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Hope and quality of life in hospice patients with cancer

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Hope and Quality of Life in Hospice Patients with Cancer

by

Cynthia Brown

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science
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University of South Florida

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Hope and Quality of Life in Hospice Patients with Cancer

Cynthia Brown

ABSTRACT

Hope is considered to have a positive influence upon health. Cancer patients may enter hospice care after a rigorous course of medical treatment, having hoped for a cure or long remission. While the hope for cure is important, hope is no less important at the end of life when the goal of care is quality of life. This study examined the relationship between hope and quality of life in hospice patients with cancer.

Thirty-one patients with cancer, who were alert, oriented, living with a caregiver, and aware of their diagnosis were sampled from a hospice program. The instruments used were the Herth Hope Index (HHI) and the Hospice Quality of Life Index (HQLI).

The HHI total scores and the HQLI total scores were significantly positively correlated ($r = .356$; $p = .049$). This finding suggests that hope is a different concept than quality of life but that these concepts are related. A high level of hope (mean of 42.84 out of a possible 48) was maintained by subjects. The HQLI subscale of social/spiritual well-being and the total HHI scores were also positively correlated ($r = .51$; $p = .003$) suggesting that hope can be influenced by this aspect of quality of life which includes a relationship with God, support from family, friends and healthcare providers, and spiritual support from the healthcare team.

The findings of this study underscore the importance of the healthcare provider in promoting hope at the end of life, and suggests that hope is not taken away by admission into a hospice program.

Chapter One

Introduction

Cancer is the second leading cause of death in the United States. The estimated number of cancer deaths for 2004 was 563,700 (American Cancer Society, 2004). For 2003, the National Hospice and Palliative Care Organization (NHPCO, 2005) reported that 930,000 patients were served by hospice programs. Approximately 49 percent of these patients were admitted into hospice with a diagnosis of cancer. Hospice care is offered when life expectancy is six months or less.

Modern hospice care has its origin in the work of Cicely Saunders, a nurse, social worker and physician, who founded Saint Christopher's hospice in England in 1967 (Clark, 1999). Hospice care began in the United States in the 1970's. The philosophy of hospice espouses death with dignity, at home, surrounded by family, and free from uncomfortable symptoms. It has become an alternative to dying in a hospital.

Hospice care is delivered by an interdisciplinary team, often comprised of physicians, nurses, home health aides, clergy and trained volunteers (NHPCO, 2003). Rather than focusing on the disease and cure, hospice care focuses on the quality of life of the patient and family. Goals are defined in terms of patient comfort, and quality of life takes precedence over quantity of life (Egan & Labyak, 2001). Patients entering hospice care, if mentally competent, must give informed consent. Hospice patients are aware of both their diagnosis and prognosis.

Problem Statement

Many cancer patients enter hospice care after a rigorous course of medical treatment that provided hope for a cure or long remission. Hope in this case seems to be in the hands of physicians who offer it in the form of technical intervention (Elliott & Olver, 2002). There may be a loss of hope experienced by those for whom continued treatment is no longer appropriate (Nekolaichuk & Bruera, 1998). The goal of end of life care is quality of life, and hope is considered to have a positive influence upon health. Hope has been viewed in terms of hopes for cure, however, there are few published studies regarding hope in hospice care in the research literature. The purpose of this study was to examine the relationship between hope and quality of life in terminally ill hospice patients with cancer.

Research Questions

The proposed study explored the following research questions:

1. What is the mean level of quality of life in hospice patients with cancer?
2. What is the mean level of hope in hospice patients with cancer?
3. Is there a significant positive relationship between quality of life and hope in hospice patients with cancer?

Definition of Terms

For the purposes of this study, the following terms are defined:

1. *Quality of life (QOL)*. Quality of life is subjective and can only be determined by the patient. Quality of life is individualized and is more aptly described as a “quality of being” (Benner, 1985 p. 5). Cella (1995) notes that quality of life encompasses those domains which are associated with well-being. McMillan and Weitzner (1998)

conceptualized quality of life to include three domains: psychophysiological, functional and social/spiritual well-being.

2. *Hope*. Dufault and Martocchio (1985, p. 380) conceptualized hope as “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant.”

Significance to Nursing

While the hope the cancer person holds while seeking a cure is important, hope has been found to be no less important at the end of life (Hall, 1990). Hope is a vital coping mechanism for the cancer patient (Herth, 1989) and is a constant subjective resource within each person (Dufault & Martocchio, 1985). A vital role of hospice is to reframe the meaning of hope and help the person find meaning in the face of his or her illness, therefore improving the quality of life (Hall, 1990). Results of this study may shed light on the importance of hope at the end of life and therefore support the role of nursing in promoting hope.

Chapter Two

Review of Literature

The review of literature details the characteristics of hope explicated in the research literature. This chapter focuses on the quality of life framework (McMillan & Weitzner, 1998) and the conceptual model of hope (Dufault and Martocchio, 1985). Studies related to the domains of quality of life and hope are analyzed and applied to the quality of life framework. Following a review of the domains of quality of life in relation to hope and a review of the temporal dimension of hope, research involving nursing interventions to promote hope in cancer patients are reviewed. A series of studies have been conducted, and these are discussed within the QOL framework developed by McMillan and Weitzner (1993).

Conceptual Model

Quality of Life

The Hospice Quality of Life Index (HQLI) was developed by McMillan and Weitzner (1998) after review of QOL literature and consultations with hospice staff. The quality of life framework was conceptualized to include three domains: psychophysiological, functional and social/spiritual well-being.

The psychophysiological domain of the quality of life framework includes anxiety, pain, worry, anger, sleep, sex life, breathlessness, constipation and the concept of hope. The functional domain includes the ability to concentrate, social life of the patient

and family, and the ability to maintain a sense of independence. The social/spiritual domain includes support from family and friends, healthcare team, a relationship with God (however God is defined for the person) and meaning in life. The factor structure of the HQLI was validated in a sample of home care hospice patients with cancer (n = 255). Included in the psychophysiological domain is the concept of hope (McMillan & Weitzner, 1998). However, others have measured hope as a completely separate concept.

Rustoen, Wiklund, Hanestad, and Moum (1998) randomized newly diagnosed patients with cancer into a nursing intervention group designed to increase hope, a second group into a standard coping program, and a third into a control group. The hope group had increased in levels of hope ($p = .020$), but no increase in quality of life. The investigators concluded that hope and quality of life are separate phenomena.

