment to her profession. The value of realizing how much she cared for her patients provided a rich background for the interviewer to understand her as an individual.

Dorothy is a 56 year-old female with a new diagnosis of non-Hodgkin's lymphoma and a history of lung cancer six years ago. As a respiratory therapist working full-time, she sat with her head scarf to cover her alopecia (loss of hair). She reported working at this hospital for a number of years and loved to work with her patients and loved her job. This researcher was in awe of her positive attitude, her compassion for others, and perseverance with combating her cancers.

When discussing her cancer diagnosis, she shared that it was an unexpected event for she had had lung cancer without a reoccurrence. "I found that I had eight different areas that had lymphomas. Had no symptoms. The only way that they found it was that I had an annual CAT scan...He said, Oh my God Dorothy, this is not good." A follow-up PET scan showed what someone said that she "glowed like a Christmas tree" and "the one on the chest was really, really big." At this point she reported that "the decision to start on the treatment was really fast." She shared that the decision was made by herself and the oncologist. "I felt very relieved once I had made the decisions, it was, it was like a weight off my shoulder and said let's do it then, yeah it was like okay, now I know

what it is and let's just go on!" The theme of shock and disbelief was apparent in Dorothy's statements.

Dorothy sought out information from articles, physicians at the hospital where she worked and on the Web to understand what she would be going through for treatment. However, she trusted the oncologist and said to him "okay, I've got faith in you, we will do whatever you think is best!" One of the ways that the physician gained confidence in Dorothy is through sharing a personal story. "Then he told me, he said my father-in-law who is eighty five had this same type of Hodgkin's lymphoma, it was called large cell. ...He took the time to share a personal story with me!...to foster hope...This is the best way to treat it, because my father-in-law had it, we started him on this and he's still alive today, doing great. So he related a story to me about a personal matter to him and that helped me decide." These comments seemed to show that the oncologist had allowed her to know of a situation that was very personal and used this to foster confidence and hope in Dorothy.

In discussing a personal story from her physician, she acknowledged that she has shared some of her story of her cancer to some patients. She reflected "I said, you know the first time I had cancer and I told a lot of my patients, we kind of talked about it, they would come in nervous. I said I know what you've been through, well how do you know, well I've had lung cancer, I've had a lobe removed and this is how it happens and you know, you will be fine. Have a lot of faith!" She noted that just sitting down and talking with your patients is so important and that it conveys that you care about them and their situation. This example that she gave demonstrated a desire to connect with others but with a twist of the benefit for her patients and not herself.

Open and honest communication was stressed as important to her in her career and in her personal life. She stated that her oncologist has "...always been a straight shooter with me." This oncologist also had assisted her through the first cancer and she indicated that he also was open and honest with her at that time. It was evident that this was an important theme throughout her decision-making process.

Dorothy shared that her family did influence the decision-making process and with the entire cancer experience. In just a few short minutes the interviewer felt she knew much of her family "...my biggest worry was my kids. My husband, I knew he could probably take care of himself. I didn't know how my kids would deal with it. The first time (that she had cancer) they were younger, they were twenty and seventeen and they were all just in their own little worlds, well now they are a little older and little more aware of things.....I have a daughter that had just moved...for school, I had a son who had just gotten married. ...right in the middle of it, my son and his new wife just decided that they didn't want their grandchildren to grow up and not know their grandmother, so they got pregnant. So now I have a new grandbaby on the way." These events seemed to be very much on her mind. It was evident that the relationships with her family were of utmost importance and this theme was interwoven throughout the interview.

Her husband also had a need for support as he recently had prostate cancer and treatment. "So we had just finished with him, thought we were sailing free, and I find out in September. He needs a lot of support, I don't. I need support but not a hovering amount of support... so it was harder for me, 'cause he gets really nervous. It's like when the kids fall and hurt themselves, you know, he just kind of freaked out." These comments led the researcher to believe that she feels that she needs to be strong for others

in her family. The theme of perseverance came to light with her second cancer diagnosis and how she kept moving forward as if it was just another day.

Dorothy's positive attitude appeared to be highlighted throughout the interview as important in her life and the decision making process. This positive attitude was also interwoven with her spirituality. "We have a strong religious background and that makes a big difference I think in how everything is dealt with and they know I have a pretty positive attitude toward things. I don't look at the half empty, I look at the positive side of things. I think that makes a huge difference. People in the hospital that I see that don't make it are the ones that don't have a positive attitude. They tell them cancer, they know right away they are going to die and they will never be the same and it's all downhill. And it is. I think you truly have to have positive attitude towards the whole situation."

Dorothy's positive attitude definitely provided a strong coping mechanism for her.

Dorothy gave many examples in the interview of her concern for others such as her patients. She told of sharing the story of her cancer with her patients when they asked about her alopecia. She said that it was often a way to open the door to discuss end of life issues with her respiratory patients. It was obvious to the researcher that she offered hope and courage to those around her.

Further evidence that she had thought about end-of-life issues was noted when she stated: "I guess that I've always felt that if it was my time, it was my time...it's in God's hands no matter what, so just be prepared as you can be and that's all you can do. The first time (that had cancer) I got myself, everything organized and I did that again, got all my affairs in order, talked to the kids about financial things, talked to my husband, cause I handle all that and just even thought I didn't know which way it was going to go, I felt

better that I had got everything in order.” Becoming tearful, she also recognized that death may be inevitable. “But also, looking that I knew eventually I would probably be at the point that these people are at, that it just keeps coming back and they run out of treatment. But I’m not afraid to die.” Another example was given when talking with her family. “I always say because I pick out a psalm that I like and I say “when I die I want this Psalm played at my funeral” and just this time I found a real neat poem I said, now when I die I want this at my, I just said it to my husband yesterday.” End-of-life preparation emerged as a theme with Dorothy when discussing her situation and her patients. This theme related to the overall themes of spirituality but also of relationships for she connected her situation with some of her patients.

Few comments on the side effects of treatment were shared by Dorothy. One comment was made that led the researcher to feel that there were some rough times. “I didn’t know I felt bad!... ‘till I started feeling better.” She also shared “That whole week was tough, ‘cause I was so physically tired but I had great people, if I was tired they just let me go home, covered for me. But I think you need to have something to look forward to do, otherwise laying in bed everyday is tough.” Dorothy did not complain about her fatigue and the above comment reflects her commitment to her work and others and her perseverance even in difficult times.

The only other comment of side effects related to body image with a report that she wore a scarf instead of “that hot” wig. However, as previously noted, she focused her side effect of alopecia as a way to instill hope in her patients.

Although this interview took longer than most because of a wait at the beginning and several interruptions during the interview, it was rewarding to reveal important

information. Also, it was worthwhile to interact with an individual who was open to share her innermost feelings. Dorothy's interview seemed to exhibit many themes but most consistently the themes of relationships (concern for others, desire to connect with others in similar circumstances, and trust in health care); communication (openness and honesty, involvement in the decision, desire for more information); shock and disbelief and perseverance.

Edith. This participant brought many new perspectives into the study. Edith's transcripts gave a view of a 52 year-old with a new diagnosis of breast cancer and the challenges faced by an obese patient. She was a registered nurse working in an ambulatory outpatient setting, Edith shared her decision-making process as one of many decisions. Edith has two teenage boys and is "going through a three year divorce."

The initial diagnosis of cancer was one of shock, for she reported a painful and red lump. Stating "I thought this is very odd because I do self breast exam and I don't understand why I never felt this lump before? But ...so very unlikely that it was cancer,...I think through this whole thing that the key was that on one level I was dealing with this very intellectually and from a clinical perspective, sort of my inquiring mind if you will from a clinical perspective, I believe that kicked in over the underlying emotional." However, these emotions began to rise after the biopsy results when it was discovered that the tumor was large, "Six centimeters is huge!" Edith then shared concerns about the medical diagnostic procedures and the health care practitioners. The first exams did not accurately indicate the size and shape of the tumor. She firmly stated, "And according to the mammogram it was one centimeter and according to the ultrasound it was one and a half centimeters. So technology and surgical insight wasn't

reading this correctly in my book.” Also, the sentinel node biopsy did not play out the way she had envisioned it would leading to a procedure that she did not clearly understand and the surgeon taking more lymph nodes than expected. The picture was leading to much uneasiness and even mistrust of the health care system.

Although Edith was very satisfied with the radiation oncologist, the medical oncologist, the “nurse navigator”, and the plastic surgeon, she felt that other practitioners were not providing quality care. The nurse in the recovery room during her node dissection was reluctant to “touch” when providing support. She stated: “And so I knew that if there was a dissection done, that would indicate that I had cancer in the nodes and so I woke up, this was probably this was the lowest point of this entire experience because I was very much alone and I was coming out of anesthesia, there were no other patients in the recovery room and there were two, maybe three nurses and no human connection. It was very disappointing to me... And I said, oh my God I have cancer. And then I just sat there, I laid there, saying I trust you God, I trust you God, I have cancer, I trust you God, I trust you God. And I was crying, and I had to ask her if she could touch me...it was probably I think my lowest point.” This lack of what she called the “human connection” caused her much distress. The theme of relationship was emerging as an expectation of what she felt should come from the nurse.

Edith referred to her first surgeon as a “cowboy” and was concerned about his offer to “wait six months” for the surgery even though the cancer was aggressive. He was described as having a “pompous” attitude and “did not do a good job on my port.” These feelings of mistrust of the health care system were rising and did not increase the confidence that she had in her health care practitioners.

During her chemotherapy, Edith was searching for her final decision of the follow-up therapy. She stated “So it was very intellectual thing, but the radiation versus mastectomy was the big one. That was the big decision. I really liked the radiation oncologist; I just did not like the idea of radiation...and somewhere deep inside, radiation just did not feel right for me!” Reading the literature that was provided and some internet exploration, Edith began questioning if this radiation was the best option for her. She looked into obtaining a second opinion but did not feel that she was given this option initially.

Edith explored the positives and negatives of the breast conservation therapy followed by radiation treatment. She felt that she was told that breast conservation was recommended and she stated “I really felt like radiation, they said the words that the choice was mine...but I felt like they were urging me to do radiation.” However, she had concerns about her large breasts, the difficulty with wearing a bra after radiation, working without a bra during radiation, issues of obesity, the great potential for “feeling whipped” after radiation, and the potential later effects of radiation as lung and bone problems. She also shared that she was concerned about recurrence when saying “and the other thing that they couldn’t, the one thing they could not get out of my mind was I had a six centimeter tumor, mammogram said it was 1.5, ultrasound said it was 1.5, radiologist who traditionally over reads that very unlikely that it’s malignancy. Okay. Why should I trust that every three months what they tell me they find is right. I couldn’t deal with that. The thought of every three months worrying, wondering, thinking, dealing...” These feelings of uncertainty with the radiation after the breast conservation surgery were very

distressful for her. Her words also left the researcher to feel the theme of powerlessness coming through.

A decision to have bilateral mastectomies and not have radiation was made by Edith in spite of previous recommendations for breast conservation plus radiation. Feeling that she made the right decision, she shared "...but I tell you when I knew I made the right decision. When I went for my final chemo and the nurses went "YES!" The nurses agreed with my decision and I knew it was the right one. They cheered my decision. The doctors accepted my decision, you know, because of course, it was my choice." The theme of respect in association to seeing the decision from the patient's perspective truly stood out in her interview.

The next themes that Edith brought to the research related to her obesity and her role as a nurse. Interwoven throughout the interview were the themes related to body image, guilt and shame, and communication. Edith made several remarks about her obesity and how it affected her treatment decision. She reported that her weight and history of arthritis limited her movement and could impact her treatment. She noted that the potential for weight gain with treatment was very distressful by her remarks to the radiation oncologist: "I was given news that was frustrating in that she said it was entirely possible that I would gain weight during my treatment and I was so upset by that and she looked at me and said why do I feel like this is the worst news you got all day? I said because it is!" Communicating respect for her perspective was voiced as important.

The facilities for the surgery, chemotherapy and radiation all impacted her either physically or psychologically. She described the chemotherapy chairs as uncomfortable and small for her size and that the line of chairs looked like she was in a "nursing home

waiting to die!” She refused to have chemotherapy in these chairs. Further comments were eye opening as she stated she “was ...worried about if I would fit in the chairs? Could I get up from the chairs comfortably? All those extra things that thin people wouldn’t have on top but they definitely were a problem and a weight in part of my decision making...painful to sit in...People don’t think about that.” This participant’s unique situation did impact how she felt about treatment. The theme of body image became apparent in the remainder of the interview.

Her personal rejection of radiation also was impacted by her morbid obesity and led to anger at the health care system. She shared, “And so it was interesting because part of this process I had this sort of anger that came and it had nothing to do with my disease, it had to do with the healthcare system and not accommodating morbidly obese people, inflicting more and more, it just makes it more inherently shameful.” When contemplating her decision for radiation she reflected that “...and it just never felt right and then the ultimate was that the doctor said they had bought a new table that had a weight limit. And unless I lost a few more pounds I was going to be too much for the table. This multi million dollar table they bought, America is getting bigger and bigger and they buy a table...” These statements clearly expressed frustration and anger at the health care system. The need to move her care to another radiation oncologist because the facility could not accommodate her size only increased these feelings.

Another example of how Edith’s obesity impacted her care was during her initial biopsy. She explained about the bathroom in her patient room: “The toilet was this far

from the ground, my knees I couldn't do it...So put a sheet on, thank God it was only overnight, ...So I went to a public restroom. That's wrong!" These words depicted anger and also shame.

Body image also was reflected not only in her weight but also the alopecia and the surgery. "when I get morbid I say, you know, morbidly obese, bald, boobless wonder, that's me!!" Although this comment was addressed as a joke, it was evident that she was not comfortable with these issues as noted in her facial expressions and pauses in her conversation.

Guilt and shame were expressed when discussing her role as a nurse. "You know, I have a certain level of inherent shame associated with my weight, being a health professional and being morbidly obese. " Edith also noted that she felt guilty about not getting her mammogram in 2005, starting to smoke after the divorce and about "not projecting, living and exemplifying what I tell patients, what I tell my clients." She did acknowledge that healthy lifestyle is important and that stress from the divorce may have "compromised my immune system and brought this cancer." Body image again was surfacing but in regard to her lifestyle choices and not her outward appearance.

Edith did share that she had much support from her "Italian" family but they are on the eastern coast. They support her through Edith's conference calls, emails and watching over her sons during her surgery. Her close friends helped her physically and emotionally from diagnosis to post treatment. Her teenage sons helped her during the treatments. Relationships was a theme threaded throughout the interview.

Despite Edith's anger at the health care system and her acknowledgement of chronic depression and arthritic pain, she made a conscious effort to be positive. "I had a

water bottle that have affirmations on it, I had what I called my chemo bag, and I had a fragrance that I liked, kind of an energy citricy kind of thing that I would spray in the room. I bought a DVD player, portable DVD player and brought comedies to watch during chemo... So I tried to intentionally decide to make all these things around me positive, and that's not, that was a huge effort for me and a big decision..." This positive attitude was deemed important to her and attests to her determination to combat her challenges. Perseverance was also connected with portraying a positive attitude for it was clear that it was an uphill battle for her with her history of depression and chronic pain.

Spiritual influences were part of the treatment decision- making process for Edith. She reflected "My pastor, I called him immediately, my church was praying for me... My spiritual values, guided me in that I believe that God is good, I believe that if it isn't good it isn't from God. No, I don't blame God for cancer; I don't blame God for some of the other traumatic things in my life. I seek support and that sort of thing. I had lots of people praying for me all over the country and that was really awesome." Prayer and religion were part of her spirituality and a great support for her. Spirituality came through at times in the interview but was not a major theme.

Francis. This participant had previously made a decision for cancer treatment for surgery and chemotherapy about one year ago. However, Francis had just made a decision for hospice in the last three weeks, and this is the decision-making process that was the primary focus of the interview. Francis, a 72 year old female, had stage IV uterine cancer with bouts of bowel obstructions, severe anemia, and side effects from chemotherapy. The interview was conducted in her apartment with her small dog on her lap and in the presence of two close friends who were from Kansas. Francis asked the

friends to be present to have them hear her responses. The friends limited their responses to questions being asked of them and sat very attentive to her messages.

Spirituality was very important to Francis. Francis is a very devoted Jehovah's Witness and stated that she reads the Bible daily. She shared "Well they have proven in issues and documentaries on programs and in magazines that show that the spiritual side of your life is very, very important. Dealing with all the physical things that happen to people who don't have a spiritual life, don't do as well as the physical side." Francis believes that "we are created; we were created to worship an invisible God." She noted that religion is not the issue but faith in God is what is important.

Her decision for hospice was reported as being "easy" because of her faith in God and her difficulty after her last chemotherapy treatment. "Since I believe that when a person dies there is an opportunity for resurrection and I really do believe that in the resurrection I'll live in a better earth, a clean earth, earth with Jesus as the ruler and that I will be able to live a good, healthy life and that's what I really want. So the decision to die was not a big deal. Good people and bad people are all dying; they are no different than anybody else." At peace with her decision she shared, "I'm doing whatever I want to do and that's the truth. I eat what I want to eat; I sleep when I want to sleep. I go when I want to go; I'm not doing anything that I don't want to do. I just want to go exercise, always had a volunteer religion, Jehovah Witness is only a volunteer religion, you only do what you want to do that's what I tell these people. My whole life has been that I only did what I wanted to do. I've lived a good life." Her religion was a major theme for her life and the decisions that she made.

Initially, Francis shared that she really did not make the decision for radiation or surgery for “the doctors sort of worked it out really quickly...to save my life” and the cancer was considered inoperable...“they know that there are a bunch of tumors that have fused, the bladder, the colon, the uterus is all fused together and there is nothing they can do about it. It’s inoperable.” She has experienced bleeding and bowel obstructions from the tumor and side effects of the chemotherapy that she was “sick for ten days.” Reflecting that she had been in good health most of her life, she noted that she did not want to “to live another month just to have the air go in my lungs.” She seemed at peace with her decision for Hospice and her faith in God resonated during most of the interview.

