Relationship of life-change, spiritual perspective and perceived well-being to hope in adults with recurrent cancer

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The University of Arizona, 1990

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RELATIONSHIP OF LIFE-CHANGE, SPIRITUAL PERSPECTIVE AND PERCEIVED WELL-BEING TO HOPE IN ADULTS WITH RECURRENT CANCER

by

Sandra Elaine Kurtin

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STATEMENT BY AUTHOR

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APPROVAL BY THESIS DIRECTOR

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ABSTRACT

The purposes of this study were to describe the relationship of life-change, spiritual perspective and perceived well-being to hope in 24 adults with recurrent cancer, and to describe the personal meaning of cancer recurrence in the same population. Five instruments and two interview guides were used for data collection with adequate internal consistency estimated.

A significant relationship between hope and spiritual perspective was identified ($r=.39, p=.03$). No significant relationship was identified between hope and life-change or perceived well-being, although life-change was inversely related to perceived well-being ($r=.39, p=.01$). Subjects were moderately hopeful despite their knowledge of a potentially limited life-span. Treatment became a major focus in these subjects and was significantly correlated to the level of hope ($r=.45, p=.04$). Relationships with significant others were identified as changing for the better and positively impacting the subjects' perceptions of their own situations. The experience of cancer recurrence was described as unique requiring cognitive adaptation to assimilate the changes imposed by the diagnosis and treatment. Implications for nursing practice and further research were identified.
INTRODUCTION

The diagnosis of cancer is well documented as a stressful life event. Cancer challenges an individual's physical condition as well as demanding mobilization of the individual's social and emotional resources. Although a given cancer diagnosis can frequently be validated with the presence of a set of signs and symptoms, the social and emotional response to living with cancer is more complex. Cancer treatment produces additional stressors, including the possibility of a limited response to therapy and the recurrence of the cancer. Identifying the response to the recurrence of disease in cancer patients presents a unique challenge.

Given the current advances in clinical therapies, an individual with cancer may have several treatment options available, with varying degrees of tumor response. For those individuals with a favorable initial response to treatment, cancer recurrence requires acknowledgement of disease progression, reappraisal of resources, and the recognition of new demands. Progression of disease generally denotes a less favorable prognosis for survival,
declining physical status, and an uncertain course of disease. The reality of life and death becomes apparent. The ability to overcome the adversity and maximize the effectiveness of available resources may be affected by the individual's perceptions of the situation, its impact on normal routines, and the ability to look beyond the immediate situation.

Hope can be a powerful tool in coping with cancer (Nowotny, 1989; Stoner, 1985; Weisman, 1979). Hope allows an individual to maintain an orientation toward living while faced with the possibility of death (Casciato & Lowitz, 1988). Kubler-Ross (1969) identified hope as a maintaining force which allows the individual to endure suffering. The presence of hope increases the ability to cope with the stresses encountered in the uncertainty of the cancer experience (Mishel, Hostetter, King, & Graham, 1984). Hope is generally defined as an active, multidimensional, motivational phenomenon involving anticipation of attaining future goals (Miller & Powers, 1988; Nowotny, 1989; Stotland, 1969). Thus, a continued state of hopefulness, regardless of the object of hope, may increase the cancer patient's ability to persevere.
The concept of hope is identified in the literature as an important component of oncology nursing practice (Barsevick & McCarthy, 1988; Hickey, 1986; Miller, 1985; Stoner, 1988). "Nursing is accountable for managing the response to actual or potential health problems, and hope is one potential response that can fortify psychological and physiological defenses against illness" (McGee, 1984, p.43). The significance of hopefulness in nursing care of patients with cancer is widely recognized by practitioners, yet there is little empirical data to substantiate its role in oncology nursing (Dufault & Martocchio, 1985; Stoner, 1988). Fostering, enabling, inspiring, instilling, maintaining, supporting, and restoring hope are described in the literature as components of professional nursing practice (Dufault & Martocchio, 1985; Hickey, 1986; Hinds, 1984; Miller, 1985; Miller & Powers, 1988; Stoner & Keampfer, 1985). There is an obvious need to further describe the concept of hope, its significance to professional nursing practice, and the relationship of hope and patient responses to specific disease states.

**Purpose of The Study**

Recent studies of the psychosocial impact of cancer have concentrated on the response to the initial cancer
diagnosis, symptom management, and the terminal stages of disease. There is a dearth of information which focuses on the responses of individuals to cancer recurrence. Empirical studies of hope in cancer patients are lacking. Although there has been a renewed interest in the concept as it relates to cancer care, hope is still poorly understood (Stoner, 1988). The purposes of this study were (1) to describe the relationship of selected variables to the level of hope in a population of adults with recurrent cancer, and (2) to describe the personal meaning of cancer recurrence in the same population. The variables selected included life-change, spiritual perspective, and perceived well-being, all of which are proposed to be related to hope in the literature (Reed, 1987; Stoner & Keampfer, 1985; Young & Longman, 1883).

**Definition of Terms**

**Cancer recurrence.** The reappearance of clinically detectable cancer following treatment induced remission (Casciato & Lowitz, 1988).

**Hope.** A multidimensional and dynamic force which provides motivation and the ability to formulate goals which are perceived as important and attainable (Lynch, 1965; Stoner, 1987; Stotland, 1969).
Life-change. The perceived amount of change in normal daily routines since diagnosis of recurrent cancer (Graham & Longman, 1987).

Spiritual-perspective. The belief in and sense of relatedness to a transcendent dimension which extends spatial and temporal boundaries (Reed, 1987).

Well-being. The perceived level of satisfaction with current life experiences (Campbell, 1976).

Personal-Meaning. An individual's perception of the significance of an event or experience (Davies, 1978).

Statement of The Problem

Cancer recurrence imposes considerable physical and emotional demands on patients. Hope may provide patients with the fortitude to assimilate the experience of recurring cancer and optimize the use of available resources. The problem investigated in this study was the relationship of hope to selected variables and the meaning of disease in patients with recurrent cancer. The findings from this study may provide useful information for formulating effective nursing interventions.
Research Questions

1. What is the level of hope in a population of adults with recurrent cancer?

2. What is the relationship between life-change and level of hope in a population of adults with recurrent cancer?

3. What is the relationship between spiritual perspective and level of hope in a population of adults with recurrent cancer?

4. What is the relationship between perceived well-being and level of hope in this same population?

5. How do the variables of life change, spiritual perspective, and perceived well-being together correlate with the level of hope in the same population.

6. What is the personal meaning of cancer recurrence to the individual experiencing it?

Significance of the Problem

The diagnosis of cancer creates a sense of vulnerability throughout the illness experience. Cancer therapies have provided options which may prolong the cancer patients' life (Scott, Goode & Arlin, 1983). However, the
reality of the possible recurrence of disease is inherent in
the cancer experience (Barsevick & McCarthy, 1988; Casciato & Lowitz, 1988; Scott et al., 1983). The response to cancer recurrence has been compared to that of the response to the initial diagnosis (Northouse, 1981; Scott, et al., 1983). There are, however, few studies which describe the experience of cancer recurrence specifically. Some authors suggest the impact of cancer recurrence is far more complex than that of the initial diagnosis (Blumberg, Flaherty, & Lewis, 1982). The individual experiencing recurrence must fluctuate between the life and death trajectory of cancer. The reality of the failure to eradicate the cancer creates an increased sense of vulnerability. Physical, emotional and social resources are key to maintaining a sense of control and maximizing the quality of life.