Hope

Dufault and Martocchio (1985) studied hope in 35 cancer patients who were 65 or older. The data was then generalized to other terminally ill adults with various diagnoses. They defined hope as both generalized and particularized. Generalized hope is not encumbered by time or the particulars of specific goals, whereas particularized hope is specific in regards to time and goals. Both generalized and particularized hopes are multidimensional and comprised of six dimensions: affective (emotions), cognitive (imagination, thinking, state of being), behavioral (actions taken to achieve a hope), affiliative (relationships), temporal (past, present, future and being), and contextual (context of life) (Appendix A).

Review of Research

Hope and the Psychophysiological Domain

Chen (2003) evaluated the effect of pain on hope in a convenience sample of patients with cancer ($n = 226$). The subjects were divided into two groups, one group with pain ($n = 91$) and one group without pain ($n = 135$), in order to measure the effect of pain upon both levels of hope and the perceived meaning of pain. Instruments administered were the Perceived Meaning of Cancer Pain Inventory (PMCPI), the Herth Hope Index (HHI), a pain assessment form developed by Chen, and the Karnofsky Performance Scale. Chen (2003) correlated the level of hope to the meaning of cancer pain. The PMCPI was sensitive to a perception of the cancer pain as challenge, loss or threat. Those who perceived their pain as a challenge had higher hope scores, and those who saw their pain as a threat or loss had lower hope scores. Therefore, assessment of pain must include an assessment of the meaning of the pain.

Lin, Lai and Ward (2003a) compared a convenience sample of 484 patients with cancer, who were with pain ($n = 233$), and without pain ($n = 251$) to examine how cancer pain affects performance status, mood and levels of hope. Instruments included the Profile of Mood States (POMS), the HHI, the Brief Pain Inventory (BPI) and the Karnofsky Performance Scale. Significant findings in this study were that levels of hope did not differ in those with or without pain; however, the impact of how pain interfered with daily life did negatively correlate with levels of hope ($r = -.31$, $p = .001$). The investigators postulated that cancer pain alone does not impose as great an impact on levels of hope as the effect of cancer pain on one's ability to perform activities of daily living.

Hope and the Functional Domain

A study by Herth (1989) correlated levels of hope with levels of coping in cancer patients ($n = 120$) who were receiving chemotherapy. Instruments used were the Herth Hope Scale (HHS), the Jalowiec Coping Scale (JCS), and a demographic data form which included three items asking about job and family responsibilities and religious beliefs. Herth (1989) found a moderately strong ($r = 0.80$, $p = .001$) relationship between the HHS and the JCS with a 64% co-variance, reflecting that high levels of hope related to high levels of coping. Significant findings from the study were that a loss of ability to fulfill family responsibilities but not job responsibilities could influence hope or coping. Those who had strong religious beliefs had higher levels of hope and coping than those with a weak or no faith.

Lin, et al. (2003b) designed a cross-sectional study of oncology patients ($n = 124$), of whom 21% were unaware of their cancer diagnosis. This study occurred in Taiwan where it is considered ethically acceptable to withhold a diagnosis from the patient and reveal it to family members only. The instruments used were the HHI and a demographic and disease data collection sheet. Those who described their disease process as either benign tumor or other, as opposed to cancer or malignancy, were considered unaware of their diagnosis. Levels of hope in the subjects were evaluated at 3, 6, 12 months and greater than 12 months after patients had been told their diagnosis. The study revealed that the 79% who knew their diagnosis maintained higher levels of hope than the group without cancer diagnosis disclosure. It may be inferred from the study that withholding a hospice referral in an attempt not to disclose or discuss the terminal illness will not promote hope.

Hope and the Social/Spiritual Domain

O'Connor, Wicker, and Germino (1990) analyzed the randomly selected interview data of thirty newly diagnosed patients with cancer. Consistent themes emerged from the interview data as having importance in the search for meaning in patients with cancer. Six themes emerged, with some patients identifying more than one theme. Six themes were identified: personal significance, consequences of diagnosis, changes in outlook on life, living with cancer, review of one's life and hope. The definition of hope was consistent with Dufault and Martocchio's (1985). The hopes of participants were on a future event such as taking a trip, attending a wedding or awaiting a birth. Some placed hope in treatments and doctors. For 30% of the subjects, religion and God were sources of hope. One subject had hope for a peaceful death and another was encouraged that others had quit smoking because of his lung cancer.

A descriptive, correlational study by Ebright and Lyon (2002) evaluated the effects of social support, self-esteem and religious beliefs on levels of hope. The convenience sample consisted of recently diagnosed breast cancer patients who had completed breast surgery ($n = 73$). At 1 to 3 months after diagnosis and 10 to 12 months after surgery, subjects completed the HHI, an emotional and appraisal measurement, a social support questionnaire, the Rosenberg Self-Esteem Scale, and a one-item question regarding religious beliefs. The results demonstrated that coping, self-esteem and social support were contributors to hope.

Raleigh (1992) examined how people with chronic illnesses maintained hope. The sample consisted of an oncology group who had completed treatment and had no metastases ($n = 45$) and a group with chronic illnesses ($n = 45$). Explored were sources of

hope, and differences in levels of hope and future orientation between those with cancer as opposed to other illnesses. The instrument used was the Sources of Support Interview Schedule developed by the investigator. The questions were designed to guide the interview process toward the subject's illness experience and ways the subjects were able to support their hopefulness. Study outcomes revealed religion, family and friends as supports which helped patients maintain a positive outlook in the face of illness. Having people visit, talk with, or help with physical needs such as activities of daily living were identified by subjects as ways others help to maintain hope.

A study by Ballard, Green, McCaa and Logsdon (1997) compared levels of hope in newly diagnosed cancer patients ($n = 20$) and those with recurrence ($n = 18$). The instrument used was the 30 item HHS. An open-ended question also was added: "What gives you the most hope at the present time?" (Ballard, et al., p. 899). There were no statistical differences between the groups except in sources of hope. The newly diagnosed placed their hope in health care professionals, whereas those with a recurrence of cancer placed their hope in their faith, as reflected in this response: "...I'm a Christian. I know that doctors can only go so far—there is higher power" (Ballard, et al., p. 903).