Francis reported that her sisters and close friends have helped her and are supportive of her decision for hospice. She reported a step sister who “would run over thorn bushes to do something for me.” However, her 90 year old mother did have some difficulty with the decision. “She understands that where I am at and what I am doing, she just doesn’t like it. I’m her first born.” Francis did seem to understand her mother’s feelings but wanted me to know that it is her decision.

She also shared that her pet dog helps her have a routine for the day and “gives her some company.” She also shared a story that demonstrates her love of animals when she “repossessed a dog” from her ex-husband because of abuse. This example also showed how determined she is when she drove a thousand miles to get the dog even though she was only six weeks out of the hospital for a bowel obstruction.

Sharing her experience with her first bowel obstruction, she reported that she was at her close friend’s house for a Jehovah’s Witness convention. That night she became ill

and drove herself to the hospital. She was determined to get out by the time the convention started, so she convinced the physician to release her early. Perseverance emerged from this and other stories that she shared. The themes of spirituality, perseverance, family support (relationships) and being involved in the decision for treatment were similar to other participants.

During this interview with Francis, the cancer experience began to emerge as being one of many decisions. Also, it was noted that not all decisions are completed in the same time frame---some fast and furious and some longer and more well thought out. When the interview started, she made attempts to talk about the decision for hospice but noted that the decisions were not just about treatment, but also about life changes. For example, she moved into an independent living apartment and sold her car as she became ill.

Gerry. This interview was conducted at an oncology office just prior to his chemotherapy. After his chemotherapy and radiation regimen, it is planned that he undergo surgery for his colorectal cancer. Gerry is a 58 year-old male who is a retired police officer. The interview was carried strongly by the theme of how the cancer and the Nebraska weather “really messed up” his life. Although he is currently living here in the Midwest, he is here primarily to follow his two grandchildren. His son is in the Air Force and stationed in the Omaha area. He and his wife live in a recreational vehicle (RV) outside of town.

Gerry identified financial burdens as a major theme from the beginning to the end of the interview. Stating “Yeah, it’s going to cost way, way more than I want to pay. But what are you going to say. This is frustrating since I am retired and I was about to reach

my sixtieth birthday when all the big things were going to change (more coverage with health insurance) and I was just really pissed off that it was changing my plans.” He discussed financial concerns as a negative issue in nine statements relating cost of treatments, travel issues, lack of insurance coverage, transferring their extra money from travel funds to medical funds, his inability to work, and weather problems. The financial concerns seemed to highlight a feeling of powerlessness.

Living in an RV during the Nebraska winter months, he shared the many difficulties that he and his wife had with the severe cold weather this winter. “Well the weather has been hell!” The wind and bitter cold had compromised his home with physical and mechanical problems. It became apparent that he was very unhappy with Nebraska and even angered that he had to deal with the weather.

“Annoyance” and determination were two other themes that seemed to be threaded throughout the interview with Gerry. Starting the interview, Gerry stated: “...I wasn’t sure the degree, how severe the cancer was and I also said, in fact I told the doctor that I am not going to die from cancer I promise you that! So, because I had visions in my head of total debilitation and being bed ridden and I told him that’s not going to happen. So, initially yeah pissed off, but then just an annoyance.” Anger emerged as a common theme for Gerry.

Gerry’s diagnosis was discovered “by accident...in another study for diabetes...discovered that I had severe anemia... So it was kind of a whirl wind thing, it just happened boom boom, boom and it wasn’t really like I had a whole lot of time to reflect on it.” The fast pace and unexpected diagnosis threw his life into a tail spin.

The side effects (tiredness; constant stomach problems) and the many appointments were also considered “annoyances” that made changes in his life. He shared that “taking a trip is all going down the tubes now with this stuff so, and I can’t work mostly because I can’t ever know whether I am going to make a full day or not because my stomach will start to acting up and it’s just at the most inopportune times ...” The cancer and the cancer treatments were definitely changing his life plans for travel. Anger was again the theme in the interview but the feelings of powerlessness about the side effects was also coming to light with these statements.

Gerry was a very organized individual and a person who was very much in control in his life. These “annoyances” certainly got in the way of his day to day life and his plans to travel. He voiced concerns about “juggling so many appointments” and stated that it was very time consuming going to the physician’s offices. At times these situations were described as causing him anger, frustration, and stress. In addition to the common theme of anger, the powerlessness of his situation seemed more than annoying for him.

The many appointments needed for someone undergoing both chemotherapy and radiation and having specialists for oncology, diabetes, and cardiology have increased stress in his life. “Well, yeah, there are, there are signs of stress every now and then. I guess people need to be aware of, even if you don’t feel stress, there are times. I blew up on a parking attendant here Friday for really not a legitimate reason and it was a combination stress....” Gerry concluded that it was stress in combination with the many facets of his experiences. The powerlessness theme seemed to continue as he shared his story.

Attempts were made to regain some of the control through organization and by gaining information. Gerry had his bag of activities with him and it is obvious that he did not sit and waste time during treatments. His seeking knowledge is evident in the following: “No, I demand information, probably more than most people ask. I, I somewhere along the lines, background in biology and stuff and I ask a lot of questions and watch a lot of TV shows and stuff. I ask a lot of questions. I expect direct answers and that’s why I’ve been real happy with the doctors that I’ve got because they haven’t tried to give me a song and dance. I would have different doctors if they had, ‘cause I don’t, I don’t like that.” These statements seem to carry the theme of determination.

Gerry identified having trust in his medical care even though “lots of people” have tried to “kill me and I’ve survived.” However, it was very apparent that this trust needed to be earned through detailed information and validation with information that he has gained through reading and other resources. Also, he reported that these “brushes with death” do not “faze” him much. These end-of-life themes are apparent but the details of these experiences were not shared.

Although Gerry seemed very stoic in the interview, it was very evident that he cared about his family. He was concerned about his family, especially his younger brother. He made it well known to them that they needed to have a colonoscopy. Little information was shared about his wife or son but frequently brought up the importance of his grandchildren in his life. He kept his personal life very private in the interview. In summary, the themes of relationships, communication, perseverance and powerlessness emerged in listening to Gerry.

Harriet. This interview was completed at a local restaurant that specializes in natural foods. This location was symbolic of one of the themes that emerged from the interview. Harriet is a 69 year-old female who is from a religious order. She is a teacher and works on issues of non violence and peace. Her diagnosis of breast cancer was treated with a lumpectomy but her recommended mastectomy and follow-up radiation treatment were refused. She chose a non conventional treatment focusing on a healthy lifestyle and the holistic aspects of health.

Harriet's obvious willingness to share her decision story was noted in her emailing me seven pages of detailed answers to my interview questions, meeting with me over a 95 minute lunch to discuss the interview questions, with her willingness to share my study with others who had similar views on health care decisions, and thanking the researcher for an "interesting opportunity." This individual presented herself in a very open manner and she displayed a very independent and proactive personality.

The themes that were discovered with Harriet's interview included some previously uncovered themes from the first seven interviews including shock at the diagnosis, spirituality, leaving a legacy, fears of disability, having a positive attitude, perseverance to fight the disease, seeking knowledge, the cancer getting in the way of life plans, previous experiences impacting the decision for treatment, mistrust of the health care system and health care providers, financial issues of treatment, and the importance of being included with the decision for treatment. Although many of these themes were identified in previous interviews, this participant did bring some slightly different views.

What this interview brought new to this research is Harriet's focus on taking control of her health through a healthy lifestyle with a focus on nutrition, stress reduction,

immune boosting strategies, and exercise. Being a part of a religious order, she had to seek the approval for cost of the non conventional treatment regimen she chose not to complete chemotherapy or radiation. Harriet's story provided intimate details of an overwhelming burden of her treatment decision-making process. This participant presented the importance for health care providers to listen intently to their patients and seek out the individual's personal perspective to truly assist them with this process.

One of the first reactions to Harriet's diagnosis was one of shock, disbelief and high anxiety. "I discovered a large lump and went into shock for a couple of days. I KNEW I had cancer! I had to wait more than a month before I could begin to check it out and I became more calm." She put the cancer diagnosis "aside" when first identified the lump because of another person in the order who was dying and the fact that she had her jubilee. Care of this dying person came first. Also, Harriet delayed treatment because of her desire for her and her family to have fun at her jubilee party. She said that informing them about the cancer and going through the tests prior to the party would "put a damper" on the celebration. She wanted their "first trip to Nebraska to be enjoyable." Her delay was focusing on a concern for others or she could be in denial.

Not assuming that spirituality was a major focus in Harriet's life because she is a Catholic nun, this theme did emerge in her interview. She reflected: "I'm really more okay with what happens to me because I don't think, I didn't ignore my health, I didn't bring the cancer onsome people could have by neglecting it for a couple years; I didn't do any of that. I didn't do anything wrong, in a way. So for some reason it came, and I have it and so that's the thing. So, then if I have it, and I'm going to learn some things. I am also a member of a big community of women, a lot like myself. As a teacher,

do I have a job to do? What am I suppose to do with this information? So, I do feel called to share, to share my experience and if it helps other people to think things through, then I think it's a gift and that's, that makes it worth while and it also gives it a purpose rather than just being something about sitting in the corner crying about." This theme was surely focusing on a search for the meaning of the experience.

Harriet had asked the oncologist her predicted length of life if she decided on no follow-up treatment and related it to her age (69) and she reported it was approximately two years. She said "I decided that time (2 years before I would get sick) was ok. I have one project at work that I would like to do...we were supposed to start when I got my diagnosis..... and two years would be enough time to do it. No one has told me how long I will live if I take chemo and radiation. Either way it is a gamble." This project is very important to her and this is something that she felt she could start and it would keep going. End-of-life and leaving a legacy themes seem to be intertwined with the uncertainty of her predicted length of life (age) and a sense of powerlessness. She said that she had "no desire for longevity...I am single with no living dependents and I have lived a very good life so far."

Harriet had a positive attitude about her fight against the cancer and her health as noted by her stating: "All of the doctors who treated me observed with surprise that I am not on any medication (at 70 years of age). So in many ways I am quite healthy...I just got cancer!!! Go figure. I will need all of my resources and I cannot risk diminishment of any of them because I am dealing with a killer disease that is equally determined to live and take my life in the process." She referred to the cancer as a chronic illness and was determined to keep it "at bay" and be as healthy as possible.

Harriet shared some fears in the cancer treatment and these included the threat of physical deterioration, potential problems with nutrition, and the side effects of chemotherapy and radiation. She stated: “I recall telling the breast surgeon that I was not afraid of my cancer. The treatment was more intimidating. I was given a sheet by the doctor listing multiple side effects. I had seen two friends die from cancer in four years and neither was very pretty. I feel certain that one of them starved to death and I learned that this is fairly common with cancer patients.” These experiences definitely made a strong impression on her. The exposure to her friend’s death also encouraged her to seek more knowledge on healthy lifestyle and cancer.

The mistrust and verbalized anger at the health care system and health care providers emerged as an important theme in Harriet’s case. Numerous examples given included long and unpleasant diagnostics in which she was given unhealthy Gatorade with “loaded sugar;” hearing about having a “rather harmless type of thyroid cancer” when reading her scan results but no one informed her of this; having constant pain since the lumpectomy and a fear the pain worsening with the next surgery; the discovery that she had “some cancer in the lymph nodes that I did not know of in the beginning;” that “seven lymph nodes were not diseased” and yet removed with resulting compromised left arm; the feeling like treatment is “a guessing game” or “crap shoot;” the lack of “acknowledgement that stress or lifestyle had anything to do with causing my cancer;” the pattern that the “individual gets lost” in the health care system; and her belief that “female medicine has disappeared” in today’s health care system.

She gave an interesting story to relate to what she identified as the “gender conflict” in today’s health care. She reflected: “Remember Joan of Arc was killed as a

witch!? ...A witch is a person who has special powers and if it's a woman who has special powers she's suspect. All the women healers of the middle ages were killed, they killed more than a million women across Europe, their husbands delivered them up to be killed over a period of a century and a half. That's where female medicine disappeared in my thinking." This strong belief in gender disparity also emerged when she discussed her skeptical attitude about politics with the peace movement that she is involved with and in being a female in the Catholic Church. Powerlessness appeared to be emerging as a strong theme in her interview.

Harriet is very passionate about the importance of taking part in her own decision-making process. She sees the tie with religion and our paternal health care system. She declares: "We put the priest and the doctor in Guru positions! I mean, religion lets us do this. And people are afraid to challenge their church because God will zap them, we have created this God that has, don't get me started. But all of it is connected. Because we live in this system that is all related and it functions because people believe it." Harriet was sending the message that taking control of your own health is important.

The lack of inclusion in decision-making was another frustrating issue for her and it clouded her development of trust in the health care system. "I was never asked how I felt about treatment...People around me assumed I would be taking chemo and radiation, and I gave them the date the treatment would begin." She did not feel engaged in the decision-making process and Harriet also had a concern that the health care providers were not listening to her story or even trying to see her perspective. Listening is a basic skill of therapeutic communication, and Harriet's reflections shows a theme of a feeling of disrespect to her as a person.

Other concerns that overlaid her decision for cancer treatment included her concern for losing her appetite; inadequate nutritional support; destruction of the immune system with treatment; that there is “no guarantee” with conventional therapy and a greater likelihood of a secondary cancer if radiation or chemotherapy is accepted; unsure of who will continue her ministry if she is out of it for a year or two; the fatigue and the overall quality of life issues; the lack of making her schedule a priority when treatment or appointments are done; and the potential for depression. Her thoughts were that she would not be able to work well if chemotherapy was completed. She explicitly stated: “Because I’m kind of a wimp! When I don’t feel good, I go home. Like I’m not the kind of person that can go with a headache to work and perform well. I get owly, I don’t have much tolerance for discomfort because I’ve never had to put up with it. I’ve had a few times in my life when I was ill, and I was ill and everything else just stopped. I’m not a multi-tasker...” She felt that all of these issues would deter her from functioning well and this led her to non conventional therapy such as acupuncture. The theme of self-concept was emerging as she shared expected physical limitations, the effects of treatment, and her views of holistic health.

One difficulty in using non conventional therapy is that Medicare does not pay for most of this type of treatment. Harriet had to present her case to her religious community. Even though the cost of conventional is very expensive, it is covered by Medicare for it is supported by research evidence. Therefore, the order needs to incur the financial burden. In the end, Harriet did not get approval for her chosen therapy and will need to use her own limited personal funds for this type of treatment. She does not blame anyone except

the current “philosophy of the health care system.” The themes of uncertainty related to her financial burden of the non conventional treatment became very apparent.

Harriet has chosen to change her life style with nutrition, exercise, work life, spiritual practice, and complementary therapies such as acupuncture. She recognizes this as a conscious decision that she will be “very difficult to sustain”... needs to commit “to do a great deal of work... It is a decision that shifts the burden for my wellness more completely on me.” Her decision was based on her belief that chemotherapy and radiation treatment will “harm organs and systems in my body”...and “seems violent and damaging for a questionable outcome.” She also adds that she feels that “our body is pharmacy...a complete pharmacy and... I think, and I think I believe that, tend to believe that, that we nurture that and strengthen that and take care of that and it will take care of us.” Her focus is to heal her body through a holistic approach and she is very committed to this plan of action. Harriet acknowledges that she may have a “shorter stand with a better quality” but is happy with her choice. When asked how she felt when the decision for treatment had been made, Harriet responded: “Free!!!” This latter statement was testament to her beliefs and to her perseverance to deal with her cancer experience.

Ivan. Ivan is a 63 year-old male with prostate cancer. This individual is not characteristic of the other participants and brings some distinct themes to the study. Ivan met the researcher at a restaurant near his work. During a nearly two hour interview, Ivan was very friendly, professional and enthusiastic about his approach to health care.

Ivan was diagnosed with prostate cancer longer than the six months ago but has kept a diary of his cancer experience and has shared his story with many people. He has kept a detailed log of his decisions and a diary reflecting his experience. Because of the

different perspective that this individual brings to the study and his detailed recording of his thoughts, feelings and knowledge, this participant was deemed as valuable to be included in the study.

Becoming ill about three years ago, Ivan was diagnosed with prostate and kidney cancer. His diagnosis also included renal failure. Ivan accepted surgical treatment but refused further conventional treatment. He chose healthy nutrition, stress reduction, exercise, and positive attitude as a non conventional therapy to follow-up treatment. The themes of holistic health and positive attitude were very visible throughout the interview.

Ivan reported that his decision for treatment was made prior to the hospitalization and the diagnosis of cancer. He had a family history (father) die of cancer. Therefore, he had thought about it and read about it then came to a conclusion that he “would tackle it the natural way.” He always felt that he would not undergo chemotherapy or radiation therapy. He reported discovering Co-Q10 as a supplement to “cure cancer.” He also changed his diet and “give my body every possible opportunity to do whatever it had to do to get rid of the cancer.” Ivan also “started reading about pH and acidosis and alkalinity and how getting our alkaline and pH numbers up improves our health all around.” He is very determined to follow a holistic approach that improved his immune system and has completed this since being diagnosed with cancer. He also is using vitamin supplements and Ivan’s cancer is currently in remission and his renal failure is nearly resolved. Although he does go to traditional medical doctors, he relies on a chiropractor that is really into nutrition for most of his care. His focus is “fixing the body so it can heal itself.” The holistic view in the connection between body, mind, and spirit was detailed in his interview.