Hope is a universal phenomenon in the cancer experience, occurring in various degrees based on the individual’s perception of the impact of disease recurrence on normal routines, social, spiritual and emotional resources, and the ability to formulate goals (McGee, 1984; Stoner & Keampfer, 1985). Hope as a motivational force which reduces the impact of stressors and increases the individual’s sense of purpose in life is described in the
literature (Hickey, 1986; Kubler-Ross, 1969; Mishel, et al., 1984). Among the variables found to influence hope are life-change, spiritual perspective, and perceived well-being (Hickey, 1986; Miller & Powers, 1988; Miller, 1985; Owen, 1989). Describing the relationship of each of these variables to the level of hope in patients experiencing recurrent cancer can serve to more clearly define the concept of hope, the response of individuals to cancer recurrence, and to identify implications for oncology nursing practice.

**Summary**

Although recent authors have shown a renewed interest in the concept of hope very little empirical information exists to provide conceptual clarity and formulation of nursing interventions which promote hopefulness in cancer patients. Several authors acknowledge the significance of promoting hopefulness in patients with cancer (Dufault, et al., 1985; Hickey, 1986; Hinds, 1984; Miller, 1985; Stoner & Keampfer, 1985). There is a dearth of information describing the experience of cancer recurrence, yet the fear of recurrence is almost universal in patients with cancer (Blumberg et al., 1982; Dirksen, 1987; O'Neill, 1981). An
investigation of hope and selected variables associated with hopefulness in a population of adults with recurrent cancer was proposed. The empirical findings obtained can serve to further define the concept of hope, describe the experience of cancer recurrence, identify the relationship between hope, life-change, spiritual perspective, and perceived well-being, and provide direction for nursing interventions which facilitate hopefulness in patients with recurrent cancer.
CHAPTER TWO

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Included in this chapter is the conceptual framework for this study and a selected literature review based on the constructs, concepts, and operational indicators within the conceptual framework. The conceptual framework, as depicted in Figure 1, represents the correlates of hope in relation to cancer recurrence within the context of the Neuman Health Care Systems Model, namely, stress and adaptive responses (Neuman, 1980). The framework was constructed from selected variables which are proposed to be associated with hopefulness in the literature. Operational indicators are described for each concept, and were selected based on their proven psychometric properties in similar populations.

Construct Level

Stress and Adaptive Responses. The central theme of the Neuman Health-Care Systems Model is the response of an individual to the impact of stressors. This represents the dynamic relationship between person and environment. The individual is considered unique within a set of common traits and responses. Physiological, psychological,
Figure 1. Conceptual Framework: Correlates of Hope in Adults With Recurrent Cancer
sociocultural, and developmental variables represent the
dynamic nature of person interacting with environment, and
constitute the characteristics of an individual's flexible
line of defense, normal line of defense, and line of
resistance, which collectively determine the response to the
impact of stressors. "By a process of interaction and
adjustment the individual maintains varying degrees of
harmony and balance between his internal and external
environment" (Neuman, 1980, p. 122).

Both stressors and adaptive responses are comprised of
intraperonal, interpersonal, and extrapersonal factors.
The line of resistance and normal line of defense constitute
the individual's internal set of resistance factors and
normal range of responses evolved over time. Interacting
with these, the flexible line of defense provides the
predominant repertoire of adaptive responses at a given
point in time.

The discussion of stress and adaptive responses
acknowledges the multidimensional yet individual nature of
individuals confronted with stressful life events. One must
cconsider the total person and his or her environment.
Illnesses, such as cancer, are known to produce multiple
stressors requiring the mobilization of physical, emotional,
social, and cultural resources. Nursing is in a unique position to provide support of an individual encountering stressors based on assessment of the total person and his environment and the nature of the stressors, facilitating maximal mobilization of adaptive responses.

**Cancer stress and adaptation.** Cancer is an unyielding disease which impacts every dimension of human life. The diagnosis of cancer implies vulnerability and stress becomes an integral component of daily life. Cancer remains the second leading cause of death in the United States (American Cancer Society, 1988), is among the most feared diseases, and is generally associated with a painful and certain death (Priestman, 1986). "Because it produces drastic changes in a victim's life, cancer is a catastrophic experience" (McCorkle & Quint-Benoliel, 1983, p. 431).

The uncertainty associated with cancer treatment creates additional stressors (Mishel et al. 1984). The continual development of "promising" treatments creates considerable emotional stress as the individual is faced with the task of reappraisal based on the new information (Stoll, 1986). Once involved in the cycle of considering new treatments, it becomes difficult for the individual to refrain from the cycle of focusing on potential longevity or
dealing with the reality of death. In addition to cyclic reappraisal processes, the current trends in diverse and aggressive cancer therapies have strained the trust basic to the patient/physician relationship (Stoll, 1986). This, in turn, impacts the interaction with nurses and other health care professionals. The variable course of malignancies and the uncertain nature of response to therapy contributes to the strain on the relationship with health professionals and consequently produces stressors which impact the individual seeking treatment.

Recent literature has focused on the chronic nature of the cancer experience. Over five million Americans are living with a diagnosis of cancer (American Cancer Society, 1988). Three million have lived five or more years since initial diagnosis (American Cancer Society, 1988). Rapidly developing and increasingly sophisticated detection and treatment options have created the potential for multiple remissions in patients who normally would have limited treatment options and a poor prognosis for survival. The duration of symptom-free survival may vary from one to 10 years (Gray, Adler, Fleming, & Brescia, 1988).

Unlike other chronic illnesses with predictable prognosis based on proven methods of treatment, the
uncertain nature of cancer and its treatment creates a continued state of vulnerability (Blumberg, Flaherty, & Lewis, 1982). The treatment of cancer imposes stressors which are often perceived as worse than the disease itself. The potential for cancer recurrence is always present and each evaluation renews the sense of vulnerability. The fear of recurrent cancer is almost universal (Cherkyn, 1984; Northouse, 1981; O’Neill, 1975).

Silberfarb (1982) suggested the concept of adaptation best addresses the response of patients to the chronic nature of cancer, as opposed to coping which denotes a more acute state. Integral to understanding the adaptation to cancer recurrence is consideration of the impact of stressors on the adaptive capacity of individuals experiencing it. The uncertainty inherent in living with cancer mandates mobilization of adaptive responses which allow the cancer patient to assimilate the variability and maintain a sense of control. The hope for eradication of the cancer and renewed longevity enables individuals to endure the suffering associated with cancer and its treatment (Barsevick & McCarthy, 1988; Blumberg et al., 1982, Stoll, 1986). Hope is a multidimensional and dynamic
force which motivates the cancer patient to persevere and endure the variability of the cancer experience.