Herth (1990) studied 30 terminally ill adults in order to further explore the meaning of hope in the dying. Eleven of the participants were diagnosed with cancer. The Herth Hope Index, interview and Background Data Form (BDF) were the instruments used in a method of methodological triangulation. Five questions were used in the interview in order to elicit from subjects their thoughts on the meaning of hope. The questions related to the meaning of hope, what is hoped for, sources of hope, and how each person maintained hope. The background data collected included demographics and

an item on fatigue and activity level to control for these variables in the study. The subjects identified six hope-fostering strategies. These aspects of hope were “interpersonal/connectedness, light-heartedness, personal attributes, attainable aims, spiritual base, uplifting memories and affirmation of worth” (Herth, p.1254). The subjects also identified threats to hope. These included uncontrolled pain, abandonment and isolation, and threats to dignity. Physical debility was not identified as a threat to hope. Hope was identified as an inner power and was active in all subjects. Ten subjects were followed longitudinally until their death in order to monitor the stability of hope. As death approached, the sources of hope narrowed to relationships, attainable aims and spirituality. To be able to experience an inner peace was also conveyed as a hope of subjects nearing death.

Hope, Quality of Life and the Temporal Dimension

Herth (1993) investigated insight into hope time frames and quality of life in the elderly is gleaned in a cross-sectional study of people age 60 and older living in either a private home, housing facility or long term care facility (n = 60, cluster sampling). The sample was further stratified into an old-old group (over 80), and the young-old (65-80). The investigator used a methodological triangulation approach with the same instrumentation as the previous study in 1990 and added an interview question that asked how the person regained hope when levels of hope were low. To control for the potential negative influence of holidays and extreme winter weather, the study was conducted in April, May and June.

The findings revealed different focuses of hope based upon age, place of residence and health. Those 65 to 80 years old who lived in their own homes with good

health and function had hopes that were self-focused and goals that were projected over a 1 to 3 year period. Those who were over 80 and living in the senior citizen housing with good health and function had hopes focused upon others and goals projected into the nearer future (weeks to months). Those who were living in the long-term care facility with poor health and function had hopes focused on friends and their caregivers and on the very near future (days to weeks), and any hopes for themselves were in a life after death. As the person neared death, the focus was found to be on the present, an example of the concept of being, which Dufault and Martocchio (1985) described.

Hope could be inhibited for the subjects by the “hopelessness in others” such as friends, caregivers and healthcare professionals (Herth, 1993, p. 147). Other hope inhibitors were loss of personal energy, uncontrolled pain and suffering, and a loss of cognitive ability. The overall hope scores were similar with the exception of the subjects living in a long-term care facility and experiencing fatigue. Through the interviews, eight hope fostering strategies were identified: “interconnectedness with self/others/world; purposeful activities; uplifting memories; cognitive strategies; hope objects; refocused time; lightheartedness; spiritual beliefs and practices” (Herth, 1993, p. 148). The most significant category of hope promotion in all of the subjects was found in the interconnectedness with others and God.

A study by Rustoen and Wiklund (2000) was conducted to evaluate the levels of hope for patients (n = 131) who had a recent diagnosis of cancer and a life expectancy of at least one year. Sixty-one percent were receiving treatment at the time of the study. The Nowotny Hope Scale, quality of life questionnaires and a demographic questionnaire were mailed to the homes of the subjects. Findings indicated that neither time since the

diagnosis nor the age of the patient had an effect on levels of hope. Additionally, those who lived with someone had higher levels of hope.

Nursing Interventions to Increase Hope in the Patient with Cancer

A study was designed by Herth (2000) to evaluate whether a nursing intervention designed to promote hope could positively influence levels of hope in patients receiving cancer treatment following a first recurrence of cancer. Patients (n = 115) were randomized into one of three groups. Group one, the hope intervention group, received a nurse-led intervention designed to promote support and nurturing in the small groups of 8 to 10. Group two focused on cognitive understanding of cancer, and received information only and was an attention group designed to control for the variable of attention. Group three, the control group received no intervention other than standard care.

The instruments used were the HHI, Cancer Rehabilitation and Evaluation Systems—Short Form (CARES-SF) for measuring quality of life, and demographic data. Data was collected before the interventions were administered to the hope and attention groups. Both the attention and the hope groups received eight, two-hour sessions. The hope intervention was based upon the Hope Process Framework (Farran, Herth, and Popovich, 1995) and focused upon creating a supportive and caring environment through sessions designed to enhance the awareness and expression of the thoughts, feelings, relationships, goals and spirituality of participants. Following completion of the hope and attention interventions, all subjects completed the HHI and the CARES-SF. The instruments were again administered at three, six and nine months following the interventions.

The results of the study revealed that the hope intervention group reflected higher levels of hope in each data collection period. Those in the intervention group also reflected increasing levels of quality of life from the baseline before the intervention, while those in the control and attention groups reflected decreases in quality of life. This study lends evidence to the significance of the nurse's role in influencing hope and hope's influence on increasing quality of life.

Rustoen, et al. (1998) designed and implemented a hope promotion intervention by randomizing patients recently diagnosed with cancer ($n = 96$) into three groups: control group, cancer information group, and hope promotion group. Before the intervention, the subjects completed the Nowotny Hope Scale (NHS), Ferrans and Powers Quality of Life Index and Cancer Rehabilitation and Evaluation Systems (CARES) questionnaires. Pre-intervention hope scores revealed moderate hopefulness in all subjects. Dufault and Martocchio's (1985) model of hope supports the idea that when specific hopes are not attained, then generalized hopes will continue the maintenance of hope which will allow a person to cope with stress. Rustoen, et al. also surmised that the high levels of hope could have been due to denial (a coping mechanism with a cancer diagnosis).

The intervention administered to the hope intervention group was created by Rustoen and Hanestad (1998), who developed a nurse-led intervention for hope. The intervention focused on eight two-hour sessions to strengthen the nature of hope: believing in self, emotional reactions, relationships, active involvement, spirituality and faith, and acknowledgement that there is a future. Two weeks following completion of the intervention, all of the subjects completed the NHS, the Ferrans and Powers Quality

of Life Index and the CARES. This was completed again at six months following the intervention.

Significant findings of the study included that those who were in the hope promotion group had much higher levels of hope than the control or cancer information group two weeks following the intervention. At six months Rustoen, et al. (1998) readministered the scale and all groups had the same levels of hope. The dynamic nature of hope may require a hope intervention as an ongoing process rather than a one-time event.

Summary

Both hope and quality of life are multidimensional concepts of importance to the cancer patient. Quality of life, as conceptualized by McMillan and Weitzner (1998) includes three domains of well-being: psychophysiological (anxiety, pain, worry, anger, sleep, sex life, breathlessness, constipation and the concept of hope); functional (ability to concentrate, social life of the patient and family, and the ability to maintain a sense of independence); and social/spiritual (support from family and friends, healthcare team, a relationship with God, and meaning in life). The relationship of quality of life and hope in each of these domains is born out in research studies which explored levels of hope in relation to pain, functional ability, social support and God. Hope was identified as an inner power and was active in all subjects. Nursing interventions to increase hope reflected increasing levels of hope and quality of life in the nurse intervention group in comparison to those in the control groups experiencing decreases in quality of life.