In addition to nutritional aspects for his treatment, he feels that a “positive attitude is important in every area of life. I think our body reacts to our thoughts and if we tell ourselves that we are sick we will eventually get sick...when the cancer diagnosis came along it was no big deal. It was just something that needed to be addressed and I knew that I’d do it and so I did it.” A positive attitude was displayed in every plan discussed for his health and thus emerged a sense of positive coping as a theme in the interview.

Spirituality and self responsibility also emerged in the interview with Ivan. He shared examples from his church and in his life experiences. He stated “prayer works and we believe in prayer.” He believes that God can heal anything but we as humans must take some accountability for the cure and that “even God can’t steer a parked car, you know.” He used himself as a testament by saying that God has blessed him and his “numbers are falling like a rock.” His belief is that attaining knowledge is part of this self-responsibility. However, he cautions others to be “in charge of your own health” with his overt and passionate mistrust of the health care system.

Ivan demonstrates much mistrust of the health care system and sees it as being a large problem in our society. He comments: “cancer is not a demon ...but modern medicine is the demon.” He feels that chemotherapy is a “horrible treatment” and this pharmaceutical product is “money driven” and it destroys the immune system. Ivan strongly suggests that there are many “cures are sitting on the table, but doctors are forbidden to use them by the FDA, discouraged by the AMA, um, that’s a crime. And so it’s up to us as individuals, to look out for our own health and to me, putting chemo in that destroys your immune system, creates acidosis in your body, creates a seabed for

cancer, it's a horrible approach. It's like throwing kerosene on a fire." It is unmistakable that Ivan has great mistrust of the cancer treatments and the health care system itself.

His belief about pharmaceuticals is that many of the natural products do not have financial gains, there are no randomized clinical trials being completed because of this, and then ultimately, the natural products will not be promoted. He goes on to say that "I'm a layman, but I don't believe that with natural products you need placebo controlled double blind studies, these are not toxic drugs. Toxic drugs, you need those studies to make sure they are not going to kill somebody, you know, but with natural products, for the most part they are harmless, and they are either going to do the job or they won't. I'm the kind of person that if read in there from a credible source..." Although many natural products are less expensive than the chemotherapies, he admits that the insurance industry will not pay for them. He refutes this with noting that his hospital bill for 13 days was \$43,000. The mistrust is highlighted when he states that he feels that the "drug companies and the insurance companies and the hospitals and the AMA and all of them are all working together." Ivan strongly believes that the health care industry is damaging the economy and ultimately individual people. This mistrust of the industry is similar to previous participants but Ivan seems to be greater than others.

Ivan does recommend standing up to the doctors for they may not include you in the decision making process. He states: "...be prepared for the doctors to come at you with both barrels. You have got to have treatment, you have got to do what I am telling you to do, you've got to do it now. And the pressure is going to be so great and you have to be prepared with your belief system in what you are doing to be able to stand up to them and say no, and if you waver or if you are not sure, that these things will work then

you are going the doctor route.” Again, this approach is similar to others who have demanded participation in the decisions, but Ivan may be taking to the extreme.

Physically Ivan is a testament to a holistic health approach to reduce the cancer progress. He promotes healthy nutrition and supplements to enhance the immune system. His prostate cancer tumor markers have shown the cancer to be reduced. His kidney cancer is in remission and he has only slight renal insufficiency at this time. Ivan’s interview carries the themes of positive coping, perseverance of his beliefs on holistic health, and a positive attitude with self responsibility. These themes are parallel to other participants previously identified.

Jillian. This interview was completed after Jillian’s work shift in a room off of the hospital cafeteria. Jillian, a 52 year old mother, was just diagnosed with breast cancer. She is currently being treated with hormone chemotherapy and will undergo surgery in the next few months. She is a health care provider and in this characteristic is similar to four other participants.

Her interview carried an overall theme of fear. She stated “ I know the first feeling that I had was fear!” She also reported a feeling of disbelief but stated “mostly fear, I mean it’s scary, you know someone tells you well it looks suspicious and then they come back and say its carcinoma. And of course sadness, I mean I kept my cool until I got home and then I just broke down and cried all night.” Jillian provided a perspective of fear of body image changes secondary to the treatment for her breast cancer, fear of mastectomy and mutilation, fear that others will know that she has cancer, and fear of the side effects of chemotherapy and radiation.

Another fear that has not been exposed by other participants was the fear of an increased awareness of the cancers around her. She stated: “Well and then just in this last month some of the people that work in this hospital, it’s the same thing happened to them, what’s going on here? I mean, it’s scary……. Maybe I never pay that much attention, but boom, boom, boom, there are three people I know have biopsies, I thought oh my, gosh!” The statements seem to create a picture of breast cancer exploding in her work setting. She acknowledged that she may be more keenly aware but still states it is frightening.

Jillian reported that her diagnosis of breast cancer was very fast and this is similar to other participants. “Maybe that was a good thing that I went right from mammo to ultrasound to the biopsy, just boom, boom, boom. I never got out of my gown. All happened in one day!” However, she reported delaying her mammogram for three months even though she felt a lump. She admits that “But I had that lump there for about three months and I guess I was in denial. I kept thinking it might go away or it was just a cyst.” Again, her fears seemed to overlay the interview.

The new themes that emerged that have not been identified with the other participants are the concern for privacy in her cancer experience. She seemed to be a very private person and felt that the treatments would red flag her as a cancer patient.

Similar to other participants, Jillian shared having positive support from her family and friends. Informing her parents of the cancer was “one of the hardest things” for “you know, they are eighty-years-old.” Her parents, brother, boyfriend, and son all have been a support to her. Relationships were an underlying issue for her.

Themes that were identified in previous interviews and now again with Jillian included a trust in her oncologist, the stress of the importance of a positive attitude, body image disturbances, and her spirituality. Her faith in the physician was reported to be strengthened by his reputation, his willingness to listen to her concerns and his sharing all the options available for the cancer. She stated that she was trying to have a positive attitude but indicated that it was difficult at times. The body image disturbances that she feared were the mutilation from a possible mastectomy, the fear of alopecia, and other skin side effects of the treatment. She reflected after the biopsy that she said "... (I will) never forget that, I'm laying there and he goes 'it is cancerous' and the first thing I said Oh my God, I don't want to have a mastectomy." She shared some concerns about the chemotherapy side effects including weight gain, skin problems, nausea and vomiting, and fatigue. All of these concerns have been voiced by other participants previously and certainly the theme of powerlessness was coming through.

Her great fear of a mastectomy and chemotherapy came through loud and clear when discussing the options with her boyfriend. Her boyfriend was worried and wished that she "would just get it over with" and have the surgery because of his fear that it may spread while waiting. He stated: "I wish you wouldn't fool around with this experimental stuff" when referring to waiting for the hormonal treatment to shrink the tumor prior to surgery. Jillian reflected that there was no "guarantee that I still wouldn't have to have chemo afterwards (the surgery)" and this seemed to increase her uneasiness with the treatment. The theme of uncertainty of the outcome of the various treatment regimens seemed to be in the background of the entire interview session.

There often appeared to be a ‘tug-of-war’ within her about the treatment options and this further highlighted the theme of uncertainty. She reported not being overwhelmed with the information but then mentioned one website said that her life expectancy was only 15 years and her boyfriend encouraged her to not keep looking on the internet. Jillian acknowledged that she was slightly overweight so should try to gain a healthier perspective. She also indicated that if she had to have chemotherapy or radiation, it would negatively impact her summer life for she has gone camping every summer since she was a teenager. “The only thing that I think about is the timing of all of this, like it’s going to be summer, do I want to be, of course I guess it can’t be helped, if let’s say I had to have chemo, oh my gosh, you know is my summer going to be ruined or.....you know, that’s probably not the most important thing.” These thoughts indicate a struggle to change her plans even though she knew that she may need to have further treatment. The theme of disruptions in her life plans was also coming to light.

Jillian indicated that she did not want the cancer to spread but struggled with the timing of the treatment. “Just like having this biopsy next week, Dr. S. said it is entirely up to me but it’s in my best interest if I have it, but I don’t have to. But I am going to do it. ... guess I don’t want a have it spread, I don’t want to die. Yeah that’s right and of course with summer coming, and I do remember it sticks out in my mind, Dr. S. says we can go ahead and do this lumpectomy and have it done and we can do your radiation and by May you will be all, you know.....but I didn’t....I wanted to see if I could shrink this first. But see, the tumor it’s in a, it’s very close to the nipple so I don’t even know if it shrinks he still might have to, I don’t know. It’s in a bad location.” These competing demands seem to again surface fears and a theme of uncertainty.

A feeling of powerlessness came through the interview when discussing the issue of hormonal treatment and the issue of privacy. When sharing concern of if the hormonal treatment would shrink the tumor, Jillian noted that “So I don’t know what’s going to happen after they do the biopsy, if they say it’s working, if I am just going to continue for a while or if he says, well I don’t see any change, I don’t know what he’s going to do.” However, Jillian noted that the booklet on the medication did not say it would shrink but a “surprise” encounter from a friend told her that she knows someone from another state that “it worked for her.” Her “surprise” came at the fact that this friend knew about her breast cancer. Responding to this fact that she was aware of the cancer, she said: “So, I guess that was a good thing... well yeah, like you wonder if she’s going to go upstairs now and tell everybody she works with? It’s not that I broadcast it or anything, but to me I feel almost better that people know, you don’t have to try to hide it from them. Sooner or later they are going to find out, you know, after I have my surgery I would think I’d be gone for at least a couple weeks. You know, I feel better that I am not hiding it. I don’t go around broadcasting it but yet I don’t hide it.” These comments suggest that she really is not certain it is best that others know. Again, the issue of privacy was noted to be important to her.

When discussing spirituality influences, the issue of uncertainty again arose. She noted that spirituality “didn’t really influence my choice, I mean I, I’ve done a lot of praying, of course I’m Catholic and, but as far as my choice...I wouldn’t say it was it was really spiritual.” However, when discussing prayer, she reported feeling “guilty because I always pray and that, but it seems like when something goes wrong you really pray more and I don’t know if you should really do that, you know what I mean. I, in

fact the Friday well it was Ash Wednesday and then I made a special point to go to Mass here and I tried to be more religious and I almost feel guilty because what made me be this way is being diagnosed with cancer.” This was followed by a discussion of her coworkers and friends and how they say they are praying for her and then stated “I guess it’s like a hope, you know you have to hope that there is somebody out there looking out for you.” The uncertainty theme comes forward as being intertwined with the theme of hope for Jillian.

Kenneth. Kenneth is a 75 year-old male with a recent history of prostate cancer and has undergone radiation treatments. The interview was conducted at home in the presence of his wife. However, his wife limited her interaction in the session to only answering questions if he wanted her input. He had a non distinct, rapid speech that led to some difficulties with the transcriptions. He was noted to answer in a very methodical, orderly manner and this corresponded to his military background (retired Air Force).

Kenneth had and continues to have much support from his wife and children. His daughter is an oncology nurse, and she was very active in helping him with his options. He is very proud of his marriage, his wife and his military career. He discussed his 50th anniversary more than once during the interview. He delayed his radiation treatment until after their celebration so he could enjoy it. However, he used the anniversary as a motivator to go through treatment saying: “But you know, fiftieth anniversary, I’ve got this far now why give up now, I’m not that bad off any way with the cancer...” He discussed the volunteer activities at church, nursing homes and at the Veteran’s hospital. These activities presented his taking pride in his accomplishments indicating the theme of leaving a legacy in addition to the theme of relationships.

He reported that he was “kind of” shocked with the diagnosis of cancer but was not overwhelmed. Although he said that the physician was the primary influence for the treatment decision, he said “I guess I had made my own mind that I’d have treatment. I’m seventy-five. But he ...while you understand this doctor assured that you don’t have to do anything, just let it ride, you know, wait and see. That didn’t sound good, I want to live for another twenty-five years, so that didn’t sound good... I didn’t want to live with it. I didn’t want to take a chance.” So the decision was a collaborative decision with him being involved with it.

Kenneth’s age and comorbid diseases did play a factor in the treatment decision. Surgery was not recommended as an option because he is 75 years of age and has heart disease and chronic obstructive pulmonary disease (COPD). “I was kind of relieved in a sense, when the doctor, the outcome was, I don’t want cancer, I don’t want surgery, well that’s fine.” He stated that the radiation “seeds” were an option but he did not fully understand them and thought that the external radiation would be best. The uncertainty of the type of treatment and their effects related to his age and other chronic illness were a concern for Kenneth.

Spirituality was very much a part of the cancer experience as noted as he discussed his Catholic religion and the prayer group. “... because oh yeah, of course you never know how long you’re gonna last.” He did indicate that he was not afraid of dying but did plan on living much longer, maybe even 25 more years. This latter comment touches on the end-of-life issues.

Few difficulties from the treatment were mentioned except for fatigue and dysuria. Although the dysuria was reduced by a new medication, he indicated that the

fatigue after the radiation was great. “Oh, very tired after the radiation!” This treatment effect led to very real physical limitations and ultimately some changes in his lifestyle and roles.

Similar themes were identified with Kenneth’s interview. Primary themes for this participant were family support, leaving a legacy, spirituality, trust in the health care providers, and powerlessness related to his age, physical limitations, and comorbid conditions.

Loretta. The twelfth interview saw themes come through similar to the previous eleven. However, uncertainty seemed to be an underlying issue of her discussions. A 51 year-old female named Loretta was interviewed in her daughter’s home where she is staying during treatment. Plans are that she will return to work and to her efficiency apartment when she is feeling stronger. Loretta is proud of her work at the court house offices and has been there for a number of years.

Loretta had surgery and chemotherapy for ovarian and colorectal cancer. She indicated her race as ‘other’ but the interviewer noted that she and her family members did have distinct characteristics of the African American race. Her family is supportive and she has a daughter who is a psychiatry resident.

When confronted with the diagnosis, Loretta reported being “surprised but not totally surprised.” She reported that the physician drove the treatment regimen for she was recovering from surgery and was in pain. “I was just kind of following along...” She indicated that her family and the physician wanted her to have follow-up chemotherapy because of the two cancers and the size of the ovarian tumor. She said: “My family, period, everybody was do it, do it!” However, she had some second thoughts about it for

she had known people who did not do “too well” and she was unfamiliar with this type of treatment. She reflected on the time before chemotherapy and stated: “Actually I didn’t really want to start the chemo, that was just a grade (tumor grade), but I knew I should.” But she did make the decision for chemotherapy to appease her family. She said: “I think it made everybody relax more and felt better that Mom’s doing and sister, whatever, doing chemo or whatever.” She seemed to be really struggling within herself to know if bringing in a “poison” into her body was really the best thing. It was clear that she had ambivalence toward this treatment and a sense of powerlessness came forward.

A theme of uncertainty in whether to complete chemotherapy was emerging. “You take chemo on faith. You know there’s a lot of chemicals involved and their reactions and okay, maybe my cancer gets cured up or to a big point but at the same time there’s also these little warnings about what it could do to this or that. Do I want to trade one for the other or do I just want to, you know, I don’t know.”

Some of her ambivalent feelings toward chemotherapy were explained by her previous experiences. Loretta shared a story about a friend’s father who had a reaction to his chemotherapy. Also, from her experience working at the court house, she expressed her thoughts on the potential for errors when giving chemotherapy. “You just don’t know and even if the doctor’s office and everybody does think totally right, I work in an office where you see the tapes so much that you know the people are fixing up the bags for the chemo, there could be a little error here and there, wearing the bag home and keeping it on.” This concern of potential problems compounded the uncertainty and seemed to also lead to mistrust of health care providers and system.

She offered two in-hospital situations that added to her mistrust of health care providers. Prior to surgery she was told that she would not have a nasogastric (NG) tube postoperatively. However, she did have this tube for over one week after surgery. The next situation shared also was about this NG tube. She called this latter situation the “nightmare on (the hospital’s name) street.” Here she explained that a nurse’s aide had caused the secretions to back up into her stomach. Both of these situations did not foster confidence in her care.

Loretta reflected what she saw as the most difficult part of chemotherapy—the pump used for chemotherapy. She referred to the intravenous pump as something “scary” and she voiced a fear of hooking it on something, a potential malfunction, alarm procedures, and overall “just wearing that home and dealing with it.” Her discomfort with the equipment only increased her discomfort with the chemotherapy.

During the interview she was not on chemotherapy. She reported having a cold starting and was feeling very weak. “If it was the chemo that it would have not had to do that, maybe I would have meant to go the full length, then again maybe not? ‘cause here at the very end it was, I was just feeling to worn down.” Her discussions indicated that she continues to have uncertainty about the chemotherapy even during a break in her treatment.

Fatigue and weakness was discussed as a symptom that affected her life. Loretta shared that she had difficulty working and “could hardly stand up.” She looked forward to feeling better and going back to work stating that “going back to work is easier than not going and just laying around.” It was evident that she wanted to be a productive individual. She also indicated her positive relationships with the people at her work.

Loretta's interview carried a spiritual theme exploring why she got the cancer but again came back to the chemotherapy treatment. "I've got a lot of spiritual thoughts on it, but some of my spiritual values make me wonder if I should do the chemo, too.....kind of a poison into my body to kill something that could help other things but at the same time I know what it's purpose is and I know people who have gone through it and they have come out beautifully." These statements again reflect uncertainty and her primary concern of whether to have and continue the chemotherapy treatment.

She also discussed some end-of-life issues and these continued with a theme of uncertainty. She stated: "I always just kind of figured, you know, everybody you know, everybody is going to die sometime. So, whatever is going to get you, is going to get you, I mean even with the cancer and stuff, although it looks like something to mewill kill you or whatever, at the same time anything could happen, I could get hit by a car, or some other little problem in my body like kidney failure or who knows what, you know." Immediately after discussing death, Loretta shared an interesting belief that Nebraska has a high rate of cancer: "So I've been lucky pretty much of my life and this is okay, Nebraska is known for cancer, anyway, in a lot of ways. Yeah, super big surprise!, it was just like okay, well what do you do now?!" However, she again came back with a question of feeling insecure about her cancer.