The significance of recurrent disease in patients with cancer is well supported in the literature (Barsevick & McCarthy, 1988; Blumberg et al., 1982; Dirksen, 1987; O'Neill, 1981; Tamlyn, 1987; Stoll, 1986). Empirical studies, however, are lacking. Sensitivity to the complex nature of stressors and adaptive responses in patients experiencing cancer recurrence is essential to facilitate successful adaptation and provide effective nursing interventions.

Weisman and Worden (1985) investigated the emotional impact of cancer recurrence. The emotional and psychosocial status of 102 patients with recurrent cancer, including breast, colon, lung, gynecological, Hodgkin's disease, and malignant melanoma, was assessed. A cross-sectional analysis contrasted initial diagnosis with recurrent disease. Several key questions were posed to facilitate comparison of the two groups. These were: (1) How does the emotional distress experienced at recurrence compare with the distress experienced at first diagnosis?; (2) What factors seem to evoke the most distress and feelings of vulnerability?; (3) Are the predictive screening methods for
newly diagnosed patients applicable to patients who have recurrence?; and (4) What conclusions can be drawn about the role and relevance of counseling, support, and psychosocial intervention? The Profile of Mood States, the Index of Vulnerability, and the Inventory of Current Concerns were used to provide data addressing these questions. No psychometric properties of the instruments were provided.

The findings indicated that 30 percent of the subjects with the same cancer diagnosis experiencing disease recurrence found the average level of distress to be equal to or less than the experience at initial diagnosis. Seventy-six percent of the sample were female, with an average age of 58 years. However, the group reporting lower levels of distress had fewer symptoms and localized disease at the time of diagnosis of recurrence. In addition, no mention is made of the perceptions of the remaining 70 percent of the sample.

Factors identified as producing the most distress and perceptions of vulnerability included a high degree of surprise with the diagnosis of recurrence, and physical symptoms which altered normal daily routines. Sixty-six percent of the patients expressed complete surprise with the diagnosis of recurrence. A high degree of surprise
correlated directly with a greater emotional impact at the
time of diagnosis. The presence of physical symptoms which
impaired the ability to maintain normal routines explained
40 percent of the variance in mood disturbance and
correlated with a pessimistic view about recovery.
"Nevertheless, only the rare patient conceded feeling
despondent and hopeless, even when the clinical
circumstances were dire" (Weisman & Worden, 1985, p.10).

Evaluation of the relationship between length of
remission and emotional impact of recurrence identified no
correlation with the belief in potential cure and degree of
emotional impact, except in those individuals with a
remission of less than one year who did not perceive a
potential cure at any time. Individuals with remissions of
one year or more varied in the degree of emotional impact.
In addition, the physical symptoms and life-change
experienced, not the type of cancer, explained the degree of
emotional distress. In general, it was found that those
patients with recurrent disease were primarily concerned
with getting on with treatment, addressing health concerns,
and with existential issues.

Cherkyn (1984) conducted a descriptive correlational
study with 22 subjects to describe the meaning of cancer
recurrence to the patient, the spouse, the effect on the marital dyad, and the level of family functioning. Subjects were interviewed using an interview guide developed from the literature and reviewed by two experts for content validity. The Dyadic Adjustment Scale was used to measure family functioning with reported reliability and validity.

Cherkyn (1984) identified psychosocial stressors resulting from the impact of cancer recurrence on both the patient and the spouse by content analysis of the interviews. Eight major themes emerged: (1) difficulty with closure related to an expectation of cure or remission and repeated assault by the cancer; (2) pervasive feelings of uncertainty; (3) grief about present and potential losses; (4) feelings of injustice, anger, and fear; (5) existential concerns; (6) concern related to coping with the recurrence; (7) impact on family functioning; and (8) the absence of shared meaning of the recurrence in the marital dyad. The patients and spouses scores on the Dyadic Adjustment Scale were compared with each other and with a norming sample. No statistically significant differences were identified, and scores on the Dyadic Adjustment Scale did not indicate marital dysfunction. Findings indicated that cancer
recurrence affects the entire family, requiring adjustments and adaptive responses from all members.

The relationship between significant others and the fear of recurrence in 30 mastectomy patients in remission was studied by Northouse (1981). Northouse developed an interview guide adapted from work by several authors in the area of significant others. The instrument consisted of four questions to identify individuals with whom subjects were able to discuss disease related issues, and a fifth question which elicited information about how the individual perceived others understanding of their feelings about their disease experience. Content validity for the instrument was obtained by a panel of experts in psychosocial and oncology research. The Fear of Recurrence Questionnaire, also developed by Northouse, consisted of 22 items on a 5-point Likert scale. Content validity was obtained by the same panel of experts, and internal consistency was estimated based on rationale equivalence reliability testing.

Findings indicated a significant inverse relationship existed between the number of significant others and the subjects' fear of disease recurrence. Subjects most commonly discussed disease related concerns with spouses, relatives, and friends. Health professionals were not
identified as people with whom concerns were discussed. The potential recurrence of cancer was the most frequently identified concern of the subjects in this study.

Concept Level

Hope. The concept of hope is acknowledged as a significant factor in a positive response to living with cancer (Lee, 1986; Stoner, 1988; Weisman, 1979). The definition, clinical measurement, and clinical significance have been the focus of recent literature. Historically, hope has been documented as a significant source of motivation allowing individuals to endure extremely adverse situations (Frankl, 1984). Erikson (1975) described hope as "the earliest and most indispensable virtue inherent in the state of being alive" (p. 115). Stotland (1969) described hopefulness as essential to personal action. Miller (1985) described hope as the "salient quality of a 'survivor' attitude" (p. 23). The absence of hope has been associated with an early demise (Frankl, 1984). Despite the recognition of hope as a significant adaptive response to the stressors inherent in the cancer experience, empirical studies of hope in cancer patients are lacking.
Several recent studies have focused on defining the concept of hope. McGee (1984) described hope as one of many affective responses to stressful stimuli. Hope consists of cognitive, social, psychological, and physiological factors, each with internal and external dimensions, which determines one's perceived probability of obtaining a desired goal. Hope is described by McGee (1984) as a subjective response based on perceptions of current life situations. McGee (1984) further described hope as consisting of both state and trait characteristics. Personality attributes of hopefulness and pessimism are proposed to be characteristics of one's life perspective developed over time. State variables denote characteristics of the individual's perceptions of goal attainment, resource availability, and goal significance at a given point in time. Thus, hope is multidimensional and time specific, yet dependent on attributes which are developed over time.

Using grounded theory methodology, Hinds (1984) induced a definition of hope based on interviews with a group of adolescents. Hinds (1984) proposed a construct definition of hope consisting of four categories along a continuum. The continuum denoted degree and correlates with the hierarchical level of the four categories. Forced effort,
personal possibilities, expectation of a better tomorrow, and anticipation of a personal future were the categories identified based on content analysis of the interviews. Hinds (1984) supported the definition of hope as a dynamic force which occurs in increments based on the perceptions of an individual at a given point in time.