Chapter Three

Methods

The relationship between quality of life and hope in the hospice cancer patient was evaluated using a non-experimental, correlational design. This chapter discusses the setting, the sample, the instruments, the procedures, and the data analysis.

Setting

The setting for this study was Hernando-Pasco Hospice, located in two counties north of Tampa. The hospice has an average daily census of 650 patients. Thirty-five percent of the patients are admitted with a cancer diagnosis. Patients are cared for by this hospice in their home, nursing home, assisted living facility, foster home, and hospice house or hospice inpatient unit.

Sample

The sample size was determined using power analytic techniques. With alpha of .05 and power set at .80, a sample of 88 would have been needed to reveal a moderate effect size. It would have been desirable to increase to 100 to account for those who withdrew from the study. The sample was a convenience sample of hospice cancer patients.

The inclusion criteria were: stage IV cancer, home patient with a caregiver, alert, oriented, and aware of diagnosis and predicted prognosis. The subjects were also able to

read and understand English. Exclusion criteria included those who would experience respondent burden and those with uncontrolled symptoms, such as dyspnea and pain.

Instruments

This study used two instruments: The Hospice Quality of Life Index, and the Herth Hope Index. Verbal permission was granted for use of the Hospice Quality of Life Index in this study from McMillan. Herth granted written permission for the use of the Herth Hope Index (Appendix B).

The Hospice Quality of Life Index

The Hospice Quality of Life Index (HQLI) is a three-factor scale comprised of 28 items designed to capture the quality of life status of hospice patients with cancer (McMillan & Weitzner, 1998). Each item is rated on a 0 to 10 scale with items summed for a total score ranging from 0 to 280 (Appendix C). The subscales are psychophysiological, functional and social/spiritual well-being.

Validity. Validity for the HQLI was evidenced by factor analysis that yielded 3 subscales. In addition, correlation with the Eastern Cooperative Oncology Group Performance Status Rating resulted in the expected relationship ($r = .26$, $p < .05$). Finally, the response of healthy adults as compared to hospice cancer patients showed a significant difference.

Reliability. The Cronbach alpha for the total scale was $r = .88$, and the Cronbach alpha for each subscale was $r = .84$, supporting the reliability of the HQLI. The HQLI is reliable with strong internal consistency. The hospice patients were not subjected to test-retest reliability due to the advanced illness of hospice patients and because the changes

in condition which hospice patients undergo would make a test-retest impractical (McMillan & Weitzner, 1998).

Herth Hope Index

The Herth Hope Index (HHI) is a clinical-setting adaptation of the Herth Hope Scale (HHS) (Herth, 1992). The HHS consists of 30 items that are related to the six dimensions of hope, which were conceptualized by Dufault and Martocchio's Model of Hope (Dufault & Martocchio, 1985). Herth then combined the six dimensions into three subscales: cognitive-temporal; affective-behavioral; and, affiliative-contextual (Herth, 1992).

The HHI is shortened from the HHS to a 12-item instrument for clinical applicability (Appendix D). The items in the HHI are in a Likert-format scale from 1 to 4, with 1 being strongly disagree and 4 being strongly agree. The HHI is divided into three subscales (as is the HHS). The total scores of the HHI could range from 12 to 48, with a higher score equating to a higher level of hope (Herth, 1992).

Validity. The face and content validity was secured through a panel of experts (Herth, 1992). The construct validity of the HHI was evidenced by factor analysis that yielded a significant loading of the HHI scale on one of the three original subscales of the Herth Hope Scale (HHS). The three subscales were temporality and future, positive readiness and lastly, interconnectedness. Further construct validation of the HHI included correlations of the HHI with the HHS ($r = 0.92$), the Existential Well-Being Scale ($r = 0.84$) and the Nowotny Hope Scale ($r = 0.81$). Finally, the HHI was correlated with the Hopelessness Scale for divergent validity ($r = -0.73$).

Reliability. The HHI was tested with a convenience sample of 172 ill adults. The alpha coefficient was 0.97 with a test-retest reliability after two weeks of 0.91.

Demographic Data Form

The demographic data form (Appendix E) served as a guideline for the collection of information about each subject. The information included: years of education; age; race/ethnicity; religion and degree of participation; diagnosis; length of time since diagnosis; length of time since last chemotherapy or radiation treatment; and a social support item asking “overall, in the past month, how satisfied have you been with support from others?”

Data Collection

This study involved several procedural steps. The first step was approval from Hernando-Pasco Hospice to conduct the study, followed by Institutional Review Board (IRB) approval from the University of South Florida.

Following approval, eligible subjects were identified for inclusion through weekly team meeting participation by the researcher in which admitted patients were reviewed by the hospice team. Once identified, potential subjects were approached regarding study participation. If the subject agreed to participate, the study was explained, and the subject had the opportunity to ask questions. A signed consent (Appendix F) was obtained with a copy given to the subject. Following signed consent to participate, the Herth Hope Index, the Hospice Quality of Life Index and a demographic data form were administered.

Data Analysis

The data analysis involved two steps. The first step was an analysis of demographic data using descriptive statistics. The form is composed of interval data

except for nominal data items regarding race/ethnicity and religion. Step two involved answering the research questions:

1. What is the mean level of quality of life in hospice patients with cancer?
2. What is the mean level of hope in hospice patients with cancer?
3. Is there a significant positive relationship between quality of life and hope in hospice patients with cancer?

After examining frequencies and descriptive data for the first two research questions, the data were analyzed using a Pearson's correlation to answer research question 3.

Chapter Four

Results, Discussion and Conclusions

This chapter presents the findings of the study. Included in this chapter are the study results with a discussion of the results, conclusions, and recommendations for future research.

Results

Demographic Data

The sample consisted of 31 patients (20 males and 11 females), ages ranging from 43 to 90 with a mean age of 70.2 (SD = 12.3). Years of education ranged from 7 to 22 years with a mean of 12.5 years. The majority of patients ($n = 29$) were white. All of the patients claimed a religious affiliation, with 8 Catholics and 23 Protestants. The mean level of involvement with religion indicated occasional religious involvement. The social support item, which asked about the patient's overall satisfaction with the care they had received from family and friends in the past month, was scored at a mean between satisfied and very satisfied.