Throughout her interview Loretta gave examples of people she knew or stories of others that she heard who had been treated with chemotherapy and were now cancer free. These stories seemed to give her hope that she too would be one of the successes after her chemotherapy. It was as if she was trying to convince herself with them.

The interview with Loretta also had the researcher struggling to step back and not influence her in any way. When she would ask questions on the therapy, it was difficult to refrain from the teaching role.

Millie. The thirteenth and final interview brought a person with a very positive attitude to discuss her treatment decision-making process. She was definitely “full of life.” This interview saw no new themes to the study and it was felt that saturation for this qualitative study was met.

This 65 year old female had a new diagnosis of breast cancer and a history of breast cancer 20 years ago but without any recurrence. It was very difficult to set a time and date of the interview. Millie is a very involved woman and it was not easy to try to find a few minutes in her active schedule. This African American woman was very committed to her family and community. She participates in her family’s activities, has a catering business that she was planning an expansion to open a restaurant, and is involved with prison ministry. Her dream of opening the restaurant was a priority in her life and she did not want the cancer experience to deter her from this goal. It was very apparent that she was very independent and a person who would not be pushed around.

Millie’s first reaction to her recent cancer was fear and this was fear of the cancer, fear of reoccurrence and fear of the unknown. She reflected: “Just fear, that’s all, fear, ‘cause I thought I was through with this. I had gone for twenty years and I figured I would never have to be bothered with that again,...But I just thought I was through with cancer. So it was just fear. You know the unknown, is it, whatever. So that’s all.”

Throughout the interview she willingly shared her feelings and situations from the current cancer diagnosis and the first diagnosis from 20 years ago. Her positive attitude

about people and life seemed to be a basis of the interview. She also seemed to be very sincere in her discussions.

Millie has six daughters and they are very much a part of her life. She shared that one daughter is a registered nurse and one daughter is still in school. It was clear that she is concerned about all of her family and an example is her gift to them that was intended to remind them to take care of themselves and prevent cancer. “So this year I gave them all, I used the little crystal stones, so I gave them all crystal stone with a note, “I don’t want you to go through what I’ve been through, these are the things that I know that I’ve been told that are helpful, and so they all just cherish. I gave that to all my daughters, my granddaughters and my nieces.” Millie shares her knowledge with the intent of helping others.

Millie discussed that she made the decisions for treatment but was happy to have the family’s support. She stated “I’m not the type of person that’s really influenced by my family and friends. I influenced my family and friends.” She said that she had to “convince them that this is what I should do.” She reflected that “You know, they were shocked and didn’t understand. They all would look at me, think I was going to die, I remember my daughters sitting around this table crying, you know, like you know, I’m going to die. I still had one more daughter at home and I had to convince them that’s what I need to do.” These statements validated her independent nature and her head strong approach to life. The theme of perseverance was clearly emerging in the interview.

Millie was appreciative of her family’s support saying “I mean, they were there!!!... They were there every step of the way.” However, she reflected “One of them was always there as if I wouldn’t tell them the truth or something, or I wouldn’t tell them

everything. And we would be in the doctor's office, the doctor would ask me a question and they would answer. It was something else." Family support was seen as a great part of her life but speaking for herself was also important to her.

Support was received from her "church family" but she is proud of the fact that she also gains support from helping others. She gets support from helping others: "I'm the type of person that people can't believe that I ever have sick days or am sick. You know what I am saying, I'm always lifting everybody else up and then when I come to people when I need help, they look at me like I'm crazy! You have problems?!!! You have fears and worries??" Millie's concern for others and altruistic approach was very apparent.

The treatment decision for her second cancer was voiced as being an easier decision than the first. She noted that "Too many things I want to do, you know, yet! And so this is something I can't be bothered, so let's just remove this breast, so it was no, there was no difficulty...Absolutely!" However, it was interesting that they did not complete the mastectomy until December when she was diagnosed in September.

In recalling her first cancer twenty years ago, she reflected that health care communication was more open and honest currently. "You know, so I really appreciate that, everything was open, it wasn't all hush, hush, quiet, quiet, you know that type of thing." She shared that she felt "it's a burden that's shared is lightened, you know once you talk about it." This theme of open and honest communication was considered a way to reduce the burden of the cancer treatment decision.

Twenty years ago she said when the doctor told her that he recommended a radical mastectomy, she "was horrified!...Because people in church were saying, um

cause you know well you don't have any faith, God can heal, all that kind of crazy stuff. And then everybody that I talked to that met me, always tell me these gloom and doom stories about, all she had and she died and she came here and all this kind of stuff. So I called the cancer society and I said "Look, I need somebody to talk to me that's had this, survived it, and they have survived it more than five years. I need to talk to somebody because I don't really know what to do, this is so bewildering." The cancer society sent someone out but she still did not feel that she knew enough. She sought out more information and worked her way into a class for nurses and learned more about her cancer. "I learned a lot. So after that I had no fear or problems with what to do, I was ready to face the challenge of what was ahead of me." Her diligence in seeking out knowledge was remarkable especially for the climate of health care twenty years ago. Again, the theme of perseverance comes through and also this situation shows a desire for more information.

Millie did not have all of the "bad experiences that everyone else had" the first time that she had cancer. "I worked every day. I was determined to go to work every day, so I went to work every day. I didn't lose my hair. Gained a little weight. I would get disoriented...I wasn't throwing up, sickness, all the other things people have, I didn't have that. Praise God, Praise God for that!" This positive personal experience may have impacted her outlook on treatment in the second round and empowered her to move ahead with treatment and her life plans.

For support she did become involved in an organization called the Sister's Keepers. Although she thought that this organization would provide her with contact of women who had survived cancer, she found this organization to focus on the negatives

such as recurrence and medications that did not pertain to her. She said: “I mean, I don’t need that...” She stopped attending the meetings but feels that their purpose and functions are worthwhile so continues to support the organization. The current cancer experience demonstrated her commitment to knowledge about her cancer and its treatment. Millie continued to seek out knowledge through her health care providers, the American Cancer Society, and other organizations. She continues to gain knowledge and focuses on a healthy lifestyle. This focus on healthy eating currently is impacting her catering business and the plans for her future restaurant to foster healthy food preparation. The active seeking of knowledge, the goal setting and her focus on her healthy lifestyle pulls in the theme of Millie having a strong self-concept.

Millie continues to plan for her restaurant and to “live another twenty years...I don’t want to sit around and dwell on, on getting cancer. Her positive outlook on life is contagious with those around her. This positive outlook on life is similar to others in the study especially with Andrew, the first participant.

Another major theme with Millie’s interview was the mistrust in the health care system. This theme has been identified in several previous participants. Her first example of mistrust came from the concern of possible cancer in her second breast with a cyst biopsy in 1999. With this situation she asked for the breast to be removed but the insurance would not pay for it. She indicated that this would reduce the risk of cancer.

She also voiced much discontent with the second surgery. Her comments suggest that she feels that it was not done well. Millie felt that the surgeon did not listen to her concerns about the extra skin flap and the subsequent rashes that have ensued.

With her ‘inquiring mind’, she has asked health care providers if she is now more susceptible to cancer than the average person. She feels that she still does not have the answer. “And that question has never been answered to me. For me, to my satisfaction, so, so whatever caused this, does it just disappear? Or do I have the type of body that is susceptible to cancer? No one has every given me a good answer....Oh come on, all the research that’s been done, all the tens of thousands of dollars they know about this disease. They know!” This question is one that could be answered by the health care providers so it is surprising that an answer was not presented to Millie. This again highlights her mistrust of health care providers.

Although Millie did not present new themes, she did display primary themes in her interview. They included communication, seeking out information, positive coping, relationships, spirituality, perseverance, concern for others, and powerlessness.

Interview Summary. The 13 participants of this study made treatment decisions to include conventional surgery, radiation, and chemotherapy. Also, some of the participants chose non conventional treatments of acupuncture, vitamins, supplements, nutrition, exercise, and stress reduction. Table 3 provides a summary of the study participants including the treatment decisions made.

Emerging Themes

Although each participant communicated a distinctive account of their cancer treatment decision-making process, some similarities were noted and themes emerged as the participants told their story. Five main themes came forward and they included: the importance of relationships; therapeutic communication; spirituality; positive coping; and powerlessness.

The meaning of decision- making for these individuals is complex, unique and overlapping. The interconnectedness of the themes seemed to play out showing the dynamic nature of their journey with cancer. Each individual's reflection showed courage through their difficult journey of decision-making.

Table 3 Summary of Cancer Type and Treatment

Participant*	Cancer Type	Cancer Treatment
Andrew	colorectal	surgery chemotherapy
Barbara	breast	surgery: lumpectomy radiation
Catherine	breast	surgery: mastectomy chemotherapy radiation
Dorothy	non Hodgkin's lymphoma	chemotherapy
Edith	breast	surgery: mastectomy chemotherapy
Francis	uterine	surgery chemotherapy then hospice
Gerry	colorectal	chemotherapy radiation planned surgery
Harriet	breast thyroid	surgery: lumpectomy non conventional
Ivan	prostate kidney	surgery non conventional
Jillian	breast	hormone chemotherapy later surgery
Kenneth	prostate	radiation
Loretta	ovarian colorectal	surgery chemotherapy
Millie	breast	surgery: mastectomy chemotherapy

*Names are fictitious to maintain confidentiality.

The first theme to become apparent was relationships with family, friends, and health care providers. Also, the relationship with God was noted to be part of this theme for a relationship with God is a relationship and it relates to the theme of spirituality. Most of the participants demonstrated a concern for others and often the concern was for their families. The participants shared their frustration with their plans being “messed up” by the cancer and the cancer treatment. Some of these plans that showed a connection to relationships included caring for others; reversing roles; transportation to appointments; changing travel plans with spouses; moving to be with children; and communicating with family, friends or health care providers. The message that the humanness or “human connection” that one participant shared was a sub theme that was very important in some of the interviews. Ultimately, relationships were seen as overarching theme for treatment decision-making in these 13 individuals.

Communication is the next main theme identified and it was very much a part of all of the relationships. However, some specific sub-themes related to the communication process ensued during the interviews. These sub-themes included the need for openness and honesty in all information; individual involvement in the decision-making process; the need for privacy in some individuals; and a consistent message of the need for respect of the individual with most of the individuals. Some participants desired for more information, while others were overwhelmed with the information they had received.

The theme of spirituality came into light for most of the participants of the study. Some individuals demonstrated this theme very openly and others not at all. The sub-themes of spirituality that came through were faith in God; rituals of religion such as prayer, specific church services, and reading the Bible; the concept of hope; and the

discussion of end-of- life issues. Only two of the individuals did not address at least one or more of these sub-themes in their interview.

Positive coping was apparent in seven of the 13 participants. Two of the individuals had such positive attitudes that they were contagious. It is interesting to note that these individuals started the interviews and ended them (Andrew and Millie). All of the individuals seemed to show some degree of perseverance in their journey with cancer. Some of the individual's determination was incredible. Four individuals came out with a positive coping theme related to holistic health. Two individuals focused their follow-up treatment on this body/mind/spirit connection.

Powerlessness was the fifth major theme identified in the study and this also emerged as overarching theme for treatment decision-making in these 13 individuals. The sub-themes were feelings of uncertainty and ambiguity in general; the uncertainty of the treatment effects; and the uncertainty of the effects of age and/or their comorbid conditions. The uncertainty was apparent in many facets and phases of the decision-making process for many of these individuals.

Other sub-themes of powerlessness included: the urgency of the decision; financial concerns; the individual's experience with cancer; role changes; and body image. Role changes seemed to be on many participants mind as they reflected on how they had been impacted by the cancer and/or cancer treatments. Body image surfaced as a very powerful sub theme for some individuals as noted by surgical mutilation and treatment effects. Actual or anticipatory treatment effects were extreme fatigue, gastrointestinal complications, alopecia, and dysuria.

Some of the emotions that were shared related to their feelings of powerlessness were fears and anxieties; shock and disbelief; anger; guilt and shame; depression and sadness. The most common emotions conveyed by some individuals were fears, shock and disbelief, and anger.

The uncovered main themes and sub-themes for these 13 individuals are summarized in Table 4. The five major themes do not seem to be distinct entities and common ground was noted. Relationships and communication seemed to go hand in hand when trust and confidence in health care providers were expected. Positive coping may have some crossover to spirituality. Powerlessness was noted to be increased when the communication was not open or the privacy issues were not respected.

The review of the first six transcripts led the researcher to acknowledge that there are many treatment decisions and it is sometimes difficult to see which one is being discussed. These decisions seem to be dynamic and often go hand in hand with day-to-day decisions such as transportation issues, work, family availability, health care providers, appointments, and even what coping mechanisms to use.

Although the interview questions focused on the treatment decisions, it was noted during the discussions that it was difficult to see the treatment decision as only one decision. There seemed to be many decisions when dealing with a new diagnosis of cancer. The journey is often complicated by the relationships they have, the communications that they experience, the beliefs that they have, the attitudes and emotions that exist, and the uncertainties of the condition.

Table 4 Related Themes in the Treatment Decision-Making Process

Themes	Sub-themes
Importance of Relationships	<ul style="list-style-type: none"> Concern for others Disruption in life plans Desire to leave a legacy Desire to connect with others in similar circumstances Trust and confidence in health care providers and system Humanness Experiences with cancer (others and self)
Therapeutic Communication	<ul style="list-style-type: none"> Openness and Honesty Involvement in the decision Desire for more information Overwhelmed with information Privacy Respect
Spirituality	<ul style="list-style-type: none"> Faith in God Rituals of Religion Hope End of Life Issues
Positive Coping	<ul style="list-style-type: none"> Positive Attitude Perseverance Self responsibility Coping by using alternative treatments <ul style="list-style-type: none"> —holistic view of body/mind/spirit
Powerlessness	<ul style="list-style-type: none"> Shock and disbelief Guilt and shame Uncertainty Anger Treatment side effects Comorbid conditions Financial burden Urgency of decision Body Image changes Role Changes Physical limitations Fears and/or anxiety Depression Sadness

Practice Participant Data

The research process for the study also included a practice participant. A brief discussion of this participant is worth noting for similar themes were manifested in the interview. A 74 year old practice participant, Carmella, was interviewed to enhance the competency of the researcher with the questions and the equipment. Although she did not have cancer, it is notable that she had some similar themes emerge from her story. As this woman looked for meaning in her decision for treatment of a serious illness, spirituality was voiced in the following statements: “You have to, you have to put your faith and your trust in God when all, and don’t wait till all other fails. You know like this is a last resort, I don’t think that’s fair, I don’t think that’s fair to God. I think God should come first, God I need you, I need you now to help me with what’s going to be coming off or what’s going to be going on. I don’t want you to be left out, I don’t want you to feel, I don’t want you to think that this is, you are my last chance because it’s not, it’s my first chance, it’s my first chance to, to have an intercession with Him, so He can pull me out of this... You’ve got to have, it’s an anchor, you’ve got to hold on to this anchor.” God as an ‘anchor’ in her life is how this individual can get through the difficult times of her life.

Carmella shared her family support frequently and how her children and grandchildren uplifted her physically and psychosocially when health issues were confronted. She also stated that her children who were nurses provided her with knowledge and support during hospitalizations.

The issues of loss of mobility came through a discussion of knee problems. Carmella stated: “I haven’t told anybody, but the idea of, of, of,...I can just see the wheelchair, you know I can almost visualize a wheelchair and its just panic stricken me,

because I am having such a hard time walking now. Before with just one it wasn't too bad and now all of a sudden this right knee went out, oh my God, and they've been on my case now for the last six months, you've got to slow down Mom. You go too much, you go too much, you go too much and I'm thinking maybe God, maybe this was God's way of saying to keep going as long as you can. And all of a sudden if I hit that wall, you know then what?" The fear of loss of functioning and how scary this must be for an individual is unquestionably expressed in this statement.

This practice participant not only assisted the researcher with the process of data collection but also demonstrated similar themes of spirituality, relationships with family, communication, uncertainty, and fear of loss of function. Although this individual did not have cancer, these issues for the older adult with a serious illness may be considered when providing care.

Recruitment

The number of individuals who called to participate in the study was remarkable and at times overwhelming. Although all of these prospective participants did not meet the criteria, it was clearly evident that they wanted to share their story. Calls were received from spouses, sisters, brothers, and even physicians who were not initially contacted. Some of the calls were time consuming but rewarding.

One call remains embedded into this researcher's memory lasted nearly an hour. A wife whose husband had died about a year ago clearly wanted to tell her story about her husband's "courageous fight" with cancer and considered even "writing a book." She wanted to tell me about their 53 years of marriage how important family was during the times of treatment decisions. She stated: "My children and grandchildren were so

important to us during this process.” The conversation indicated strong religious beliefs of Catholicism and the importance of spirituality and prayer. The confidence in the physicians was communicated through many compliments of them and statements of trusting relationships. Optimism, honesty and humor “even in the hard times” were important to this woman. Family needs were conveyed in one of her last remarks: “People need to know it’s okay to share, care, cry and share again.” This caller validated some of the themes of my participants as well as the importance of allowing cancer patients and their families to share their stories.

Another woman called and said that she and her husband would like to be in the study. She said that he had cancer of the skin six years ago and no recurrence and only minor surgery needed. This woman discussed family members and friends who had cancer. Indicating that she did not have cancer but had “thought about it” and “knew that as she got older that she could get it,” demonstrated the need for her to talk about her fears of this disease. During the 45 minute conversation, it was obvious that her story needed to be expressed to a listening ear.

Seven people called to be in the study but had their cancer over five years ago. These individuals shared that the cancer had not returned and most stated that they “had done great.” Some of these individuals shared difficulties from cancer treatment related to weakness and fatigue with two saying that the “fatigue was overwhelming.”