Dufault and Martocchio (1985) collected clinical data on 35 elderly cancer patients using participant observation over a two year period. A description of hope was proposed based on the empirical data. Hope was described as having two spheres with six common dimensions (Dufault & Martocchio, 1985). The two spheres included generalized hope and particularized hope which are interrelated but differ in terms of degree of abstraction. Generalized hope supplies the motivation to maintain daily routines and responsibilities, as well as allowing adaptation to change based on life perspective. Particularized hope denotes a specific hope object which may be either concrete or abstract.

The six dimensions of hope described by Dufault and Martocchio (1985) included affective, cognitive, behavioral, affiliative, temporal, and contextual dimensions. In response to stimuli, an individual may use different
dimensions of hope to maintain or attempt to attain a level of hope which facilitates adaptation. Nursing interventions are based on assessment of each dimension, with attention to the unique characteristics of each individual. Dufault and Martocchio (1985) identified facilitation and support of hope in cancer patients throughout the illness experience as the role of the nurse. They suggested methods for assessment of each dimension, and provided examples of interventions which serve to therapeutically influence hope in late stage cancer patients.

The clinical measurement of hope, including development of instruments, has been the focus of other recent studies. Stoner and Keampfer (1985) investigated the relationship of level of hope to recalled life expectancy and phase of illness in 55 cancer patients. A convenience, non-probability sample, represented patients in varying stages of illness with varying cancer diagnoses. Sample characteristics included 22 females and 33 males ranging in age from 18 to 84 years, with the time since diagnosis ranging from one to five years.

The Stoner Hope Scale (1982) and an interview guide served as data collection tools. The hope scale was
developed by Stoner based on a review of the literature, and adapted from work by Erickson, Post, and Paige (1975), and Stotland (1969). The scale is based on the conceptualization of hope as the importance and probability of attaining future-oriented goals, encompassing intrapersonal, interpersonal, and global dimensions (Stoner & Keampfer, 1985).

The findings indicated a statistically significant difference (p = <.05) in the level of hope between those individuals who had no recall of receiving life expectancy information and those who received life expectancy information. The type of prognostic information, favorable or unfavorable, was not reported with the findings. Higher hope scores existed among those who had no recall of receiving information regarding their prognosis (Stoner & Keampfer, 1985). Phase of illness seemed to have no relation to the level of hope in this population. Of interest however, are the differences identified by the researchers. The highest levels of hope were among individuals in remission who had no recollection of prognostic information. Subjects who recalled receiving life expectancy information and were currently receiving treatment had the lowest scores on the hope scale. These
findings are in contrast to findings cited by Mishel et al. (1984) which suggested information about the extent of disease decreases uncertainty and generates optimism and motivation.

Miller and Powers (1988) developed an instrument to measure hope using 522 healthy adults to test its psychometric properties. Instrument development was based on a review of the literature and qualitative data obtained through interviews with adults who survived a critical illness in an attempt to establish norms prior to using the instrument on ill populations. Content validity was established by a panel of experts in the area of hope. The instrument, the Miller Hope Scale (MHS), consists of 40 items using a five-point Likert format.

"Hope was viewed in this study as a state of being characterized by an anticipation for a continued good state, an improved state, or a release from a perceived entrapment" (Miller & Powers, 1988, p. 6). Ten critical elements of hope were identified: (a) mutuality-affiliation; (b) sense of the possible; (c) avoidance of absolutizing; (d) anticipation; (e) achieving goals; (f) psychological well-being and coping; (g) purpose and meaning in life; (h) freedom; (i) reality surveillance-optimism; and
mental and physical activism. The critical elements were derived from a review of the literature and served as a framework for formulating items on the MHS.

The psychometric properties of this scale were tested using correlations with established scales. Psychological well-being, r = .71, and purpose and meaning in life, r = .82, proposed by Miller and Powers (1988) to be constructs integral to hope, were measured to estimate construct validity of the MHS. The negative correlation of hopelessness, r = -.54, to the MHS established discriminant validation, further supporting the construct validity of this tool. Based on the findings of this study, Miller and Powers (1988), proposed further studies using the MHS to substantiate its sensitivity to measuring the concept of hope in samples representative of age, gender, culture, and specific disease states.

Nowotny (1989), developed an instrument to measure hope based on qualitative studies, nurse experts, and a review of the literature in psychology, psychiatry, theology, and nursing. Six critical attributes of hope were described: (1) future orientation; (2) active involvement; (3) internal and related to trust; (4) based on realistic goals; (5) involved interaction with others; and (6) spiritual beliefs
The framework of stress, appraisal and coping based on the work of Lazarus was used to identify the critical attributes and generate items for the Nowotny Hope Scale (NHS). Hope was defined as a multidimensional attribute comprised of six critical attributes and dynamic in nature (Nowotny, 1989).

The NHS and the Hopelessness Scale previously described were used to investigate the dimensions of hope after a stressful event in a population of cancer patients (n=150), and a sample of well adults (n=156). Cronbach’s coefficient alpha for the NHS was 0.90. A negative correlation \( r = -0.47, p= 0.001 \) with hopelessness and the NHS further established the validity of this tool.

The sample was comprised primarily of females between the ages of 20 and 50 years. No mention of specific cancer sites, severity of the cancer, or the time since diagnosis was made. Of those with cancer, 53 percent \( (n=79) \) were currently receiving treatment. The most frequently identified stressful events by both groups were health and job-related situations. Seventy-five percent of the cancer patients were moderately hopeful, while 79 percent of the healthy group were moderately hopeful. Nowotny (1989) proposed the NHS be used as an assessment tool to identify
the level of hope to intervene, thus facilitating hopefulness.

Herth (1989) investigated the relationship between level of hope and level of coping response, as well as selected environmental, interpersonal, and illness-related variables. Herth (1989) also used the work of Lazarus as a framework for coping, and the work of Stotland (1969) as the framework for hope. The Herth Hope Scale and the Jaloweiec Coping scale were used in a population of 120 adults with cancer who were currently receiving treatment in various settings. Reliability and validity were estimated for both instruments.

Sample characteristics of sex, age, and education were evenly distributed. The most common diagnoses were lung and breast cancer, with means of 27, 20, and 18 months since time of diagnosis for subjects receiving treatment as inpatients, outpatients, and at home respectively. A statistically significant positive relationship between level of hope and level of coping response ($r = .80, p < .05$) was identified. The disruption of family role responsibilities and religious convictions also showed a significant ($p < .05$) relationship to the level of hope and level of coping response. The setting in which treatment
was received was also significantly (p< .05) related to the level of hope and level of coping response with the subjects receiving treatment as inpatients or outpatients showing significantly higher levels than those subjects receiving treatment at home.

Owen (1989) took a different approach to defining the concept of hope. Grounded theory was used to elicit generalized knowledge about the concept of hope from interviews with six oncology clinical nurse specialists asked to describe hopeful cancer patients. Content analysis of the interviews resulted in six subthemes: (1) goal setting; (2) positive personal attributes; (3) future redefinition; (4) meaning in life; (5) peace; and (6) energy. The subtheme of energy was identified by each of the six subjects as related to the level of hopefulness and its fluctuation along a continuum at a given point in time based on the personal situation and perceptions of the patient. Owen (1989) also supports the conceptualization of hope as a dynamic force which responds to fluctuations in life events.