The types of cancer varied with lung cancer the most commonly reported. Other cancers reported commonly were breast, esophageal, non-Hodgkins' lymphoma and colorectal (Table 1). The length of time since chemotherapy or radiation ranged from 1 week to 60 months, with a mean of 6.37 months. Thirteen patients (41.9%) elected not to

be treated with chemotherapy or radiation. The range of pain responses was from 0 as no pain, to 10 as the worst pain. The mean pain intensity was 5.2.

Table 1

Types of Cancer in Sample

| <u>Cancer Diagnosis</u> | <u>n</u> | <u>Percentage</u> |
|-------------------------|----------|-------------------|
| Lung | 8 | 25.8% |
| Breast | 4 | 12.9% |
| Esophageal | 3 | 9.7% |
| Non-Hodgkins' Lymphoma | 3 | 9.7% |
| Colorectal | 3 | 9.7% |
| Prostate | 1 | 3.2% |
| Head and Neck | 1 | 3.2% |
| Pancreatic | 1 | 3.2% |
| Renal Cell | 1 | 3.2% |
| Bladder | 1 | 3.2% |
| Pharyngeal | 1 | 3.2% |
| Gastric | 1 | 3.2% |
| Brain | 1 | 3.2% |
| Liver | 1 | 3.2% |
| Ovarian | 1 | 3.2% |

Research Objective One

To answer research objective one, what is the mean level of quality of life in hospice patients with cancer, a mean score was calculated. The mean level of the HQLI scores was 207.3 (SD = 30.2), representing 74.9% of the highest possible score of 280. The range of scores reported was 154 to 271.

Research Objective Two

To answer the second research objective, what is the mean level of hope in hospice patients with cancer, a mean score was computed. The mean level was 42.8 on the HHI scores, representing 89.3% of the highest possible score of 48. The range of HHI scores reported by the subjects was 34 to 48.

Research Objective Three

To answer the third research objective, is there a significant positive relationship between quality of life and hope in hospice patients with cancer, the HQLI scores were correlated with the HHI scores using Pearson's correlation. The correlation was weak to moderate, but significant ($r = .356$, $p = .049$).

Hope Index and the Subscales of the Hospice Quality of Life Index

Further discovery of the relationship between hope and quality of life was achieved by a correlation of HHI scores with the scores of the three HQLI subscales (Table 2). A statistically significant relationship was found between psychophysiological well being and hope ($r = .37$, $p = .040$). There was not a statistically significant relationship between functional well being and hope ($r = .07$, $p = .730$). The strongest relationship, at a statistically significant level, was the correlation between social/spiritual well-being and the HHI scores ($r = .51$, $p = .003$).

Table 2

Correlations Between Quality of Life Subscales and Hope Index Scores

| | Functional | Social/ Spiritual | Psycho- Physiological | HQLI Total |
|------------|------------|----------------------|--------------------------|---------------|
| Hope Index | $r = .07$ | $r = .51$ | $r = .37$ | $r = .36$ |
| | $p = .730$ | $p = .003$ | $p = .040$ | $p = .049$ |

Hope Index Scores, Worst Pain and Pain Relief

Within the psychophysiological domain of the HQLI is a question about how completely pain was relieved, on a scale of 1 to 10. The mean level of pain relief was 9.2 (SD = 2.6) out of a complete pain relief total of 10. There was an additional item which asked how bad pain was at its worst. The mean level of worst pain was 5.2 (SD = 2.7). Each of these was correlated with the HHI scores (Table 3). The item regarding the level of pain relief correlated with the HHI score at a statistically significant, moderate level ($p = .37$, $p = .043$). The item regarding the worst pain experienced negatively correlated with the HHI at a low, statistically insignificant level. ($r = -.27$, $p = .140$).

Table 3

Correlations Between Hope Index, Worst Pain and Pain Relief

| | Worst Pain | Pain Relieved |
|------------|-------------------------|------------------------|
| Hope Score | $r = -.27$, $p = .140$ | $r = .37$, $p = .043$ |

Discussion

After IRB approval from the University of South Florida, data collection began in August, 2004 and continued through December. During a two-month time period (August, 2004 through October, 2004) four hurricanes affected the communities in which this study took place. Preparations and recovery from each storm may have created unique circumstances that affected accrual into the study. Additionally, screening by patient caregivers who did not want patients subjected to questions about pain, anger, sadness, loneliness or the meaningfulness of life created barriers to accrual. Some caregivers offered to answer the questions for the patient in order to participate. The investigator declined these offers. Two patients who had agreed to the study then became too debilitated to participate in the study, and two patients died between giving telephone consent and the investigator's arrival for the scheduled interview. Several potential patients did not meet the inclusion criteria of being able to speak and understand the English language.

The difficulties in accruing hospice patients, along with the natural phenomena of inclement weather, facilitated new goals for accrual. Though the initial goal for accrual was 88 patients, the Pearson's correlation is a robust method, and sufficient power was obtained with a sample of 31 to achieve a statistically significant correlation between the hope and quality of life scores.

Demographic Data

The sample consisted of a convenience sample of 31 hospice patients with cancer who were invited to take part in the study. There were less women (35%) in the sample than men (65%) which is inconsistent with the NHPCO statistics reporting 54 percent

men and 46 percent women. This may be accounted for by the exclusion of nursing home patients from the study.

The patients were alert and oriented, and aware of their diagnosis and terminal prognosis. The patients also spoke, read and wrote in English. After an explanation of the study and an opportunity for participants to ask questions, informed consent was obtained (Appendix F). Several patients requested that the investigator read the questions and mark their responses due to the patient's poor vision, hand tremors, or paresthesias secondary to brain metastasis. These patients were given a copy of the instruments to look at while the questions were read.

Limitations to this study are noted. First, this was a convenience sample of hospice patients stable enough in their disease process to participate and agreeable to answering questions. The sample was mostly Caucasian, Christian and elderly. This study does not include those patients whose caregivers screened the investigator's questions and would not allow the patient to be asked about sadness, loneliness, anger or meaningfulness of life. This suggests that those who participated may have always maintained high levels of hope in the face of difficulties and that they, and their caregivers were prepared to discuss difficult issues at the end of life due to a consistent level of hopefulness in the face of difficulties. This also suggests that those patients who were not prepared to discuss end of life issues and who were generally less hopeful were the patients who did not agree to participate in the study, biasing results. In addition, these patients were able to interact with the investigator in a meaningful way and had caregivers. Again, this study is missing data from those patients who could not interact or who did not have caregivers.