A few callers communicated the fact that they made many decisions, and it was difficult to say which one to address. Although these individuals did not meet the criteria for the study, it was evident that they were interested in the decision making process. The overwhelming response to my study demonstrates that there is much more that could be

explored in relationship to cancer and cancer treatment. It is interesting to note that those not included in the study did hint at the themes of relationships, communication, positive coping, and powerlessness.

Field Issues

The interview had some easy and difficult moments in the research process. The easy part was listening to the stories for this is so much a part of nursing care. The difficult part of the interview is removing the nursing action from the interview. For example, 'bracketing' personal beliefs on the treatments or not including knowledge on an issue for the purpose of the interview was to collect data and not provide care. The first painful feelings of the need to keep the nursing role separate occurred in the second interview. The researcher wanted to explain the definitions, explain why the physician completed the therapy and had a desire to provide more information. Often the participants were asking the researcher specific questions that a health care provider should be able to answer. The researcher did refer questions to the participant's health care provider and/or to commonly accepted resources. However, roles did seem blurred at times especially when attentive listening seemed to be more than data collection but a therapeutic role.

Another issue related to the interview process. Writing down notes during the interview was limited to increase eye contact and encourage more verbal conversation during the interview. The researcher felt this was important to increase trust with the interviewee.

The aspects of confidentiality and noise reduction caused some problems for the researchers. A desire to increase participant control in the interview setting led to last

minute hustling to find more private spots. This activity did increase the researcher's anxiety and may have impacted the interviews in a negative way. For example, one subject wanted to meet after work in the hospital cafeteria. The researcher arrived early to find that there were no private or quiet spots. A small conference room was found near the cafeteria but permissions for use of this room had to be attained at the last-minute. This did leave the researcher to feel rushed and not as relaxed at the start of the interview. Also, a housekeeping person interrupted the interview for he thought we did not have a formal meeting. The location of the interview did create some interesting scenarios to work around.

The interview questions at times seemed to get in the way of telling the patient's story. For example, Kenneth was very structured and seemed to want to go down the list of questions rather than tell his personal story. A less structured format is recommended for future research.

Summary

Chapter 4 has presented a description of the study's sample, a summary of the findings, a discussion of field issues encountered, recruitment issues and field issues. Five major themes and sub-themes were identified after an in-depth review of each of the 13 transcripts. The research questions will be evaluated and conclusions and recommendations are addressed in Chapter 5.

Chapter 5

Conclusions and Implications

Introduction

The cancer treatment decision-making process of 13 individuals over the age of 50 was explored. Five major themes related to treatment decision-making in adults with cancer were identified for these participants. The themes included relationships, communication, spirituality, positive coping, and powerlessness. Each of the five major themes had sub-themes as previously summarized in Table 4 (see Chapter 4).

Findings of this phenomenological study add to the limited research on this difficult health care issue. This chapter attempts to see what Patton (2002) calls “new perspectives and meanings” (p. 487). Limitations of the study are acknowledged. Conclusions and implications from the findings are offered. The relationship of theory to relevant literature and the implications of theory for future research and nursing practice are addressed in this chapter.

Discussion

This qualitative research study did provide rich and valuable data during the face-to-face interviews of amazing individuals. The depth of the information that the participants were willing to share in one short interview seemed to have only touched the surface of the knowledge that underlies the treatment decision-making process for the adult with cancer. A summary of the themes that came forward in the interviews and the research questions follows.

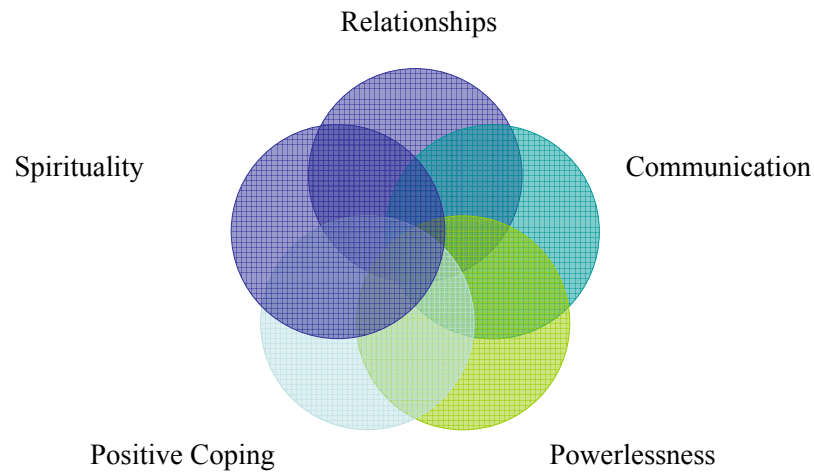
Themes

The five major themes that emerged from the study were (1) the importance of relationships, (2) therapeutic communication, (3) spirituality, (4) positive coping, and (5) powerlessness. These major themes were interwoven throughout each interview and all of the interviews had at least four of the five themes.

The interconnections of the themes became apparent in all of the interviews. Relationships were enmeshed with communication. Communication and relationships with one's health care providers set the stage for trust or mistrust of the providers or the health care system itself. Powerlessness appeared to be intertwined with emotions and coping. Statements of a relationship with God were connected with a determination to live or to persevere through the cancer treatments. Trust and confidence in the health care providers was stated to have been strengthened by open and honest communication. The lack of the health care providers' response to personal needs was noted to escalate fears and reduce confidence in health care providers in some participants. When privacy was not respected, powerlessness ensued in some participants. These interrelationships of the themes of the study appear to highlight the complexity of the treatment decision-making process and the cancer experience for these 13 individuals.

To visually show the interconnectedness of the major themes that emerged from the study, Figure 1 is presented below. As this figure shows, the themes are very complex and seem to overlap in some areas.

Figure 1 Treatment Decision-Making Themes



Research Questions

This qualitative study was guided by a grand tour question of ‘What is the experience of the older adult when making decisions for cancer treatment?’ and research questions. The discussion continues with a review of each of the individual research questions.

Research Question 1. From the perspective of the person with cancer, what is the process of the treatment decision?

The treatment decision-making process was seen as an intricate, dynamic process that is as unique as the 13 participants. Some of the patterns that emerged were involvement in the decision; urgency of the decision; the response to cancer and cancer treatment; the many decisions to be made; the information about the cancer and cancer treatment; and overall complexity surrounding the treatment decision. Each of these

major patterns surrounding the process will be briefly discussed to answer this research question.

Involvement in the Decision-Making Process

The individuals with cancer were very unique and brought different values, beliefs, and experiences with them. However, most of the participants voiced a desire to be involved in the treatment decision-making process. Some mentioned concerns that family or physicians did not include their personal views in the process.

The desire to be included in the decision-making process came through in all of the participants to varying degrees. All of the participants wanted to be included in the discussions of care even if it is only a small part. The need to be in control with his/her life was evident.

The desire for participation in cancer treatment decision-making has been seen in previous research (Davidson, Burdage, & Feldman-Stewart, 1999; Fischer, et al., 2006). However, the literature is not clear on the extent and what terminology such as “shared decision-making” really means. The participants in this study indicated a desire to be involved in their treatment decisions, and most wanted to also have family involved. One individual said it well when she noted that she thought relationships brought a “shared burden” to the situation and indicated that this was comforting.

Urgency of the Decision

Nearly half of the individuals had to have an initial therapy in an urgent manner due to a complication such as bleeding or obstruction; a delay in diagnosis; or the aggressive nature of the cancer. It was noted that decisions often need to be made in a short amount of time and under much duress and this urgency was also noted by Lacey

(2002). The necessity of the speed of the decisions did elicit strong language of the type of stress it placed on the individuals. It was interesting that three of the 13 individuals talked about the process with the exact phrase of “boom, boom, boom.” This characterizes the hurried nature of the decision-making process for many of the individuals and the feeling of lack of self-control.

This rapid decision-making process may leave individuals to place their trust in the health care providers that they have chosen. However, mistrust in the health care system was noted by several participants of the present study. This mistrust would also place even more stress on the individual with cancer during the treatment decision.

Response to Cancer and Cancer Treatment

The decision-making process often led to an emotional response from the individual. A common emotion that came across in many of the interviews was a shock and disbelief that they had cancer. The fears that were expressed during the decision-making process included loss of independence, body image changes, role changes, changes in life plans, side effects of treatment, death, financial concerns, lack of privacy, and family burden. Even the word cancer seemed to be an issue for one participant.

The cancer and cancer treatment also impacted the decisions. Some individuals expected certain physical effects or certain impacts on their life. Most expected to have the side effect of fatigue and weakness. Some participants expected body image changes. All of the individuals had to change their lives in some ways due to the cancer or cancer treatment or to life style changes.

Many Decisions

The data suggests that cancer treatment decisions should not be looked on as one decision and as an isolated event. Most participants had difficulty honing in on the decision making process if looked at as a single entity. Their stories indicated the cancer treatment decision making process was an ongoing experience with many changes along the way and the decision-making was not in a sequential step-by-step process. Some decisions seemed small and some are extremely large and with many consequences. The decisions were often changed due to factors related to physical or personal responses. For example, decisions had to be made on family issues, treatment issues, role changes, changes in treatment because of no response or complications, and even during vacations.

Information on the Cancer and Cancer Treatment

Participants voiced a desire for more knowledge on their cancer and/or treatment or some were overwhelmed with information. Both limited and too much information was thought to influence the treatment decision-making process.

Being overwhelmed with the cancer diagnosis and with the information presented was noted by several participants. They often needed to make decisions on treatment and life events in a short amount of time while learning new and complicated regimens.

The Complexity of the Treatment Decision

The complexity of the treatment decisions was expressed as great by all participants even though most stated an understanding of the regimens laid out before them. The complexity involved past decision-making processes of the individual, past experiences with others with cancer, their own personal experiences with cancer, their family's influences, the cancer itself, the cancer treatment regimen, and the risks/effects

of the therapies. Health care providers and the health care systems were certainly involved in the decision-making process for these participants. The participants shared stories of empathy, compassion, information sharing, financial concerns, effective and poor communication, respect and disrespect, and even poor care.

In summary, no definite step-by-step process of decision-making was noted in the 13 individuals. However, several issues related to the process were mentioned as involvement in the decision; urgency of the decision; the response to cancer and cancer treatment; the many decisions to be made; the information about the cancer and cancer treatment options; and overall complexity surrounding the treatment decision.

Research Question 2. What or who are the influences in the decision-making process when older adults decide on treatment for a new diagnosis of cancer?

The influences of treatment decision-making were complex, and the influences and the processes seem to be interrelated. The importance of the influences changed from person to person and from the context of the decision to the actual decision to be made. Each person brought their own set of personal experiences to the cancer treatment decision-making process and these did influence their treatment choices. Some of the influences led to delays in treatment, some led them to make different choices, and others assisted them in the process itself.

The decision-making process to accept or reject treatment may be affected by individuals, experiences, or emotions. In the present study the influences of treatment decision-making for the 13 participants included personal experiences, life events, the relationships surrounding the decisions, communication, trust and confidence in the

health care providers, personal attitudes and emotions, feelings of uncertainty, spirituality, body image, and quality of life issues.

Personal Experiences

All participants indicated that their decision for cancer treatment and cancer treatment decision-making process was influenced by family, friends, and health care providers either directly or indirectly. It was noted that these relationships were impacted by the communication process through support and information sharing. Open and honest communication between all mentioned as valuable in most of the participants. All of the participants sought out information actively.

Most individuals had family and/or friends who had experienced cancer and shared both positive and negative stories about them. Five participants had or are currently working in the health care system and may bias the sample due to their expectations and background. Two individuals had experienced a treatment decision for a previous cancer and discussed the experiences as having a positive impact to continue on with treatment.

Some of the participants shared concerns that their treatment would negatively impact their family and or friends and sought ways to minimize this burden. The concern for how the treatment decisions will impact family was also found by other investigators (Kutner, et al., 2000; Roberto, et al., 2001). In the present study, these impacts led to delays in treatment or changes in regimens for some of the individuals.

Life Events

Some individuals elected to put their treatment decisions off for life events or life events had to be postponed. Four participants delayed their first treatment and chose to

continue their plans of important celebrations or vacations. Several others indicated that the cancer and/or treatment really “got in the way” of their lives. This often led to changes in roles or postponement of planned events during treatment. So, in essence, cancer patients are not just making decisions on the cancer treatment, but also on situations and relationships surrounding the treatments. The realization was that the treatment decision-making process is not just a single decision but one of many that includes day-to-day living and major life events.

Decisions may also relate to the diagnostics prior to therapy. Two participants delayed diagnostics because of other important life events even though both “knew it was cancer.” Cancer treatment decisions were noted to be many in a series of decisions starting with diagnosis and then continuing with the different treatments and changes in treatment regimens.

Relationships Surrounding the Decisions

All 13 individuals mentioned positive relationships that supported, informed, or argued their decisions for treatment. Some of these included family, friends, a religious order, and health care professionals. Family and friends influenced their decisions both positively and negatively and is congruent with others (Kutner, et al., 2000; Roberto, et al., 2001). Some of the individuals reported families as not agreeing with their decisions but made a point that it was “their” decision and not the families. The religious community made a decision not to pay for the non traditional therapies but this only made the individual more determined to focus on her decided path.

Strong relationships with God were voiced as having a positive influence on the decision-making process in most of the participants. This relationship was shared as a source of strength and courage during this difficult journey.

Health care professionals and systems also impacted the decisions of these participants through information, communication, and physical settings. Information sharing from health care professionals was expected and deemed as a positive influencing factor of their decision. Communication from health care professionals seemed to be mixed. When communication was trusted, it was a positive influence, and when mistrust was suggested, then it was reported as a negative influence on their decisions. The health care setting was voiced as a negative impact in several individuals with note of equipment not available for the obese patient, difficulty in getting to frequent appointments, long waits in the offices, and arrangements of treatment rooms as a place to “wait for death.” Even the physical nature of the system seemed to affect the relationship of the health care system and provider with the individual with cancer.

Communication and Confidence in Health Care

Communication was a major theme with this qualitative research study. The issues related to communication centered on the health care provider’s response to the participants and included their sense of urgency, their ability to display a humanistic approach, and credibility. Open and honest communication from health care providers was valued by the participants. Most participants voiced a need to be recognized as a unique individual who is worthy of the health care professional’s expertise, care and compassion.

An underlying theme was the importance of trust as a basis for therapeutic communication for health care professionals. The lack of trust may influence decision-making roles (Kraetschmer, Sharpe, Urowitz, & Deber, 2004) and the personal choices of treatment and health care providers (Salkeld, Solomon, Short, & Butow, 2004).

Personal Attitudes and Emotions

Attitudes and emotions were verbalized as influencing decisions. Some individuals reported very positive attitudes and said that this helped them make the choices that they did. Fear and anxiety were expressed as having an impact on decisions. Anger was discussed as having relevance to their decision, especially with Edith who rejected radiation. Guilt, depression and sadness were also other emotions that may have influenced decisions. However, these latter emotions were only discussed by two of the individuals.

The positive attitude of some of the participants was noted as having a strong influence on their cancer experience. This is consistent with the research of Wilkes, O’Baugh, Luke, & George (2003). Their qualitative study defined positive attitude as optimism and revealed that relationships with health care providers, having supportive people around them, and the environment at the treatment center had an effect on their attitude. This is consistent with the current study.

Attitude was related to quality of life and life satisfaction in a study of breast cancer survivors (Kessler, 2002). The present study showed evidence to support that those with a positive attitude also considered their quality of life to be positive.

Feelings of Uncertainty or Powerlessness

The theme of powerlessness was one of the strongest and most common messages that came through with the participants. These included physical, psychosocial, and spiritual issues. Feelings of powerlessness or uncertainty impacted most of the participants for treatment decisions in a negative way. The participants verbalized that the treatment effects, the cancer's effects on their existing diseases, financial concerns, age, the feelings of uncertainty, older age effects of treatment, and comparisons to previous experiences of cancer treatment as leading to them feeling vulnerable during this process.

Spirituality

Spirituality was discussed as influencing treatment decisions for all but two of the participants and is congruent with other cancer studies (Ferrell, Smith, Juarez, & Melancon, 2003; Felder, 2004; Dickerson, Boehmke, Ogle, & Brown, 2006). Some examples from the present study included statements of faith in God, prayer, church attendance, and expressions of hope. Hope and spirituality seemed to be intertwined in the present study; this was also noted by other investigators (Ferrell, Smith, et al., 2003; Wilkes, et al., 2003). The end-of-life issues were identified in the patients who were older (>65 years of age), those who had a poorer prognosis and those who had a medical background.

Body Image

Privacy seemed to be especially important in those individuals who expressed concerns of body image. The issues of obesity, surgical deformities, physical effects of treatment, and others knowing that they had cancer were the issues identified as having a negative effect on the decisions for cancer treatment.

The present study found similar influences as previously found in another qualitative study of cancer treatment decision-making (Halkett, Arbon, Scutter, & Borg, 2005). The influences found from the research on breast cancer patients included communication by health care professions relationships, urgency, information sharing/knowledge, personal preference, and body image.

Quality of Life

Together, the five themes that emerged from this study form the essence of cancer treatment decision making for these participants. This phenomenon is complex and includes social, psychological, spiritual, and physical dimensions and is consistent with the definition of quality of life identified earlier in this paper and by other researchers (Chang, et al., 2000; Dolbeault, et al., 1999; Ferrell, et al., 1999). The complexity of the influences is seen in the overlapping nature of quality of life.