Similarities among each of the studies cited are apparent. The conceptualization of hope as a multidimensional dynamic life force, occurring along a
continuum, fluctuating from moment to moment based on the individual's perception of the impact of stressors on normal routines and goal attainment, is supported in the review of the literature. Spiritual perspective and perceived well-being are consistently identified to be significantly related to hopefulness. Other similarities include a future orientation, activism and motivation, and interaction with others.

Several instruments have been described which were developed to provide valid measures of the concept of hope. The literature base for each is very similar. The clinical applicability of each instrument is dependent on further clinical investigation. Of particular interest to this study is the scale developed by Stoner (1982) which was used to measure the level of hope in cancer patients at varying stages of illness.

**Hope and Cancer Recurrence.** The level of hope during cancer recurrence has not been studied specifically. Stoner and Keampfer, (1985) investigated the relationship among phase of illness, level of hope, and recurred life expectancy. No significant relationship was identified between phase of illness and level of hope. The
conceptualization of cancer recurrence as a stressful life event is supported in the review of the literature. Stressful life events and hopefulness have been studied by recent authors (McGee, 1984; Miller & Powers, 1988; Nowotny, 1989).

Scott, Goode, and Arlin (1983) analyzed the psychodynamics of multiple remissions based on a three year case study of a patient with leukemia. Observation of clinical findings, interaction with family members and health professionals as well as personal interviews with the patient, family and staff, provided data describing some of the processes which occurred over the three years. The subject experienced five remissions during the study.

The researchers identified four major behavioral indicators: (1) volatility of emotion; (2) progressive reduction in stamina; (3) resurfacing of unresolved issues; and (4) attempts to remain in control. The progressive reduction in stamina defined by the authors as a total energy encompassing hope and physical endurance, became increasingly apparent with each remission experienced by the patient in this study. Diminished physical endurance interfered with the subjects' activities of daily living, the focus of hope changed to more existential issues (Scott
at al., 1983). The progressive reduction in stamina, and thus level of hope in this study, is described as a unidirectional and irreversible decline.

**Correlates of Hope.** Life-change, spiritual perspective, and perceived well-being are cited in the literature as significant correlates of hope. These three variables, as previously defined, serve to more precisely define the concept of hope and the process of cancer recurrence. A brief review of the literature on each concept as it relates to hope and cancer recurrence is presented.

**Life-change.** Cancer recurrence imposes numerous stressors on the individual experiencing it. Stressors mandate adaptive responses (McCorkle & Quint-Benoliel, 1983; Mishel et al., 1984; Neuman, 1980). Adaptation implies modification of normal daily routines. Interruption of daily activities creates life-change (Young & Longman, 1983). The impact of the alterations in normal daily activities is affected by the perceptions of the individual and the adaptive responses available (Graham & Longman, 1987; Longman & Graham, 1986; Mishel et al., 1984; Ware, 1985).

Of particular interest to this study is the work on life-change in persons living with melanoma. Life-change as
defined by Young and Longman (1983) was the perceived degree of change in normal daily activities since the time of diagnosis. Emphasis on the individual's perceptions as opposed to those of the observer is stressed. Thus, life-change as a subjective experience, may vary in degree based on the perceived impact of stressors and the availability of adaptive responses.

Young and Longman (1983), Longman and Graham (1986) and Graham and Longman (1987) described the investigation of variables related to perceived quality of life in persons diagnosed with melanoma. Life-change was one variable selected based on extensive review of the literature.

Sixty persons diagnosed with melanoma comprised the sample. Sample characteristics included 32 males and 28 females with ages ranging from 20 to 83 years. The time since diagnosis varied from one month to more than five years, with the majority (48) reporting less than two years since diagnosis. The severity of disease was described as either localized (n=29) or metastatic (n= 22), with 11 subjects not categorized due to insufficient data. Prognosis, defined in relation to the probability of recurrence, was good (low probability of recurrence) for
24 of the subjects, and poor (high probability of recurrence) for 25 of the subjects.

The degree of life-change was measured using an 18 item scale developed by Young and Longman (1983). The items included questions pertaining to relationships with significant others, self-achievement, physical performance, and social involvement (Graham & Longman, 1987). A Likert-type format generated quantitative results, indicating no significant relationships between life-change and quality of life. Reliability and validity of the tool were established. Administration of the Likert-type scale was conducted using an interview guide to elicit qualitative data for each of the 18 items. Content analysis of the interviews (n=60) generated six categories: Living with Cancer, Thoughts About Treatment for Melanoma, Changes in Making Life Meaningful, Alterations in Life-Style, Relationships with Others and Social Support Adaptation (Longman & Graham, 1986).

Findings support the concept of hope as an important component of living with cancer. Goal-directed behavior is identified as the most common response among subjects receiving treatment (Longman & Young, 1986). It is suggested that the progression of disease results in a
reorganization of priorities, and reliance on adaptive responses such as maintaining a positive attitude about daily life, changing the focus of future outlook, and drawing upon the strength provided by spiritual perspective and significant others to facilitate adaptation to living with cancer and its treatment (Longman & Graham, 1986; Graham & Longman, 1987).

**Spiritual perspective.** The significance of spirituality as an effective adaptive response to the impact of stressors inherent in the cancer experience is well supported in the literature. Spirituality was described by Moberg (1979) as the "totality of man's inner resources, the ultimate concerns around which all others values are focused, the central philosophy of life that guides conduct, and the meaning-giving center of human life which influences all individual and social behavior" (p. 2). One's spirituality is related to a perception of a greater being which is beyond spatial and temporal boundaries, and is not dependent upon traditional religious affiliations (Reed, 1987).

The relationship of spiritual perspectives to level of hope in cancer patients is supported in the review of the
literature. Definitions of hope consistently address a spiritual dimension (Dufault & Martocchio; McGee, 1984; Miller et al., 1988; Nowotny, 1989; Stoner & Keampfer, 1985). Spirituality is positively correlated to level of hope (Miller et al., 1988; Nowotny, 1989; Stoner, 1987). Activities commonly cited as indicators of spiritual perspectives include reading the Bible or other religious literature, praying, a sense of closeness to a higher being, meditation, participation in religious rituals such as communion, and interaction with others (Moberg, 1982; Reed, 1987; Sodestrom & Martinson, 1987).

Reed (1987) investigated spiritual perspectives in a population of 300 adults. Three groups of 100 each were matched on age, gender, education, and religious background. Non-hospitalized healthy adults, hospitalized adults with non-life-threatening illnesses, and adults hospitalized with the occurrence or recurrence of incurable cancer who were aware of their prognosis comprised the three groups (Reed, 1987). The results supported the hypothesis that terminally ill hospitalized adults indicated greater spiritual perspective than either of the two other groups. A positive relationship between spirituality and well-being was also identified in the terminally ill hospitalized group.
Sodestrom and Martinson (1987) paired a convenience sample of 25 cancer patients and 25 oncology nurses to investigate the degree of agreement on spiritual coping strategies used by patients. Eighty-eight percent of the patients identified a belief in and relationship with God as providing purpose and meaning in life. The most frequently identified spiritual strategies were prayer and having others pray for you. Sixty-six percent of the patients reported an increased awareness and practice of spiritual beliefs since the diagnosis of cancer (Sodestrom & Martinson, 1987).