Research Objective One

The total quality of life score was determined through the HQLI, a self-report 28-item questionnaire. Subjects had a mean score of 207.3, which represents 74% of the highest score of 280. It is noted that these patients were able to interact with the investigator in a meaningful way and were pain and symptom free during the time of the interview. Further, caregivers blocked some patients from participating. It is also possible that the hospice was providing excellent end of life care. All of these circumstances could have influenced the high levels of quality of life in the patients interviewed.

Research Objective Two

The total hope score was determined through the HHI, a self-report 12-item questionnaire. The mean of the total scores represents that the subjects had a score of 89.3% of the highest score of 48, reflective of a high level of hope which is contrary to what may be expected when one is faced with a life-limiting condition. The high scores support the theory of Dufault and Martocchio's (1985) model of hope, which posits that hope is a constant trait which exists on two levels, one level being particularized hopes and another being generalized hopes. Particularized hopes are specific in regards to the specific time frames and details of the attainment of a future good. Generalized hope is not encumbered by the details of specific goals or timeframes, but is a trait which is an inner resource and is not outside of the person to be given or taken away by the biophysical model of medicine's ability to cure or not. Dufault and Martocchio's (1985) model relates that when one's specific or particularized hopes (i.e. cure) are not attained, then generalized hopes will continue which allows the person to cope with the stress of a life-limiting illness. However, others have considered the hope of the terminally ill to be

an indication of denial, which is considered a coping mechanism for people experiencing the losses associated with a terminal cancer diagnosis (Rustoen, et al., 1998). It must be noted here that the patients for this study were screened by the investigator for their awareness of their diagnosis and prognosis and all clearly stated cognizance of their life-limiting disease process.

Research Objective Three

The correlation between the scores of the HQLI and HHI was weak to moderate, but significant. This indicates that hope is a concept separate from quality of life, though related at a statistically significant level. The quality of life model constructed by McMillan & Weitzner (1998) included hope as a phenomenon within the psychophysiological domain, rather than as a separate item. However, Rustoen, et al. (1998) measured hope as a completely separate concept. In order to identify the domain within the HQLI subscale which is correlated at the strongest, most significant level with the HHI total scores, each of the three subscales scores within the HQLI (Table 2) were correlated with the HHI scores and further evaluated for significance.

Hope Index and the Subscales of the Hospice Quality of Life Index

When the subscale of HQLI social/spiritual scores was correlated with the HHI, there was a statistically meaningful correlation at a moderate level ($r = .510$, $p = .003$). The items within the social/spiritual subscale are: support from family and friends, physical contact with those one cares about, improved sense of well-being related to one's surroundings, physical care received, emotional and spiritual support from one's healthcare team, identifying that one's life has meaning and satisfaction with one's relationship with God. Though this study did not assess whether each patient had been

exposed to social/spiritual interventions, the high hope scores in this study could be explained by the focus of hospice care on the physical, spiritual, social and psychological well-being of the patient to which each study participant could have been exposed.

An example of how hope and the social/spiritual items are interrelated occurred during data collection. While a patient was answering the items on the Herth Hope Index that measured the level of deep inner strength and level of faith that gave comfort, the patient discovered that he did not perceive that he had an inner strength nor a faith that gave him comfort. This realization caused him to notify his hospice clergy person for counsel. The following day this patient was baptized into his faith. The need for a deeper spiritual experience, reconciliation with God, and the experience of inner peace, is a significant source of hope in those with a life-limiting disease (Ballard et al., 1992; Herth, 1990).

Hope Index Scores, Worst Pain and Pain Relief

Within the subscale of psychophysiological well being, the item of how well pain is relieved was correlated with hope at a statistically significant level, though the level of worst pain was not meaningfully related to levels of hope (Table 3), suggesting that the relief of pain has a greater influence on hope than the level of pain experienced. This is related to the findings of Lin, Lai and Ward (2003a) who found that levels of pain were not as significant as how the pain interfered with activities of daily living. The treatment of pain as well as the reassurance received from healthcare providers who acknowledge and treat pain may be more meaningful in regards to levels of hope than the pain itself. One of the key edicts of hospice is the unrelenting endeavor to keep the patient pain and symptom free within an interdisciplinary approach. This framework manages distress in

the physical domain, as well as psychological, social and spiritual domains. This intensive management of pain may provide another explanation for the high levels of hope in the hospice patients who were studied.

Conclusions

Interventions designed by nurses to promote hope reflect that nurses influence levels of hope (Herth, 2000; Rustoen, et al., 1998). It may be concluded from the results of this study that admission into hospice does not equal a loss of hope. Rather, instead of seeking hope in the form of treatments for cure, hope may be discovered through the quality of life items which include relationships with others and God, realization of the meaning of one's life and care which provides pain relief. Further, the quality of life scores were also high in the study participants, and it appears that the most hopeful patients also have the best quality of life.

Recommendations for Future Research

Although this study had some important findings, further research is needed. A study that compares patients who decline hospice admission with those who elect hospice admission could provide more information regarding the effect of hospice on quality of life and hope. In addition, a repeated measures study could be designed to follow hospice patients weekly to determine the continuum of levels of hope from hospice admission until death. Finally, an interventional study focusing on the spiritual and social needs of the patient as well as pain and symptom management could be implemented in a hospital setting. The intervention would include a standardized care plan designed especially to provide guidelines for nurses who are not trained in end of life care. The purpose of this study would be to find out if patients and families of those who die in a hospital benefit

by experiencing hope from domains outside of a one-dimensional biophysical model of medical care.