The spiritual theme was identified in most of the participants. The importance of spirituality was reflected when making decisions, during treatment and when they discussed the journey to survivorship or to the end of their life. Psychological themes in this study included positive attitude, fear and anxiety, fear of the unknown/future, concern for others, sadness, depression, body image, the need for inclusion and control, anger, shock and disbelief, and guilt. Social themes identified in this study were family support, relationships, financial concerns, changes in plans for the future, past experiences, and desire to seek knowledge. Physical themes that emerged in this study were the side effects of treatment, fatigue, functioning, body image, age, healthy lifestyle, and nutrition. Two participants used the words “humanistic” and “human connection” when telling their stories, and these descriptions give the meaning that the person with

cancer is more than just their cancer and their cancer treatment. They wanted to be considered a total being with a “body-mind-spirit connection” and as an individual and not a statistic.

It was concluded that quality of life issues have great impact on the decision-making process in this study. Acknowledging that the individual’s perspective is important, consideration of the cancer patient’s personal choices, the overall health impact that it may have on the older adult, the psychosocial and spiritual perspectives is necessary.

Implications

The implications of the present study are presented in relationship to the health care professionals’ role with an emphasis on nursing. Nursing is in a unique situation within the health care realm in that nurses are present at each step of the cancer individual’s experience of decision-making. Nurses care for those with cancer in the home setting, in outpatient clinics, in hospitals, in long-term care settings, and in the community. Although the physician is the one who presents the treatment options to the patient, nurses are the ones who are often turned to for support, clarification, and further information. This brings much responsibility for nurses to provide comprehensive care during treatment decisions. Some of the implications related to the present study are discussed using the themes of the study.

Treatment decision-making for cancer is multifaceted, has many influencing factors is made up of many decisions, and is a very personal experience. The complexity of decision-making must be taken into consideration when health care interventions are planned or developed. An understanding of the individual’s unique perspective, including

an assessment of the cancer patient's social, physical, psychological and spiritual needs and desires should be at the base of all nursing care. The older adult with cancer is a complex human being and taking a holistic view of them will lead to more individualized and effective care during this difficult journey.

Relationships

Health care professionals have an obligation to assess and recognize the importance of an individual's relationships to others and respect their goals, decisions, and past experiences. Encouraging positive social support systems are necessary to enhance quality of life (Sammarco, 2003). The nurse can provide information, encourage the family's active involvement, and provide an environment that these relationships can be enhanced.

Since the cancer can change the dynamics of relationships (Nussbaum, et al., 2003), family and friends should also be educated on the support that is available for them. If a newly diagnosed cancer patient desires to connect with someone who has gone through a similar treatment experience, provision of this opportunity should be made available through cancer organizations or institutions.

Relationships are also impacted by the cancer treatment regimen. An assessment of how the treatment regimen fits into life plans and day-to-day activities is imperative. If health care professionals do not take this into account, the patient may be unable to or refuse to complete the recommended treatment.

The health care professional and the health care system also have a relationship with the individual with cancer. Health care providers should listen intently to the patient's wants and needs regarding treatment. Health care systems need to be adaptable

to be able to respond to the individual's needs. It should be apparent that the patient is considered more than the disease of cancer and be seen as a holistic being with physical, psychological, social and spiritual needs.

Communication

Communication was shown to have positive and negative affects on the person with cancer. Therapeutic communication is required and should include openness, honesty, genuine listening, respectfulness, and a personal touch. A professional commitment is required to actively deal with the issues of mistrust including poor communication, lack of individualization, disrespect, inadequate information sharing, and not listening to their concerns.

Effective communication with the older adult is essential during this challenging time of treatment decisions. The cancer communication must be seen as a mechanism within the relationships of both the family and the health care team, and as part of formal and informal interactions (Nussbaum, Baringer, Kundrat, 2003). The communications can directly impact the cancer patient's quality of life (Nussbaum, et al., 2003) and it is the health care professional's responsibility to promote positive well-being all dimensions of the individual's quality of life---social, psychological, spiritual, and physical.

Accurate and thorough assessment of the cancer individual's desires, values, and understanding of the treatment are essential to providing effective communication. Also, health care professionals must have a method of documenting these assessments in order for all to understand the perspective of the patient.

Nurses can support the individual with cancer by genuinely listening to them. Providing an environment of active listening will impress upon the patients that they are

more important than the tasks surrounding care. Giving care that has the “human connection” is necessary to show compassion and empathy. Also, collaboration with other health care professionals is important during the decision-making process to keep the lines of communication open.

Demonstration of respect for the person’s autonomy should be completed in any discussions of decision-making. Education of the patient should strive to reduce overwhelming the patient but being comprehensive enough to allow for making an informed decision. This will require adequate and on-going assessment of the individual’s knowledge base and response to teachings.

Interventions during decisions must include what one participant described as “humanness” and another noted as “the human connection.” The message from the study’s participants was that health care providers need to clearly communicate to the cancer patient so they know that health care providers care and see them as a unique person. Respecting privacy and confidentiality is an obligation of the health care professional and should be expected during all contacts with the individual.

Spirituality

Spirituality was identified as important in most of the 13 individuals of this study. Assessing spiritual beliefs, values and needs should be part of the health care professionals care when the person is diagnosed with cancer and should be assessed throughout the cancer experience. Allowing opportunities for religious rituals and planning strategies to foster hope should be completed for those making decisions for cancer treatment.

With cancer being a life threatening disease, end-of-life issues may be discussed. These issues should be guided by the patient's perspective, respect for their individuality and autonomy, recognition of the complexities of the end-of-life, and allow for sharing of personal stories (End-of Life Nursing Education Consortium, 2004; Core, Nabe, & Core, 2006).

Positive Coping

Many of the participants displayed a positive attitude during their cancer experience. Supporting the individual's positive coping strategies through the decision-making process may enhance psychological well-being and reduce anxiety and stress. Assessment of coping strategies is necessary to assist individuals in identifying their strengths and strengthening them. Encouraging the cancer patient to maintain social support is also important for coping (Ackley & Ladwig, 2006).

Interventions to foster hope may encourage cancer patients to maintain or gain a positive attitude (Felder, 2004). Hope-inspiring strategies include many of the previously discussed interventions as open, honest communication and addressing spiritual needs.

Powerlessness

Powerlessness was identified as one of the strongest theme of this study. Health care professionals need to assess for factors that contribute to powerlessness such as immobility, hospitalization, poor prognosis, inadequate support systems, unclear information, and inflexible routine (Ackley & Ladwig, 2006). Assisting the patient to gain control is an important advocacy role. Empowerment can be derived from increased knowledge, self-care, or even in simple goal-directed activities.

Allowing individuals to share feelings can lead to identifying the aspects of life that they can control. Sharing of feelings may help the individual feel less alone in their situation, and this solidarity may lead to reduced powerlessness (de Schepper, Francke, & Abu-Saad, 1997 as cited in Ackley & Ladwig, 2006).

The attitudes and emotional state of the person with cancer can impact the decisions made for treatment. The health care provider's responsibility is to foster a positive attitude, encourage determination, allow for expression of emotions, assess for effective and destructive coping methods, provide growth opportunities for coping, and offer ongoing support.

The overall quality of life issues must be explored when assisting individuals with treatment decisions. All dimensions, physical, psychological, spiritual, and social, must be addressed. The psychosocial aspects were highlighted as being strong influences of treatment decision-making. These areas are often more difficult to address and starting where the patient's perspective leads us may not always be where the nurse is comfortable. This may mean discussing psychological distress, social issues, spirituality issues, or exploring options of complementary interventions in addition to commonly accepted treatments. Assisting the cancer patient find resources, serving as a patient advocate, and ensuring informed decisions are the responsibilities of the oncology nurse.

Limitations

Although this study does add to the evidence on the older adult with cancer, limitations must be addressed. It should be acknowledged that the older population is heterogeneous and therefore the sample was not able to include all the possible characteristics of this population with cancer. The wide range of ages from the older

middle age participants (N=7 for 51-63 years of age), to the young old (N= 4 for 65-74 years old) to the old old (N=2 for 75-83 years old) may have contributed to seeing the sub-theme of uncertainty primarily in the older middle age participants. Current life roles in the older middle age individual such as work and children, older teens and young adults, may have influenced the feelings of uncertainty. However, no other differences between these age groups were noted.

This study may be limited by gender and by type of cancer for there were only four males despite the fact that the incidence of cancer is higher in men. The types of cancers were somewhat limited in that six of the 13 had breast cancer and no lung cancer patients participated in this study. Most of the participants were Caucasian (N=11). Therefore, the study could have possibly missed pertinent themes related to males, those with lung cancer, or individuals of other races.

This study is also limited by the retrospective nature of the investigation into the participant's treatment decision-making process. Time had elapsed for the individuals and may have impacted their recall of feelings and events.

Although a conscious effort was made to set aside personal experiences with the analysis, the researcher's personal perspective of oncology nursing may have impacted the data interpretation. Despite these limitations, these 13 individuals have presented valuable insights into the cancer treatment decision-making process and future research is warranted.

Future Research

Treatment decision-making is a complex and very personal process, and continued research is needed with the older adult. This section will address the areas of research proposed.

Further research is needed on assessment of the decision-making process in the older adult with cancer with all types of cancer and in those over 75 years of age. Interventional research in the older adult cancer patient is also needed to enhance all dimensions of their quality of life. Longitudinal studies may be of benefit to better understand the decision-making process over time and to evaluate the dynamic nature of this process. Research in populations of other races is recommended to better understand the older cancer adult's perspective on decision-making.

Further study of interpersonal communication in the older adult with cancer is needed. A better understanding of communication in this population may lead to interventions to support this population during cancer treatment decisions. Investigation of specific communication techniques to enhance the patient's trust and confidence in health care providers and the health care system may also be valuable.

Many participants had a positive attitude about cancer treatment. Having a positive attitude in cancer deems further exploration. The relationship of the patient's positive attitude in cancer to quality of life and hopefulness may ultimately lead to interventions to promote a positive attitude. Also, investigating the health care professional's positive attitude on the patient's cancer experience may be worthwhile.

Because relationships were found to be important in the view of persons with cancer, the impact of the decision-making process on the individuals' families is worthy

of exploration. Assessment of the cancer patient's relationships and the impact of the decision-making process on the family are the first step in giving comprehensive care. Nursing interventions should be designed to support the relationships that are deemed important to the patient.

Most of the research on treatment decision making focuses on the patient's preference or style of decision-making and on the physician's role. Further research of the nurse's role in the treatment decision-making process is needed in order to design specific interventions to provide supportive care for cancer patients.

Exploring the quality of life dimensions at the same time as the cancer is needed to better understand the treatment decision-making process. Understanding the older cancer patient's perspective of the treatment decision and the impact on his/her life may lead to strategies to improve quality of life.

Summary

This qualitative, phenomenological study incorporated in-depth interviews with 13 adult cancer patients. As the diagnosis of cancer occurs more frequently among adults, health care professionals must be accountable to place a greater emphasis on assisting individuals with the difficult treatment decisions. The results from this phenomenological study may add to the limited knowledge on treatment decision-making in the adult cancer patient. Using Denzlin and Lincoln's analogy of a quilt (2000), it is hoped that this research provides a clearer picture of the intricate and complex parts of treatment decision-making so that health care professionals can appreciate the challenges and ultimately improve the quality of life of these individuals.

This research study identified some of the many influencing factors expressed by 13 individuals when making cancer treatment decisions. The themes focused on the view of decision-making as an ongoing, interactive process and complex process. The present research study reinforces previous research on decision-making for cancer patients. It adds to the previous research through

The findings of the present study emphasize the need to provide interventions that promote the psychosocial well-being of the older adult with cancer. Oncology patients face many challenges in their battle with cancer, and nursing has a major role in assisting these individuals to meet these challenges. Acknowledging the uniqueness of the older adult cancer patient's experience of treatment decision-making may assist health care providers to provide appropriate supportive care and improve their quality of life including the journey through all of the decisions that are made throughout their cancer treatment.

Hearing their personal stories was a privilege, and it is hoped that future cancer patients can benefit from the lessons that were learned. These cancer patients were truly inspirational and enduring.

Cancer patients have an important story to tell.

It is up to us as health care professionals to be present,

listen intently and with a passion.

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APPENDIX A

Study Protocol

Treatment Decision-making for Older Adults with Cancer

Research Study Protocol

1. **IRB approval for study via CUMC and UNL.**
 - a. The research proposal was sent for approval to both the University of Nebraska at Lincoln (UNL) and Creighton University Medical Center's (CUMC) Institutional Review Board (IRB).
 - b. Consent forms (2-UNL & CUMC), interview questions, and background data forms was submitted to the IRBs.
2. **Preparation for the study.**
 - a. Training of both researchers
 - i. Practice of the research interview questions
 - ii. Both researchers practiced using the recorders to become familiar with the devices
 - iii. Securing and practicing the use of the qualitative program NVIVO
 - b. Equipment
 - i. Copies of the data collection tools were readied but not copied until IRB approvals.
 - ii. Forms and handouts were made in 14 font.
 - iii. Obtained 2 data recording devices (both will be used to have a back up device for recording difficulties), extra batteries, and several blank tapes (high quality and long lasting), and black pens.
 - iv. Locked storage cabinet at CUMC, SON, room 233 was secured.
 - v. Obtain the compensation for the participants (\$20 Target gift certificate)
3. **Completion of IRB recommendations and obtaining final approval.**
4. **Piloted** questions with a volunteer who has made a medical decision in the last 24 months.
5. **Recruitment** (see attached recruitment letters and advertisement).
 - a. Began recruitment of subjects who meet inclusion criteria after IRB approval. Methods of recruitment included flyers, emails at CUMC, newspapers, and church bulletins. Letters of invitations were provided to those who responded.
 - b. The sites for the study were the medical offices and hospital at Creighton University Medical Center (oncology, internal medicine, family practice, and geriatric offices); cancer support groups in eastern Nebraska and western Iowa; cancer survivor education sessions; and senior education groups in this area. When using the medical offices, contact nurses at each office were provided with the necessary information on eligibility for the study.
 - c. Worked closely with physicians and nurses in the medical offices and following strict Health Information Portability and Accountability Act (HIPAA) guidelines, prospective participants were identified. A letter of invitation was placed on the chart if deemed eligible and the physician gave permission.

6. Informed consent.

- a. Potential participants were provided with written information about the study protocol, the purpose of the study, the length of time the study will take, the study procedure, and the risks and benefits of the study. They were given a copy of the background data form and interview questions to keep. All sections of both of the consent forms were reviewed with the participant
- b. They were allowed time for questions and verbalization of concerns.
- c. Individuals who made a decision not to participate were shown appreciation verbally and their explanation for refusal was recorded anonymously for future review.
- d. A mutually accepted place for the interview for those that agreed to participate was established.
- e. Efforts to reduce burden of the interview were made. Some examples include: allowing adequate time for responses to the questions; allowing the participant to set the day and time of the interview; and encouraging the participants to reschedule the interview if they were fatigued or not feeling well.
- f. Appropriate setting was established (private location, face to face, reduction of noise and adequate lighting, phones turned off, and mutually agreed upon setting).
- g. The interview was made private with only the participant and the researcher present.
- h. Consent forms were signed and a copy was provided.

7. Data collection.

- a. The interviewer brought to the interview: tapes that were labeled and in the recorders, extra tapes, 2 tape recorders, extra labels, consent forms (2 copies of each), 2 copies of the interview questions, 3 black pens
- b. Background data form was provided and the participant was asked the questions with the interviewer recording the data.
- c. An interview form was given to the participant.
- d. The interviewer read the introductory statement on the interview form.
- e. Two tape recorders were tested then turned on when the interview questions began (see interview form).
- f. The interview questions were initiated.
- g. Clarification comments and probes to illicit further information were completed by the interviewer.
- h. The interview did not exceed 90 minutes.
- i. The interviewer thanked the participant for their time and sharing of his/her experience.
- j. The tape recorder was left on until the researcher is ready to leave to ensure all data is completed.
- k. Field notes were transcribed immediately by the researcher and were reviewed after each interview. These included any additions, any description of nonverbal communication, and any other reflections from the interview.

- l. The tape recordings were reviewed immediately by the researcher and any additional notes were added.
- m. A research log was kept by the researchers to demonstrate facilitation of audit trail.
8. **Transcription of interviews by Patty Marsh in CUMC School of Medicine, Secretary.**
9. **Data management.**
 - a. Created and organized files for data
 - b. The tapes were compared to the transcription documents for accuracy.
 - c. Copies of the transcriptions were made.
 - d. Data was secured in locked file cabinet and room (room 233, Criss 2 building, CUMC, SON).
10. **Data Analyses**
 - a. Data were analyzed after every interview.
 - b. The background form information was entered into the SPSS program for descriptive data analysis.
 - c. Each participant's data were entered into the qualitative program, NVIVO (ongoing).
 - d. Reviewed each participant's data.
 - i. Read through the text as printed from the transcription (Creswell, 1998).
 - ii. On a separate page coded for the participant, "make margin notes and form initial codes" (Creswell, 1998, p. 148).
 - iii. "Describe the meaning of the experience" as interpreted by the researcher (Creswell, 1998, p. 148)
 - e. After multiple participants are transcribed, entered into the qualitative program, classification of the meanings for the individuals will then be completed. Statements were grouped into meanings or themes. (Creswell, 1998).
 - f. The descriptions were interpreted following Creswell's process by developing:
 - i. "What happened" or the words as used by the participant (use of the participants own words)
 - ii. "How the phenomenon was experienced" or the meaning from the participants view, and
 - iii. "the essence" or the overall meaning (Creswell, 1998, p. 149)
 - g. The transcriptions were read and reread with the analysis.
 - h. The use of a journal to record the research experience will be utilized as suggested by Straus and Corbin (1998). This technique will be completed to assist in bracketing any personal beliefs of the researcher as well as to record personal thoughts during the data collection and analysis.
 - i. The meaning of the experience was put into words, figures, and tables.
 - j. The NVIVO program was used to assist in the search for themes, crossing of themes, diagramming and template creation (Creswell, 1998).
 - k. Further analysis was done by using Colaizzi's (1978) phenomenological method of inquiry. This included 7 steps as follows: (1) reading the

transcripts; (2) rereading the transcripts and pulling significant phrases out; (3) making attempts to find the meanings that are hidden in the transcripts; (4) clustering and validating the themes; (5) combining all data findings into an exhaustive list that describes the phenomena; (6) formulating a statement of the essence of the phenomena; and (7) validating the exhaustive description with the research assistant and including new data that emerged (Calaizzi, 1978).