The responses of the nurses indicated awareness of the importance of spiritual perspectives as significant coping strategies in patients with cancer. Thus, it is apparent that spiritual perspectives are significant resources used by patients with cancer and can be positively impacted by nursing interventions.

**Perceived well-being.** Well-being is consistently conceptualized as a subjective perception of the individual (Dirksen, 1987). Well-being is defined by Campbell (1976) as the perceived level of satisfaction with current life
experiences. Individuals with cancer, regardless of prognosis, have been shown to perceive general well-being (Reed, 1987; Ware, 1984; Young & Longman, 1983). The perception of well-being denotes a sense of quality of life and is influenced by one's attitudes, goals, and interpretation of life events (Young & Longman, 1983).

Perceived well-being is associated with hopefulness (Dufault & Martocchio, 1985; Miller & Power, 1988; Owen, 1989; Scott et al., 1983). Perceived well-being is positively correlated with spirituality in terminally ill adults (Reed, 1987). Measurement of this concept as it relate to the level of hope may assist in more clearly defining the concept of hope.

Summary

This chapter described the conceptual framework of the correlates of hope in adults with recurrent cancer. The underlying theme is that of stress and adaptive responses as described by Neuman (1980). A review of the literature on the concept of hope in relation to cancer recurrence was provided. Life-change, spiritual perspective, and perceived well-being were identified as correlates of hope based on
consistent identification of these concepts in the literature on hope. A summary of the major studies cited for the conceptual variables of hope, life-change, spiritual perspective, and perceived well-being, and the experience of cancer recurrence is presented in Table 1.
<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Research Question/Study focus</th>
<th>Methods</th>
<th>Major Findings</th>
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<tbody>
<tr>
<td>Cherykyn, 1984</td>
<td>A descriptive correlational study about the meaning of cancer recurrence to patient and spouse and the communication exchanged by 12 women with cancer recurrence and 10 spouses.</td>
<td>The Dyadic Adjustment Scale, stated content validity</td>
<td>Eight major themes: (1) difficulty with closure; (2) pervasive feelings of uncertainty; (3) grief about losses; (4) feelings of injustice, anger, and fear; (5) existential concerns; (6) concern related to coping with the recurrence; (7) impact on family functioning; (8) the absence of shared meaning. Recurrence affects the entire family, requiring adjustments and adaptive responses from all members.</td>
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<td>Northouse, 1981</td>
<td>The relationship between significant others and fear of disease recurrence in 30 mastectomy patients in remission.</td>
<td>Fear of Recurrence Questionnaire Stated content validity</td>
<td>Significant negative relationship between the number of significant others and the subject's fear of recurrence, and a strong negative relationship between the number of significant others perceived as understanding and the fear of recurrence.</td>
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<tr>
<td>Weisman &amp; Worden, 1985</td>
<td>Cross-sectional analysis of 102 patients w/ varied diagnoses contrasting initial diagnosis with recurrent disease</td>
<td>Profile of mood states, Index of Vulnerability, Inventory of Current Concerns. No psychometric properties reported.</td>
<td>Sample: 76% female, mean age: 58. No significant difference was found in the level of distress experienced at the time of initial diagnosis and recurrence. Lower levels of distress were reported in subjects with fewer symptoms and localized disease. Higher levels of stress correlated positively with degree of surprise and presence of physical symptoms. Primary concerns: getting on with treatment, addressing health concerns, existential issues.</td>
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<td>Author/Year</td>
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<td>Herth, 1989</td>
<td>The relationship between level of hope and level of coping response and other variables in patients with cancer.</td>
<td>120 adults undergoing chemotherapy in hospital, outpatient, and home settings using the Herth Hope Scale (alpha=.89) and the Jalowesic Coping Scale (alpha=reliability and validity stated).</td>
<td>A significant positive relationship ( r=0.80, p=0.001 ) was found between level of stress and level of coping response. Religious convictions and treatment in hospital or outpatient settings were significantly related to the level of hope and coping response ( p=.05 ). Greater interference with role responsibilities correlated with lower hope and coping scores regardless of setting ( p=.05 ).</td>
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<tr>
<td>Hinds, 1982</td>
<td>Grounded theory methodology used to induce a generalized definition of hope with documentation of the process of grounded theory methodology.</td>
<td>Interview with 25 adolescents both well and hospitalized.</td>
<td>Isolation of four categories of hope which form a continuum of degree: (1) forced effort, (2) personal possibilities, (3) expectations for a better tomorrow, and (4) anticipation of a personal future.</td>
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<td>Miller &amp; Powers, 1988</td>
<td>Development of an instrument to measure hope in adults.</td>
<td>522 healthy adults were interviewed to establish the psychometric properties of the Miller Hope Scale. Psychometric properties: alpha = .93, criterion related construct validity established with correlation to well-known well-being scales ranging from .69-.82, and with the Hopelessness scale at -.54.</td>
<td>Ten critical elements of hope identified: (1) mutuality-affiliation, (2) sense of the possible, (3) avoidance of absolutizing, (4) anticipation, (5) achieving goals, (6) psychological well-being and coping, (7) purpose and meaning in life, (8) freedom, (9) reality surveillance-optimism, (10) mental and physical activism.</td>
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Nowotony, 1989: Development of a reliable and valid instrument to measure hope following a stressful life event. Sample of well adults and a sample of patients with cancer (total n=306).

Owen, 1989: Grounded theory used to induce a generalized knowledge of hope. Interviews with 6 OCNS asked to describe hopeful patients.

Scott, Goode, & Arlin, 1983: Case study describing some of the processes occurring in a patient who had five remissions in 3 years.

Stoner, 1982: Descriptive correlational study of hope and cancer patients, and evaluation of the reliability and validity of the SHS. Sample: 53 adult cancer patients cognizant of their diagnosis.

Stoner & Knapmper, 1985: What is the relationship of recalled life expectancy information and hope in cancer patients, and what effect does phase of illness have on the level of hope in cancer patients.

Nowotony Hope Scale
alpha = .90

Stoner Hope Scale
Psychometric properties: (.93). Moderate concurrent validity demonstrated by the negative correlation (r=-.47, p, .01) between the SHS and the BHS.

Health and job related situations were the most frequent causes of stress. Six dimensions of hope identified: (1) confidence, (2) relates to others, (3) future is possible, (4) spiritual beliefs, (5) active involvement, and (6) comes from within. Data were not collected on type of cancer, the extent of cancer, or the length of time since diagnosis - not generalizable to other populations with cancer.

Six subthemes: Goal setting, positive personal attributes, future redefinition, meaning in life, peace, and energy. Each subtheme described a component of the process whereby energy was exchanged, transformed, or moved resulting in the preservation or loss of hope.