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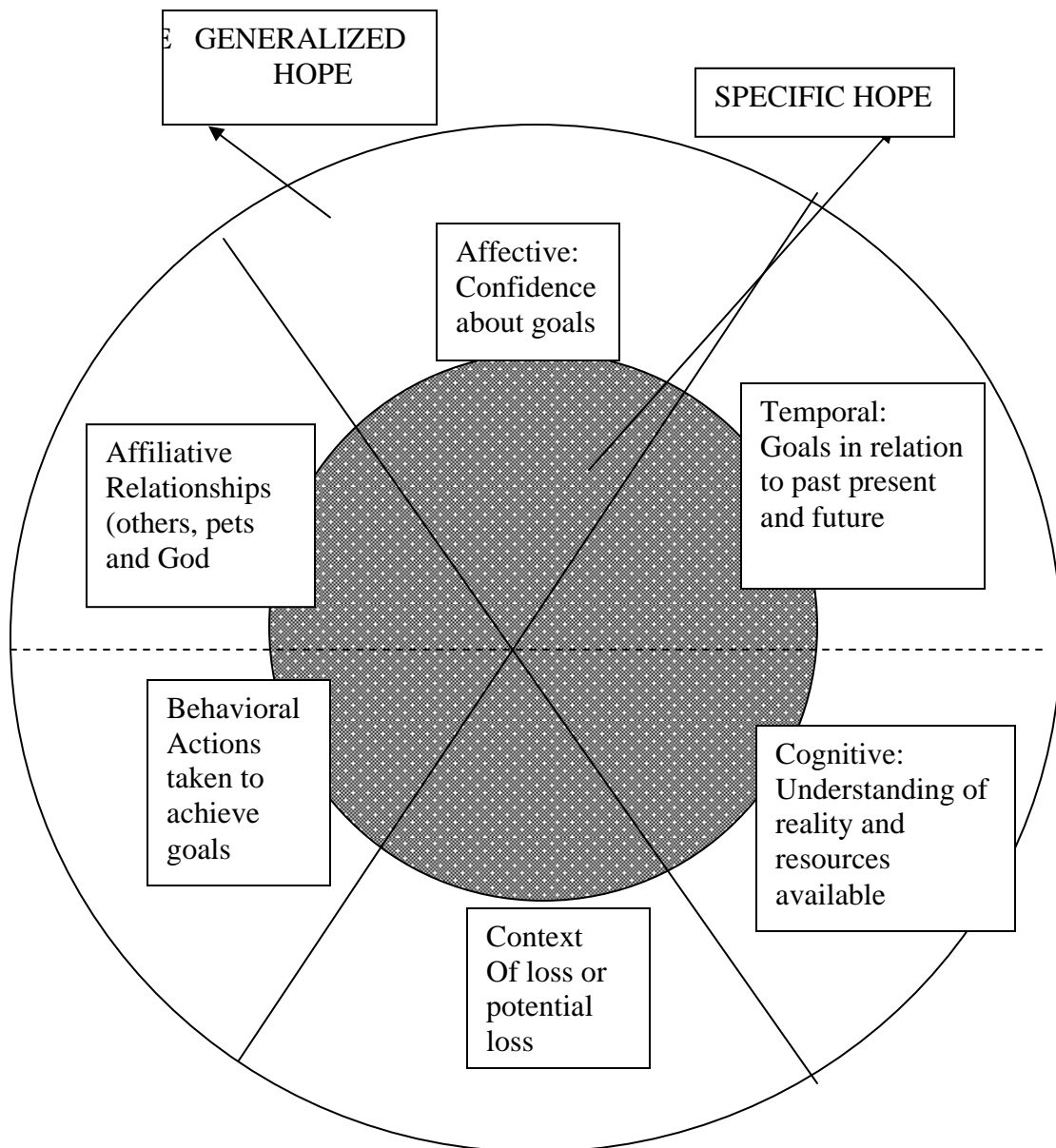
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Appendices

Appendix A: Dufault and Martocchio (1985) Hope Model



Appendix B: Permission for use of Herth Hope Index

From kaye.herth@mnsu.edu Sat Mar 13 12:06:22 2004

Cynthia,

I appreciate your interest in hope and in the Herth Hope Index. I have attached a copy of both the Herth Hope Scale and the Herth Hope Index along with scoring instructions. Both scales are currently being used in research studies by a number of investigators primarily with adults. I have enclosed several reference lists I have compiled on hope.

You have my permission to use either the Herth Hope Index or the Herth Hope Scale in your proposed research project. If you decide to use either of my tools in your research study, I would like to request that you send me an abstract of your completed research and any psychometrics pertaining to my scale. There are no charges connected with the tools.

I am excited about your proposed study exploring the correlations between hope and quality of life in hospice cancer patients and look forward to hearing more about your work. If I can be of any further assistance, please do not hesitate to contact me.

Dr. Kaye Herth
Kaye A. Herth, Ph.D., R.N., F.A.A.N.
Dean, College of Allied Health and Nursing
124 Myers Fieldhouse
Minnesota State University, Mankato
Phone: 507-389-6315
Fax: 507-389-6447
kaye.herth@mnsu.edu

-----Original Message-----

From: Cynthia Brown [mailto:cbrown@hsc.usf.edu]
Sent: Saturday, March 13, 2004 9:45 AM
To: Herth, Kaye A
Subject: Herth Hope Index

Dear Dr. Herth,

I am writing to ask for your permission to use the Herth Hope Index in my research project which is part of my graduate nursing program at USF. I am researching correlations between hope and quality of life in hospice cancer patients.

Thank-you
Cindy Brown
Graduate Student
Oncology Nurse Practitioner Program
University of South Florida
Tampa, FL

Appendix C: Hospice Quality of Life Index-Revised 1998

HOSPICE QUALITY OF LIFE INDEX-REVISED 1998

The questions listed below will ask about how you are feeling at the moment and how your illness has affected you. Please **circle the number on the line** under each of the questions, that best shows what is happening to you at the present time.

1) How tired do you feel?

extremely 0___1___2___3___4___5___6___7___8___9___10 not at all

2) How well do you sleep?

not at all 0___1___2___3___4___5___6___7___8___9___10 very well

3) How breathless do you feel?

extremely 0___1___2___3___4___5___6___7___8___9___10 not at all

4) How well do you eat?

poorly 0___1___2___3___4___5___6___7___8___9___10 very well

5) How constipated are you?

extremely 0___1___2___3___4___5___6___7___8___9___10 not at all

6) How nauseated/sick do you feel?

extremely 0___1___2___3___4___5___6___7___8___9___10 not at all

7) **For Men:** How masculine do you feel? **For Women:** How feminine do you feel?

not at all 0___1___2___3___4___5___6___7___8___9___10 extremely

Appendix C: (Continued)

8) Do you have enough physical contact with those you care about? (Touching, holding hands, hugging or other physical contact)

none 0___1___2___3___4___5___6___7___8___9___10 a great deal

9) How sad do you feel?

very sad 0___1___2___3___4___5___6___7___8___9___10 not at all

10) Do you believe that each day can still hold some good?

not at all 0___1___2___3___4___5___6___7___8___9___10 believe strongly

11) How worried do you feel about what is happening to you?

very worried 0___1___2___3___4___5___6___7___8___9___10 not at all

12) How worried do you feel about your family and friends?

very worried 0___1___2___3___4___5___6___7___8___9___10 not at all

13) How angry do you feel about what is happening to you?

very angry 0___1___2___3___4___5___6___7___8___9___10 not at all

14) How lonely do you feel?

very lonely 0___1___2___3___4___5___6___7___8___9___10 not at all

15) How satisfied do you feel with your ability to concentrate on things?

very
dissatisfied 0___1___2___3___4___5___6___7___8___9___10 very
satisfied

Appendix C (Continued)

16) How meaningful is your life?

not at all meaningful 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very meaningful

17) How much enjoyable activity do you have?

none 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 a great deal

18) How satisfied do you feel about the amount of usual daily activities you are able to do?