11. Audit of data

- a. To enhance credibility of the project, a review of the project by an expert in the phenomenological method was completed. This expert is Dr. Joan Norris, Professor and Associate Dean of Research from CUMC School of Nursing, who has completed, reviewed, and evaluated previous phenomenological studies. This audit was completed at the end of the study.

12. Report results

- a. The report was completed as chapter 4 of the dissertation process.
- b. Chapter 4 was submitted to the UNL dissertation committee:
 - i. Dr. James Thorson
 - ii. Dr. Karl Kosloski
 - iii. Dr. Karen Dwyer
 - iv. Dr. Nancy Kelley-Gillespie

13. Report conclusions and implications of the study.

- a. The report was completed as chapter 4 of the dissertation process.
- b. Chapter 4 & 5 was submitted to the UNL dissertation committee:
 - i. Dr. James Thorson
 - ii. Dr. Karl Kosloski
 - iii. Dr. Karen Dwyer
 - iv. Dr. Nancy Kelley-Gillespie

14. Presentation of the completion of the study was completed as part of the oral defense.

APPENDIX B

Background Data Collection Form

Project: Treatment Decision-making for Older Adults with Cancer

Background Data Collection Form

Time of Interview:

Date:

Location:

Interviewer:

Subject #:

Please respond to the following questions about yourself so that we may know the characteristics of the individuals participating in the study. Thank you for responding.

6. Age at last Birthday _____

7. Gender: Male _____ Female _____

8. Current Marital Status

Married _____

Widowed _____

Cohabiting _____

Divorced/Separated _____

Never Married _____

9. Current Employment Status:

Employed Full-time _____

Full-time Student _____

Employed Part-time _____

Homemaker

Unemployed _____
(not employed outside the home) _____

(not employed outside the

Retired _____

10. Roles in addition to work: (Please list any pertinent roles)

Home _____

Social _____

Volunteer

Activities _____

Other _____

11. Education Level (please check the highest level completed).

Less than 8th Grade _____
Completed 8th Grade _____
Completed some High School _____
Graduated from High School _____
Completed some College _____
Completed Baccalaureate Degree _____
Completed Graduate or Professional Degree _____

12. Yearly Family Income:

Below \$20,000 _____
\$20,000-\$40,000 _____
\$40,000-\$60,000 _____
Above \$60,000 _____
Prefer not to answer this question _____

13. Ethnic/Racial Background

Asian or Pacific Islander _____
African American _____
Hispanic/Latino _____
Native American Indian _____
Caucasian (non-Hispanic) _____
Other _____

14. Cancer Diagnosis _____

15. Length of time from Diagnosis to Treatment Decision

Less than 6 months _____
6-12 months _____
more than 12 months but less than 18 months _____
more than 18 months to 24 months _____

16.Length of time since treatment decision was made _____
(time from decision to current date)
Less than 6 months _____
6-12 months _____
more than 12 months but less than 18 months _____
more than 18 months to 24 months _____

12. Cancer Treatment Decision

Chemotherapy _____
Radiation Therapy _____
Hormonal Therapy _____
Immunotherapy _____
Other treatment _____
No treatment _____

APPENDIX C

Internal Review Board Approvals

**Institutional Review Board • Research Compliance Office**

2500 California Plaza • Omaha, Nebraska 68178

phone: 402.280.2126 • fax: 402.280.4766

<http://www.creighton.edu/researchcompliance/IRB>email: irb@creighton.edu

☒ Expedited Review
☐ Full Board Review

January 15, 2007

Maribeth Hercinger, Ph.D., R.N.
School of Nursing

RE:
IRB #: 06-14285
TITLE: TREATMENT DECISION-MAKING IN THE ADULTS WITH
CANCER

Dear Ms. Hercinger:

This office has received your letter dated January 12, 2007, along with a revised consent for the above project. The revision made to the consent does not appear to adversely affect subject safety or the process of obtaining informed consent. Therefore, the revised consent is approved for use at this site. The consent document is stamped dated January 15, 2007. Please destroy all old unsigned copies of the informed consent and use only copies of this stamped dated informed consent when enrolling subjects in this project.

Your letter dated January 12, 2007; along with the revised consent stamped dated January 15, 2007 will be placed in the protocol file for IRB #06-14285.

Sincerely,

A handwritten signature in black ink that reads "Mary Kunes-Connell, PhD".

Mary Kunes-Connell, Ph.D.
Vice Chair, Institutional Review Board

David L. Dworzack, M.D.
Chair

Mary Kunes-Connell, Ph.D.
Vice Chair

Patsy Nowatzke, RN, MHSA
IRB Director

Creighton

UNIVERSITY

Institutional Review Board • Research Compliance Office

2500 California Plaza • Omaha, Nebraska 68178

phone: 402.280.2126 • fax: 402.280.4766

<http://www.creighton.edu/researchcompliance/IRB>

December 15, 2006

Maribeth Hercinger, Ph.D., R.N.
School of Nursing

RE:

IRB #: 06-14285

TITLE: TREATMENT DECISION-MAKING IN THE ADULTS WITH
CANCER

Dear Ms. Hercinger:

This office has received your letter dated December 11, 2006, along with the revised consent, the revised protocol, the revised recruitment letters, the revised Background Data Collection Form and the revised advertisement for the above project. The changes to these documents satisfy the concerns of the Board as expressed in their letter to you dated December 7, 2006. Therefore the consent, the protocol, the recruitment letters, the Background Data Collection Form and the advertisement are approved for use at this site. The consent is stamped dated December 13, 2006. Only copies of this stamped dated informed consent may be used when enrolling subjects in this project.

HHS Form 310, certifying Institutional Review Board review and approval of the above mentioned project for a twelve month period is enclosed. The twelve month approval period is based on the determination of the Board that this project is of low risk to subjects enrolled. Approval of this project expires December 13, 2007; this project must be re-reviewed by the full board prior to this date if you wish to continue this project after the twelve month approval period.

Sincerely,



Mary Kunes-Connell, Ph.D.
Vice Chair, Institutional Review Board

David L. Dworzack, M.D.
Chair

Mary Kunes-Connell, Ph.D.
Vice Chair

Patsy Nowatzke, RN, MHSA
IRB Director

Protection of Human Subjects
Assurance Identification/Certification/Declaration
 (Common Federal Rule)

POLICY: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the common rule. See Section 101(b) the common rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the common rule.

Institutions with an assurance of compliance that covers the research to be conducted on file with the Department, Agency, or the Department of Health and Human Services (HHS) should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency. Institutions which do not have such an assurance must submit an assurance and certification of IRB review and approval within 30 days of a written request from the Department or Agency.

1. Request Type <input checked="" type="checkbox"/> ORIGINAL <input type="checkbox"/> FOLLOWUP <input type="checkbox"/> EXEMPTION	2. Type of Mechanism <input type="checkbox"/> GRANT <input type="checkbox"/> CONTRACT <input type="checkbox"/> FELLOWSHIP <input type="checkbox"/> COOPERATIVE AGREEMENT <input type="checkbox"/> OTHER: _____	3. Application or Proposal Identification No. (if known) IRB #: 06-14285
4. Title of Application or Activity TREATMENT DECISION-MAKING IN THE ADULTS WITH CANCER		5. Name of Principal Investigator, Program Director, Fellow, or Other Dr. Maribeth Hercinger

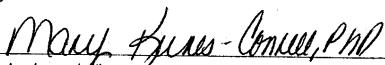
6. Assurance Status of this Project (Respond to one of the following)

- ☒ This Assurance, on file with the Department of Health and Human Services, covers this activity:
 Assurance identification no. FWA 00001078 IRB identification no. 00000155
- ☐ This Assurance, on file with (agency/dept.) _____ covers this activity.
 Assurance identification no. _____ IRB identification no. _____ (if applicable)
- ☐ No assurance has been filed for this project. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.
- ☐ **Exemption Status** Human Subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph _____

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

- ☒ This activity has been reviewed and approved by the IRB in accordance with the common rule and any other governing regulations or subparts on (date) 12/7/2006 by: ☐ Full IRB Review or ☒ Expedited Review.
- ☐ This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the common rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed and certification will be provided.		10. Name and Address of Institution Creighton University Grants Administration 2500 California Plaza Omaha, NE 68178	
11. Phone No. (with area code) (402) 280-2126	12. Fax No. (with area code) (402) 280-4766	13. Name of Official Mary Kunes-Connell, Ph.D.	
14. Title Vice Chair, Institutional Review Board		15. Signature 	
16. Date 12/7/06		Authorized for local reproduction	

OPTIONAL FORM 310 (9-92)
 Sponsored by HHS/PHS/NIH

Creighton

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Institutional Review Board • Research Compliance Office

2500 California Plaza • Omaha, Nebraska 68178

phone: 402.280.2126 • fax: 402.280.4766

<http://www.creighton.edu/researchcompliance/IRB>email: irb@creighton.edu

March 7, 2007

Maribeth Hercinger, Ph.D., R.N.
School of Nursing


RE:
IRB #: 06-14285
TITLE: TREATMENT DECISION-MAKING IN THE ADULTS WITH
CANCER

Dear Ms. Hercinger:

This office has received your letter dated February 22, 2007, along with the University of Nebraska at Lincoln IRB approval and a copy of the stamped approved consent from UNL for the above project. The approval and the consent will be placed in the protocol file for IRB #06-14285.

When enrolling subjects at Creighton University you must use the Creighton University stamped consent, approved on January 15, 2007.

Sincerely,


Mary Kunes-Connell, Ph.D.
Vice Chair, Institutional Review Board

David L. Dworzack, M.D.
Chair

Mary Kunes-Connell, Ph.D.
Vice Chair

Patsy Nowatzke, RN, MHSA
IRB Director



January 29, 2007

HUMAN RESEARCH PROTECTIONS
Institutional Review Board

Maribeth Hercinger
Dr. James Thorson
College of Education and Human Sciences
2500 California Plaza
Omaha NE 68178

IRB # 2006-12-140 EP

TITLE OF PROJECT: **Treatment Decision-Making in Older Adults with Cancer**

Dear Maribeth:

This letter is to officially notify you of the approval of your project by the Institutional Review Board (IRB) for the Protection of Human Subjects. It is the Board's opinion that you have provided adequate safeguards for the rights and welfare of the participants in this study. Your proposal seems to be in compliance with this institution's Federal Wide Assurance 00002258 and the DHHS Regulations for the Protection of Human Subjects (45 CFR 46).

Date of EP Review: 12/20/06.

You are authorized to implement this study as of the Date of Final Approval: 01/24/07. This approval is Valid Until: 01/23/08.

1. Enclosed is the IRB approved Informed Consent form for this project. Please use this form when making copies to distribute to your participants. If it is necessary to create a new informed consent form, please send us your original so that we may approve and stamp it before it is distributed to participants.

We wish to remind you that the principal investigator is responsible for reporting to this Board any of the following events within 48 hours of the event:

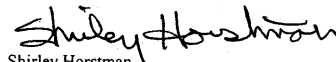
- Any serious event (including on-site and off-site adverse events, injuries, side effects, deaths, or other problems) which in the opinion of the local investigator was unanticipated, involved risk to subjects or others, and was possibly related to the research procedures;
- Any serious accidental or unintentional change to the IRB-approved protocol that involves risk or has the potential to recur;
- Any publication in the literature, safety monitoring report, interim result or other finding that indicates an unexpected change to the risk/benefit ratio of the research;
- Any breach in confidentiality or compromise in data privacy related to the subject or others; or
- Any complaint of a subject that indicates an unanticipated risk or that cannot be resolved by the research staff.

For projects which continue beyond one year from the starting date, the IRB will request continuing review and update of the research project. Your study will be due for continuing review as indicated above. The investigator must also advise the Board when this study is finished or discontinued by completing the enclosed Protocol Final Report form and returning it to the Institutional Review Board.

If you have any questions, please contact Shirley Horstman, IRB Administrator, at 472-9417 or email shorstmanl@unl.edu.

Sincerely,


Dan R. Hoyt, Chair
for the IRB


Shirley Horstman
IRB Administrator

cc: Faculty Advisor


Institutional Review Board • Research Compliance Office

2500 California Plaza • Omaha, Nebraska 68178

phone: 402.280.2126 • fax: 402.280.4766

<http://www.creighton.edu/researchcompliance/IRB>

 email: irb@creighton.edu

December 7, 2006

Maribeth Hercinger, Ph.D., R.N.
School of Nursing

RE:

IRB #: 06-14285

TITLE: TREATMENT DECISION-MAKING IN THE ADULTS WITH
CANCER

Dear Ms. Hercinger:

Thank you for sending the above project to the Institutional Review Board Office. This project was reviewed using the expedited process, in which two or more IRB members review the protocol and attachments and the consent and make recommendations as to approval and/or modification.

The reviewers for the above project have recommended that this project be approved pending the following changes to the consent, protocol, recruitment letters, Background Data Collection Form and advertisement:

1. What will happen to the tapes with recorded interviews? Please describe how they will be destroyed to protect the patient information. While this is stated in the consent, it needs to be added to the protocol.
2. In the three recruitment letters (community groups, patient chart and facility) revise the final sentence in paragraph one to read: "I believe that a more comprehensive understanding of this process may lead to improved quality of nursing care."
3. Please revise the consent form under Procedures to read: "Participation in this study will require you to fill out a short background data form and **agree** to be interviewed **for** approximately 60-90 minutes."
4. In the consent under Risks and/or Discomfort you have added a statement in the UNL consent on where the subject may seek psychological treatment. If this would occur at this site where will the patient be referred if they would suffer an adverse psychological event?
5. In the consent under Confidentiality please revise the second sentence to read: "The data will be stored in a locked cabinet in the investigator's

David L. Dworzack, M.D.
Chair

Mary Kunes-Connell, Ph.D.
Vice Chair

Patsy Nowatzke, RN, MHSA
IRB Director

office and will only be seen by the investigators, the doctoral student's committee, and the Creighton University **Institutional Review Board** and other internal departments that provide support and oversight at Creighton University/Creighton University Medical Center during the study and for three years after the study is complete." UNL IRB does not provide oversight to subjects enrolled at Creighton University/Creighton University Medical Center.

6. In the consent under Opportunity to Ask Questions, please revised the third sentence to read: "...concerns about the study, you **may** contact the..."
7. In the consent the name and phone numbers of the investigators should be place on page one of the consent.
8. On the Background Data Collection Form, page 1 of 3, under #4, the word "home)", should be directly under "(not employed outside the".
9. On the advertisement please revise the last sentence to read "You will **receive** a small compensation for your time."

Upon receiving a modified consent, protocol, recruitment letters, Background Data Collection Form and advertisement for the above project, you will be issue an HHS Form 310, certifying IRB review and approval of the above project for a 12-month period.

Sincerely,

Mary Kunes-Connell, PhD
Mary Kunes-Connell, Ph.D.
Vice Chair, Institutional Review Board

TITLE OF PROJECT: Treatment Decision-Making in Older Adults with Cancer.
IRB application CODE 136

Dan Hoyt
Chair UNL IRB
Shirley Horstman
UNL IRB Administrator

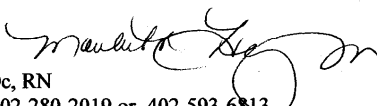
Dear Mr. Hoyt and Ms. Horstman,

This letter and corresponding information is in response to the UNL's recommendations for my research project in a letter dated December 20, 2006. I have addressed each modification/clarification as noted below.

1. Recruitment protocol
 - a. The detailed protocol is attached.
 - b. The Creighton University Medical Center's (CUMC) Institutional Review Board (IRB) has approved my study and the signed copy of the letter is attached.
 - c. I have revised the consent forms to include a more detailed statement on the risks and deleted UNL psychological clinic. These consent forms are attached (both CUMC and UNL).
 - d. No request for patient records will be completed. Therefore HIPAA will not be relevant.
 - e. The interview questions are attached (no changes)
 - f. The background data form is attached (no changes)
2. In response to the question: "If the research is being conducted in Omaha, is UNL psychological clinic referral of any value? Perhaps this needs to be a referral site in Omaha": The psychological clinic referral will be deleted for the data collection will be in the Omaha area.
3. The informed consents were revised to acknowledge that the recall of tough treatment decisions may illicit emotions to include the following:
 "There are no known risks or discomforts associated with this research. However, there may be some risk involved with participating in this study. You may feel emotions that may be distressing because of issues being brought out while answering the interview questions. If you are feeling uncomfortable, please feel free to not answer any questions or stop the interview. The investigator will discuss counseling options should you require these services. The interview questions will be made available to you prior to the study. You have the right to ask questions concerning the research before agreeing to participate or during the participation. In the event of problems resulting from participation in the study, psychological treatment is available at Creighton University Psychiatric Center, telephone (402) 345-8828."
 Please see attached including approval stamp from CUMC IRB.
4. See revised informed consents.
5. Letter from CUMC date January 15, 2007 of CUMC IRB approval is attached and the previous approval letter is also included in this packet.
6. The evidence of CITI training is attached for all participants. Please note that Patty Marsh was married and her previous name is Patty Falk.

Thank you for your review and recommendations. Please contact me if any questions.