Four preliminary characteristics common to multiple remission experience: Volatility of emotions (particularly anger and fear), progressive reduction of stamina (including hope), resurfacing of unresolved issues, and urgent attempts to remain in control. Attempts to maintain control became the most dominant feature of everyday life.

Religiosity, social support, close contact with cancer patients and femaleness positively associated with hope (p<.05). Hope was inversely related to socioeconomic status. Together these variables explained 21.5% of the variance.

A statistically significant difference in the level of hope between the individuals who had no recall of receiving life expectancy information and those who received life expectancy information. Higher hope scores were reported in those subjects with no recollection of receiving prognostic information. No relation was found between phase of illness and level of hope.
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<tr>
<td>Graham &amp; Young, 1987</td>
<td>Investigation of quality of life and its relationship to symptom distress, social dependency, behavior-morale and life change.</td>
<td>60 adults between the ages of 20 and 83 years with malignant melanoma were interviewed using the scales mentioned. 23 of the subjects were those participating in the earlier pilot study. Reliability coefficients ranged from .82 to .95.</td>
<td>Quality of life was ranked higher, symptom distress and social dependency were ranked lower. Behavior-morale was ranked higher in those who perceived a better quality of life. Findings lent support to the notion that human beings do realign their values, making cognitive adaptations when forced with a life-threatening disease.</td>
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<td>Longman &amp; Graham, 1986</td>
<td>Analysis of responses to questions in the Life Change Scale used in a quality of life study.</td>
<td>60 persons diagnosed and treated for malignant melanoma responded to open-ended questions focusing on areas of daily living and the changes that had occurred since the diagnosis of melanoma.</td>
<td>Six categories emerged from the data and serve as examples of managing one’s life after a diagnosis of cancer: Living with cancer, thoughts about treatments for melanoma, changes in making life meaningful, alterations in life-style, relationships with others, and social support adaptation.</td>
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<tr>
<td>Young &amp; Longman, 1983</td>
<td>A study to investigate variables associated with quality of life as perceived by persons diagnosed with melanoma.</td>
<td>Convenience sample of 23 subjects with melanoma. Quality of Life Scale, Symptom Distress Scale, Social Dependency Scale, Life-Change Scale, and Behavior-morale Scale. Alphas range from .82 to .90.</td>
<td>As perceived quality of life was ranked higher, symptom distress and social dependency were found to be lower. Behavior-morale was higher for those who perceived a high degree of quality of life. All subjects indicated a change for the better in social support.</td>
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### Summary of Literature Review - Spiritual Perspective

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<tr>
<td>Reed 1986</td>
<td>A comparison study of religiousness and sense of well-being in terminally ill and health adults.</td>
<td>57 adults matched for age, gender, education, and religious affiliation. Instruments: Religious Perspective Scale (.92) and Index of Well-being (.93).</td>
<td>No difference between groups on sense of well-being. A positive relationship between religiousness and well-being was found in the healthy group (r=.43, p&lt;.001), but not in the terminally ill group. Greater religiousness was associated with femaleness and terminal illness.</td>
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<td>Reed 1987</td>
<td>Extension of initial research as stated above. Three groups of 100 adults matched for age, gender, education and religious background completed two questionnaires to determine the significance of spirituality among terminally ill adults.</td>
<td></td>
<td>Terminally ill hospitalized adults indicated greater spiritual perspective than either non-terminally ill hospitalized adults or healthy non-hospitalized adults. There was a positive relationship between spiritual perspective and well-being in the terminally ill hospitalized group.</td>
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<td>Sodestrom, 1987</td>
<td>Description of spiritual coping strategies of 25 hospitalized patients with cancer and their nurses' awareness of those strategies.</td>
<td>Adaptation of McCorkle and Benoliel's Spiritual Coping Interview.</td>
<td>Data indicated patients used a variety of resource people and spiritual activities to help them cope. Most frequently used coping strategy: personal prayer and asking others to pray for them. Patients realistically aware of their diagnosis used a greater number of spiritual activities.</td>
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### Summary of Literature Review - Well-being

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<th>Author/ Year</th>
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<th>Methods</th>
<th>Major Findings</th>
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<tr>
<td>Dirksen, 1989</td>
<td>Correlational study aimed at identifying the variables that significantly influence perceived well-being in malignant melanoma survivors.</td>
<td>A convenience sample of 31 adults who had been treated for malignant melanoma and were disease free for at least five years were asked to complete six scales, four of which had reported reliability.</td>
<td>Internal locus of control (p=.03) and self-esteem (p&lt;.02) both had a significant effect on well-being. No significant relationship between social support and well-being was found. The presence of chronic illness had a negative effect on perceived well-being, while treatment with immunotherapy and vitamin A showed a positive influence on well-being.</td>
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CHAPTER THREE

METHODOLOGY

Included in this chapter are the research design, study sample, study setting, protection of human subjects, instruments used and data collection procedures for this study.

Research Design

A descriptive, correlational design was used to describe the relationship of selected variables to the level of hope in a population of adults with recurrent cancer. The variables selected included life-change, spiritual perspectives, and perceived well-being. In addition, this study attempted to describe the personal meaning of cancer recurrence in the same population.

Setting and Sample

The patient population for this study was selected from consenting individuals referred by colleagues in five settings. The five settings included a private hematology/oncology office, a private radiation/oncology office, a large outpatient radiation/oncology clinic in a
regional cancer center, an inpatient medical/oncology unit in a tertiary care center, and an outpatient hematology/oncology clinic in a regional veterans hospital. All of the oncology settings were located in a large metropolitan city in the southwestern United States.

A convenience sample of 24 adults who had experienced a recurrence of cancer within six months of the data collection period was recruited for the study. The inclusion criteria for participation in this study were:

1. Eighteen years of age.
2. Able to speak, read, and write the English language.
3. The diagnosis of clinically detectable cancer following treatment induced remission within six months of the data collection period.

Protection of Human Subjects. Written permission to conduct this study was obtained from the University of Arizona Human Subjects Committee (Appendix A). Only those subjects who voluntarily agreed to participate in the study were included. The purpose of the study was explained to subjects who met the inclusion criteria and were referred to the investigator. Subjects were informed that participation in this study was voluntary and would in no way alter the
medical or nursing care they received. All subjects were given a Subject’s Consent Form prior to participation in the study (Appendix B).

**Instruments**

Five instruments were used to collect data.

Demographic data were obtained using the Demographic Data Questionnaire (DDQ) developed for this study. The Stoner Hope Scale (SHS) was used to measure the level of hope (Stoner, 1982). Life-change was measured by the Life Change Scale (LCS) (Young & Longman, 1983). Spiritual perspective was measured using the Spiritual Perspective Scale (SPS) (Reed, 1987). The Index of Well-Being (IWB) provided data to measure perceived well-being (Campbell, Converse, & Rodgers, 1976). The conceptual variables, the corresponding instrument, subscales within each instrument if present, and number of items in each instrument are presented in Table 2.