(job, housework, chores, child care etc.)

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

19) How satisfied are you with your level of independence?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

20) How satisfied are you with the support you receive from family and friends?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

21) How satisfied are you with your social life?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

22) How satisfied are you with the physical care that you are receiving?

very dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very satisfied

Appendix C: (Continued)

23) How satisfied are you with the emotional support you get from your health care team?

very
dissatisfied 0___1___2___3___4___5___6___7___8___9___10 satisfied
very

24) How satisfied are you with your relationship with God (however you define that relationship)?

very
dissatisfied 0___1___2___3___4___5___6___7___8___9___10 satisfied
very

25) How satisfied are you with the spiritual support you get from your health care team?

very
dissatisfied 0___1___2___3___4___5___6___7___8___9___10 satisfied
very

26) Do your surroundings help improve your sense of well-being?

not at all 0___1___2___3___4___5___6___7___8___9___10 very much

27) How much do you worry about your living expenses/finances?

a great deal 0___1___2___3___4___5___6___7___8___9___10 not at all

28) If you experience pain, how completely is it relieved?

no relief 0___1___2___3___4___5___6___7___8___9___10 complete relief

How bad is your pain when it is at its worst?

no pain 0___1___2___3___4___5___6___7___8___9___10 worst possible

Appendix D: Herth Hope Index

HERTH HOPE INDEX

Study No. _____

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|--|----------------------|----------|-------|-------------------|
| 1. I have a positive outlook toward life. | | | | |
| 2. I have short and/or long range goals. | | | | |
| 3. I feel all alone. | | | | |
| 4. I can see possibilities in the midst of difficulties. | | | | |
| 5. I have a faith that gives me comfort. | | | | |
| 6. I feel scared about my future. | | | | |
| 7. I can recall happy/joyful times. | | | | |
| 8. I have deep inner strength. | | | | |
| 9. I am able to give and receive caring/love. | | | | |
| 10. I have a sense of direction. | | | | |
| 11. I believe that each day has potential. | | | | |
| 12. I feel my life has value and worth. | | | | |

© 1989 Kaye Herth
1999 items 2 & 4 reworded

Appendix E: Demographic Data Collection Form

DEMOGRAPHIC DATA COLLECTION FORM

PLEASE DO NOT INCLUDE YOUR NAME

Years of education:

Age:

Race/ethnicity:

Religion:

Degree of participation in religion (circle number)

| | | | | |
|------------------|----------|--------------------------|--------------------|-------------------|
| Very Involved | Involved | Occasionally Involved | Seldom Involved | Never Involved |
| (1) | (2) | (3) | (4) | (5) |

Diagnosis:

Length of time since diagnosis:

Length of time since last chemotherapy or radiation treatment:

Overall, in the past month, how satisfied have you been with support from others?"
(circle number)

| | | | |
|----------------|-----------|--------------------|-----------------------|
| Very Satisfied | Satisfied | Not Very Satisfied | Extremely Unsatisfied |
| (1) | (2) | (3) | (4) |

Appendix F: Consent Form (with IRB stamp)

Informed Consent

Social and Behavioral Sciences
University of South Florida

| | |
|-------------------------------------|--------|
| IRB Approval FWA 00001669 | |
| IRB Number: | 102699 |
| From | 8/3/04 |
| Thru | 8/2/05 |

Information for People Who Take Part in Research Studies

The following information is being presented to help you decide whether or not you want to take part in a minimal risk research study. Please read this carefully. If you do not understand anything, ask the person in charge of the study.

Title of Study: Hope and Quality of Life in Hospice Patients with Cancer

Principal Investigator: Cynthia Brown, RN, Graduate Student, College of Nursing

Study Location(s): Hernando-Pasco Hospice

You are being asked to participate because you will be able to add to the understanding of whether hope and quality of life are related.

General Information about the Research Study

The purpose of this research study is to find out if hope and quality of life are related.

Plan of Study

You will complete three forms. One will ask about hope, one about quality of life and one will ask questions about you. None of these will have your name on them. It will take about forty-five minutes to complete the forms and will take place in one visit.

Payment for Participation

You will not be paid for participation in this study.

Benefits of Being a Part of this Research Study

There are no direct benefits to being part of this study. However, by taking part in this research study, you may increase our overall knowledge of whether hope and quality of life are related.

Risks of Being a Part of this Research Study

There are no known risks in being part of this research study.

Confidentiality of Your Records

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board, IRB staff and others, acting on behalf of USF may inspect the records from this research project.

The results of this study may be published. However, the data obtained from you will be combined with data from others in the publication. The published results will not include your name or any other information that would personally identify you in any way. Each piece of information will be coded without using any identifying information and will be kept with the researcher in a locked brief case.

IRB Form: ICadult-LR-SBv17

Appendix F: Consent Form (Continued)

Page 2 of 2



Volunteering to Be Part of this Research Study

Your decision to participate in this research study is completely voluntary. You are free to participate in this research study or to withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive, if you stop taking part in the study.

Questions and Contacts

- If you have any questions about this research study, contact Cynthia Brown at (352)424 1733.
- If you have questions about your rights as a person who is taking part in a research study, you may contact the Division of Research Compliance of the University of South Florida at (813) 974-5638.

Consent to Take Part in This Research Study

By signing this form I agree that:

- I have fully read or have had read and explained to me this informed consent form describing this research project.
- I have had the opportunity to question one of the persons in charge of this research and have received satisfactory answers.
- I understand that I am being asked to participate in research. I understand the risks and benefits, and I freely give my consent to participate in the research project outlined in this form, under the conditions indicated in it.
- I have been given a signed copy of this informed consent form, which is mine to keep.

Signature of Participant

Printed Name of Participant

Date

Investigator Statement

I have carefully explained to the subject the nature of the above research study. I hereby certify that to the best of my knowledge the subject signing this consent form understands the nature, demands, risks, and benefits involved in participating in this study.

Signature of Investigator

Printed Name of Investigator

Date