Respectfully submitted,


Maribeth Hercinger, PhDc, RN
UNL Doctoral Student 402-280-2019 or 402-593-6813

Creighton
UNIVERSITY
Medical Center
School of Nursing

January 12, 2007

Dr. David L Dworzack, Chair
Dr. Mary Kunes-Connell, Vice Chair
Institutional Review Board
Creighton University Medical Center

RE: IRB #06-14285
Treatment Decision-Making in Adults with Cancer

Dear Drs. Dworzack and Kunes-Connell,

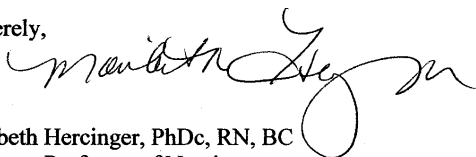
As I am a doctoral student at the University of Nebraska at Lincoln, I have also submitted my project to their Institutional Review Board. They have recommended that I address the potential recall of tough treatment decisions on my consent form. I would like to make a change in the approved consent form to add under risks:

"There may be some risk involved with participating in this study. You may feel emotions that may be distressing because of issues being brought out while answering the interview questions. If you are feeling uncomfortable, please feel free to not answer any questions or stop the interview. The investigator will discuss counseling options should you require these services. The interview questions will be made available to you prior to the study. You have the right to ask questions concerning the research before agreeing to participate or during the participation."

Please see the attached consent forms (one highlighted with the change and one proposed final draft).

Thank you for your consideration in this request.

Sincerely,



Maribeth Hercinger, PhDc, RN, BC
Assistant Professor of Nursing
Creighton University Medical Center
402-280-2019

APPENDIX D

Recruitment

HAVE YOU HAD TO MAKE A DECISION FOR CANCER TREATMENT?

If you are over 50 years of age and have had to make a decision regarding cancer treatment and it has been in the last 6 months, you may be eligible to participate in a research study investigating the experience of decision making.

This study consists of a visit from a nurse and may include an interview and a short questionnaire. You will be given a small compensation for your time.

For more information,
please contact Maribeth Hercinger,
Assistant Professor of Nursing,
Creighton University School of Nursing
at (402) 280-2019.



Facility recruitment letter

Dear

I am a doctoral student at the University of Nebraska-Lincoln Pursuing a Ph.D. in Human Science with a specialization in Gerontology. I am also a nursing educator at Creighton University Medical Center in the School of Nursing with an interest in oncology. The purpose of my dissertation research is to explore the process of cancer treatment decision-making from a personal perspective. I believe that a more comprehensive understanding this process may lead to improved quality of nursing care.

This study is a qualitative phenomenological study. This is a research project that will explore the experience of treatment decision-making for the adult cancer patient who is 50 years of age or older. I am inviting individuals who have made a treatment decision for a new cancer in the last 6 months.

My colleague Tina Miller or I would like to schedule an interview with prospective participants. This interview should take about 90 minutes and can be in a location of the participants choosing. The interview guide and personal data form is attached for you to view.

The identity of the participant will be kept confidential and an informed consent document will be provided. All participation in this research is voluntary. The research study has been approved by the Institutional Review Boards at Creighton University Medical Center and the University of Nebraska at Lincoln.

If you wish to discuss this research or have questions, please feel free to contact me. I appreciate your time and consideration in assisting me with recruitment for this study.

Sincerely,

Maribeth Hercinger, PhDc, RN
Primary Investigator
(402)-280-2019 (Office)
(402)-593-6813 (Home)

Recruitment letter for medical facilities/clinics for the patient chart

I am a doctoral student at the University of Nebraska-Lincoln Pursuing a Ph.D. in Human Science with a specialization in Gerontology. I am also a nursing educator at Creighton University Medical Center in the School of Nursing with an interest in care of cancer patients. The purpose of my dissertation research is to explore the process of cancer treatment decision-making from a personal perspective. I believe that a more comprehensive understanding this process may lead to improved quality of nursing care.

This study is a qualitative phenomenological study. This is a research project that will explore the experience of treatment decision-making for the adult cancer patient who is 50 years of age or older. You are invited to participate in this study because you have made a treatment decision for a new cancer in the last 6 months.

You have been identified as an individual who meets the criteria for this study. If you are willing to participate, my colleague Tina Miller or I would like to schedule an interview with you. This interview should take about 90 minutes of your time and can be in a location of your choosing. Your identity will be kept confidential and an informed consent document will be provided for you.

Your participation in this research is voluntary. If you wish to discuss this research or have questions, please feel free to contact me. I appreciate your time and consideration.

Sincerely,

Maribeth Hercinger, PhDc, RN
Primary Investigator
(402)-280-2019 (Office)
(402)-593-6813 (Home)

Recruitment letter for community groups as a handed out

I am a doctoral student at the University of Nebraska-Lincoln Pursuing a Ph.D. in Human Science with a specialization in Gerontology. I am also a nursing educator at Creighton University Medical Center in the School of Nursing with an interest in care of the cancer patient. The purpose of my dissertation research is to explore the process of cancer treatment decision-making from a personal perspective. I believe that a more comprehensive understanding this process may lead to improved quality of nursing care.

This study is a qualitative phenomenological study. This is a research project that will explore the experience of treatment decision-making for the adult cancer patient who is 50 years of age or older. If you have made a treatment decision for a new cancer in the last 6 months you may be eligible to participate in this study.

If you meet the criteria and are willing to participate in the study, my colleague Tina Miller or I would like to schedule an interview with you. This interview should take about 90 minutes of your time and can be in a location of your choosing. Your identity will be kept confidential and an informed consent document will be provided for you.

Your participation in this research is voluntary. If you wish to discuss this research or have questions, please feel free to contact me. I appreciate your time and consideration.

Sincerely,

Maribeth Hercinger, PhDc, RN
Primary Investigator
(402)-280-2019 (Office)
(402)-593-6813 (Home)

APPENDIX E

Consent Forms

INFORMED CONSENT FORM

IRB #: 06-14285

Title of Project: Treatment Decision-making in the Adults with Cancer

Principal Investigator: Maribeth Hercinger, Office: (402)-280-2019

Secondary Investigator: Tina Miller, Office: (402) 280-2176

Purpose of the Research: This is a research project that will explore the experience of treatment decision-making for the adult cancer patient who is 50 years of age or older. You are invited to participate in this study because you have made a treatment decision for a new cancer in the last 6 months.

Procedures: Participation in this study will require you to fill out a short background data form and agree to be interviewed for approximately 60-90 minutes. The interview will be audio-taped and transcribed in a typed format.

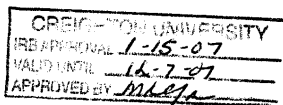
Risks and/or Discomforts: There are no known risks or discomforts associated with this research. However, there may be some risk involved with participating in this study. You may feel emotions that may be distressing because of issues being brought out while answering the interview questions. If you are feeling uncomfortable, please feel free to not answer any questions or stop the interview. The investigator will discuss counseling options should you require these services. The interview questions will be made available to you prior to the study. You have the right to ask questions concerning the research before agreeing to participate or during the participation.

In the event of problems resulting from participation in the study, psychological treatment is available at Creighton University Psychiatric Center, telephone (402) 345-8828.

Benefits: You will receive no direct benefits when participating in this study. Future cancer patients may benefit from a better understanding of the decision-making process.

Confidentiality: Any information obtained during this study which could identify you will be kept strictly confidential. The data will be stored in a locked cabinet in

Page 1 of 3 Pages



Subject's Initials: _____

the investigator's office and will only be seen by the investigators, the doctoral student's committee, and the Creighton University Institutional Review Board and other internal departments that provide support and oversight at Creighton University/Creighton University Medical Center during the study and for three years after the study is complete. In all other instances, any data under the investigator's control will, if disclosed, be presented in a manner that does not reveal the subject's identity, except as may be required by law. The information obtained in this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group data. The audiotapes will be erased after transcription.

Compensation: A \$20 gift certificate to Target will be given to show appreciation for your time spent in participating in this research project.

Opportunity to Ask Questions: You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study, you may contact the investigator at any time, office phone, (402) 280-2019, or after hours (402) 212-3508. If you have questions concerning your rights as a research subject that have not been answered by the investigator or to report any concerns about the study, you may contact the Creighton University telephone (402) 280- 2126.

Consent, Right to Receive a Copy: You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

Freedom to Withdraw: You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the investigators, the Creighton University Medical Center or the University of Nebraska at Lincoln. Your decision will not result in any loss or benefits to which you are otherwise entitled.

Consent Statement

You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled or effect on your relationship to the institution(s) involved in this research project.

Page 2 of 3 Pages

CREIGHTON UNIVERSITY	
ISSUED DATE	1-15-07
VALID DATE	4-7-07
APPROVED BY	<i>[Signature]</i>

Subject's Initials: _____

My signature below indicates that all my questions have been answered. I agree to participate in the project as described above.

Signature of Subject

Date Signed

If you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling (402) 280-2126, or addressing a letter to the Institutional Review Board, Office of Grants Administration, Creighton University, 2500 California Plaza, Omaha, NE 68178.

A copy of this form has been given to me. _____ Subject's Initials

For the Research Investigator—I have discussed with this subject the procedure(s) described above and the risks involved; I believe he/she understands the contents of the consent document and is competent to give legally effective and informed consent.

Signature of Responsible Investigator

Date Signed

Name and Phone number of investigator(s)

Maribeth Hercinger, PhD, RN, Principal Investigator

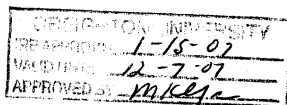
Office: (402) 280-2019

James Thorson, PhD, Advisor

Office: (402)-554-2273

Tina Miller, MSN, RN, Secondary Investigator

Office: (402) 280-2176



Subject's Initials: _____



IRB#2006-12-140 EP Date Approved: 1/24/07 Valid Until: 01/23/08

COLLEGE OF EDUCATION AND HUMAN SCIENCES
Department of Gerontology

INFORMED CONSENT FORM

Identification of Project:

Treatment Decision-making in the Adults with Cancer

Principal Investigator: Maribeth Hercinger, PhDc, RN (402) 280-2019 (office)

Secondary Investigator: Tina Miller, MSN, RN (402) 280-2176 (office)

Purpose of the Research:

This is a research project that will explore the experience of treatment decision-making for the adult cancer patient who is 50 years of age or older. You are invited to participate in this study because you have made a treatment decision for a new cancer in the last 6 months.

Procedures:

Participation in this study will require you to fill out a short background data form and agree to be interviewed for approximately 60-90 minutes. The interview will be audio-taped and transcribed in a typed format.

Risks and/or Discomforts:

There are no known risks or discomforts associated with this research. However, there may be some risk involved with participating in this study. You may feel emotions that may be distressing because of issues being brought out while answering the interview questions. If you are feeling uncomfortable, please feel free to not answer any questions or stop the interview. The investigator will discuss counseling options should you require these services. The interview questions will be made available to you prior to the study. You have the right to ask questions concerning the research before agreeing to participate or during the participation. In the event of problems resulting from participation in the study, psychological treatment is available at Creighton University Psychiatric Center, telephone (402) 345-8828.

IRB#2006-12-140 EP Date Approved: 1/24/0 Valid Until: 01/23/08
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Benefits:

You will receive no direct benefits when participating in this study. Future cancer patients may benefit from a better understanding of the decision-making process.

Confidentiality:

Any information obtained during this study which could identify you will be kept strictly confidential. The data will be stored in a locked cabinet in the investigator's office and will only be seen by the investigators, the doctoral student's committee and the University of Nebraska at Lincoln's Internal Review Board and other internal department that provide support and oversight during the study and for three years after the study is complete. In all other instances, any data under the investigator's control will, if disclosed, be presented in a manner that does not reveal the subject's identity, except as may be required by law. The information obtained in this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group data. The audiotapes will be erased after transcription.

Compensation:

A \$20 gift certificate to Target will be given to show appreciation for your time spent in participating in this research project.

Opportunity to Ask Questions:

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. You may contact the investigator at any time, office phone, (402) 280-2019, or after hours (402) 212-3508. If you have questions concerning your rights as a research subject that have not been answered by the investigator or to report any concerns about the study, you may contact the University of Nebraska-Lincoln Institutional Review Board telephone (402) 472-6965 or the Creighton University Institutional Review Board telephone (402) 280- 2126.

Freedom to Withdraw:

You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the investigators, the University of Nebraska at Lincoln or the Creighton University Medical Center. Your decision will not result in any loss or benefits to which you are otherwise entitled.

IRB#2006-12-140 EP Date Approved: 1/24/07 Valid Until: 01/23/08

Consent, Right to Receive a Copy:

You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled or effect on your relationship to the institution(s) involved in this research project.

A copy of this form has been given to me. _____ Subject's Initials

You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

_____ Initial here if you agree to be audio taped during the interview.

My signature below indicates that all my questions have been answered. I agree to participate in the project as described above.

Signature of Participant:

Signature of Research Participant

Date

A copy of this form has been given to me. _____ Subject's Initials

For the Research Investigator: I have discussed with this subject the procedure(s) described above and the risks involved; I believe he/she understands the contents of the consent document and is competent to give legally effective and informed consent.

Signature of Responsible Investigator

Date Signed

Name and Phone number of investigator(s)

Maribeth Hercinger, PhD, RN, Principal Investigator Office: (402) 280-2019

James Thorson, PhD, Advisor Office: (402)-554-2273

Tina Miller, MSN, RN, Secondary Investigator Office: (402) 280-2167

APPENDIX F

Personal Interview Form

Interview page 1 of 3

- 3. What was difficult/easy about making your decision to accept (or refuse) cancer treatment?**

Can you give me an example of what was difficult? Please explain.

Can you give me an example of what was easy? Please explain.

- 4. Did particular people influence your decision for treatment?**

Please explain how you are involved with these individuals.

Please explain how they were influences. If so, how did they influence your decision for treatment?

If no, then would you have liked someone to assist you with this decision?

- 5. How long did your decision for cancer treatment take?**

- 6. Can you describe how you made your decision for treatment?**

- 7. Can you identify certain issues that affected your decision for treatment?**

Can you prioritize these issues for me?

Did your age affect this decision? If so, how?

Interview page 2 of 3

8. Did your physical or mental health influence your decision for treatment?

If they did, please explain how they influenced your decision.

9. Did your spiritual values influence your decision for treatment?

If they did, please explain how they influenced your decision for treatment.

10. Did you feel that your treatment decision had any effect on other people in your life?

If yes, please explain who and please tell me about what you feel these effects were.

11. How did you feel when the decision for treatment had been made?

12. Is there anything else that you would like to share with me about your cancer treatment decision?

Thank you for participating in this interview.

Please note that the confidentiality of all responses will be maintained.

APPENDIX G

Background Data Form Coding

Project: Treatment Decision-making for Older Adults with Cancer
Background Data Collection Form Coding

1. Subject number (coded on form as participant A, B, etc.)
 - a. A=1
 - b. B=2
 - c. C=3
 - d. D=4
 - e. E=5
 - f. F=6
 - g. G=7
 - h. H=8
 - i. I=9
 - j. J=10
 - k. K=11
 - l. L=12
 - m. M=13
 - n. N=14
 - o. O=15
 - p. P=16
2. Time of interview=actual military time as 1500
3. Date: Actual date as 020207
4. Location:
 - a. 1=home
 - b. 2=participant's work office
 - c. 3=researcher's office
 - d. 4=restaurant or coffee house
 - e. 5=oncology office
 - f. 6=medical office
 - g. 7=other
5. Interviewer:
 - a. 1=Maribeth Hercinger
 - b. 2=Tina Miller
6. Age at last Birthday=actual age in years as 72
7. Gender:
 - a. Male=1
 - b. Female=2
8. Current Marital Status
 - a. Married=1
 - b. Widowed =2
 - c. Cohabiting=3
 - d. Divorced/Separated=4
 - e. Never Married =5
9. Current Employment Status:
 - a. Employed Full-time=1
 - b. Full-time Student=2

- c. Employed Part-time=3
- d. Not employed outside the home=4
- e. Unemployed=5
- f. Retired=6

10. Work (current)

- a. Office work=1
- b. Health care=2
- c. Government/civil service=3
- d. Laborer=4
- e. Teacher=5
- f. Other=6

11. Roles in addition to work:

- Home=1
- Social =2
- Volunteer Activities =3
- Other =4

12. Education Level (please check the highest level completed).

- Less than 8th Grade=1
- Completed 8th Grade=2
- Completed some High School=3
- Graduated from High School=4
- Completed some College=5
- Completed Baccalaureate Degree=6
- Completed Graduate or Professional Degree=7

13. Yearly Family Income:

- Below \$20,000 =1
- \$20,000-\$40,000 =2
- \$40,000-\$60,000 =3
- Above \$60,000=4
- Prefer not to answer this question =5

14. Ethnic/Racial Background

- Asian or Pacific Islander =1
- African American=2
- Hispanic/Latino=3
- Native American Indian=4
- Caucasian (non-Hispanic)=5
- Other =6

15. Cancer Diagnosis

- a. Breast=1
- b. Lung=2
- c. Colorectal=3
- d. Prostate=4
- e. Leukemia=5
- f. Non Hodgkin's Lymphoma=6

- g. Stomach=7
- h. Pancreatic=8
- i. Uterine/Cervical=9
- j. Ovarian=10
- k. Other=11

16. Length of time from Diagnosis to Treatment Decision

- Less than 6 months =1
- 6-12 months =2
- more than 12 months but less than 18 months =3
- more than 18 months to 24 months =4

17. Length of time since treatment decision was made
(time from decision to current date)

- Less than 6 months =1
- 6-12 months =2
- more than 12 months but less than 18 months =3
- more than 18 months to 24 months =4

18. Cancer Treatment Decision

- Chemotherapy=1
- Radiation Therapy=2
- Hormonal Therapy=3
- Immunotherapy=4
- Surgery=5
- Other treatment or Stop treatment=6
- No treatment =7
- Combination =8