**Demographic Data Questionnaire DDQ (DDQ).** The Demographic Data Questionnaire (Appendix C) was developed based on a review of the literature. Information was elicited to add clarity and assist with data analysis for each of the instruments previously identified. Information
<table>
<thead>
<tr>
<th>Conceptual Variable</th>
<th>Instrument</th>
<th>Format</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope</td>
<td>Stoner Hope Scale</td>
<td>4 - point</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Subscales:</td>
<td>Likert</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intrapersonal</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Interpersonal</td>
<td></td>
<td>items</td>
</tr>
<tr>
<td></td>
<td>Extrapersonal</td>
<td></td>
<td>per</td>
</tr>
<tr>
<td></td>
<td>subscale</td>
<td></td>
<td>subscale</td>
</tr>
<tr>
<td>Life-Change</td>
<td>Life-Change Scale</td>
<td>7 - point</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Likert and</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview Guide</td>
<td></td>
</tr>
<tr>
<td>Spiritual Perspective</td>
<td>Spiritual Perspective Scale</td>
<td>6 - point</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Likert</td>
<td></td>
</tr>
<tr>
<td>Perceived</td>
<td>Index of Well-Being</td>
<td>Semantic</td>
<td>9</td>
</tr>
<tr>
<td>Well-being</td>
<td></td>
<td>Differential</td>
<td></td>
</tr>
</tbody>
</table>
pertaining to age, gender, and education provides basic information. Religious affiliation is significant to the SPS and SHS (Reed, 1987; Stoner, 1987). Marital status and employment pertain primarily to the LCS (Young & Longman, 1983).

Disease related information included primary diagnosis, time since initial diagnosis, time since diagnosis of recurrence, treatments received and when, and prognosis for survival (Stoner & Keampfer, 1985; Weisman & Worden, 1985). This information assisted in evaluating the personal meaning of cancer recurrence as described by the study participants.

**Stoner Hope Scale.** The SHS was developed by Stoner (1982) to measure hope in cancer patients. Items on the scale were formulated from the work of Lynch (1965), Marcel (1979), and Stotland (1969), and a similar tool developed by Erickson, Post, and Paige (1975). The SHS measures hope, defined as the importance and probability of attainment of future oriented goals, using a 30 item 4-point Likert scale, with 1 indicating no importance and low probability and 4 indicating extreme importance and high probability respectively (Appendix D). The SHS contains 30 goals (items) representing three spheres of involvement: intrapersonal,
interpersonal and global hope. Each domain of hope contains 10 items. Scoring of the SHS is obtained by multiplying the importance score by the probability score for each item, with the sum of all products representing the total hope score (maximum=480) (Stoner, 1982). Sums of the products for each subscale are also calculated to obtain scores for the three spheres of hope.

Stoner and Keampfer (1985) used the SHS to measure the level of hope in 55 adult cancer patients. Content validity was obtained through consultation with a panel of psychiatric and oncology nurse experts. Comparison to the Beck Hopelessness Scale was used to establish concurrent validity (r=-.47) with the assumption that hope and hopelessness represent opposite ends of the same continuum (Stoner & Keampfer, 1985). Reliability was estimated by Cronbach’s alpha coefficient at .93. A mean inter-item correlation of .53, and an item-to-total correlation range of .37 to .65 was reported.

Life Change Scale. Young and Longman (1983) developed the LCS to measure life change in a population of melanoma patients (Appendix E). Life change was described as the degree of change in areas of daily living since the time of
diagnosis. The 18 items contained in this instrument were selected based on an extensive review of the literature and consultation with two experts. The items were believed to be associated with quality of life (Graham & Longman, 1987; Longman & Young, 1986; Young & Longman, 1987). The 18 items include: physical appearance; physical endurance; feelings about self; sense of independence; decision making; relationship with spouse, children, relatives, health professionals, friends, and work associates; job performance; job satisfaction; financial situation; recreational activities and hobbies; church activities; social activities; future outlook; sense of achievement; social support; style of dress; and changed by treatment.

The LCS was used initially in a pilot study conducted to investigate variables associated with quality of life in 23 persons diagnosed with melanoma. Subjects were asked to rate the degree of change experienced from the time of diagnosis on a scale of 1 (no change) to 6 (great deal of change). The range of scores for the total scale could vary from 18 to 108 and the higher the score the greater the degree of life change. The items were then presented to subjects as open-ended questions to elicit personal perceptions based on an interview guide to ensure
consistency in presentation. Findings in the pilot study indicated a significant relationship \((p< .05)\) between the 18 items on the LCS and the measures of quality of life. Due to the small sample size instrument reliability was not calculated.

Based on results obtained in the pilot study, Graham and Longman (1987) expanded the sample to include 60 subjects diagnosed with melanoma. The LCS retained the initial 18 items, with a Likert-type scale added to elicit information pertaining to the direction of life change, positive or negative. Construct validity was estimated based on identification of four pure factors isolated using Varimax factor analysis (.50 criterion level). The four factors, relationship with significant others, self achievement, physical performance, and social involvement, were judged by the researchers to be consistent with the conceptual variables being studied. Reliability was identified by standardized alpha coefficients, .93 and .89, for amount of life change and degree of life change respectively.

The qualitative data obtained from the interviews were analyzed using content analysis producing categorization of responses. Interrater reliability was established at 80
percent agreement between the two raters for the entire data set.

**Spiritual Perspective Scale (SPS).** The SPS is a 10 item scale designed to measure the perspectives of individuals concerning their spiritual beliefs and behaviors, and the extent to which their perspectives affect their lives (Appendix F) (Reed, 1987). The scale was adapted from the Dimensions of Religiosity Scale (King & Hunt, 1975) by Reed (1986) based on a review of literature.

The scale uses a Likert format with each of the 10 items ranked on a scale of 1 (low spiritual perspective) to 6 (high spiritual perspective). The arithmetic mean across all responses represents the total score for the SPS, with scores ranging from 1 to 6, with 6 representing a greater spiritual perspective. Either a structured interview or questionnaire format may be used to administer the SPS. An open-ended question is included at the end of the scale to elicit qualitative data pertaining to the importance or meaning of spirituality for each subject.

Good psychometric properties for the SPS are reported by Reed (1986, 1987) in studies conducted with over 400 adults who were terminally ill, healthy, and non-seriously
ill. Using Cronbach's alpha, reliability for the instrument is rated consistently above .90. Alpha coefficients ranging from .93 to .95 were reported by Reed (1987) in a study involving three groups (n=300). Average inter-item correlations ranged from .57 to .68 across the three groups. Construct validity was supported based on the findings of two studies by Reed (1986,1987) in that women and subjects reporting a religious background scored higher on the SPS. Qualitative data further supported the validity of this instrument.

**Index of Well-Being (IWB).** The IWB (Appendix G) was developed by Campbell, Converse and Rodgers (1976) to measure satisfaction with life as it is currently experienced. The index consists of nine items which the developers claim extract information pertaining to both cognitive and affective dimensions of well-being. The nine items include eight semantic differentials and one question rating overall life satisfaction. A 6-point Likert format is used, with 1 indicating complete dissatisfaction and 6 indicating complete satisfaction. Scoring of the IWB is obtained as a total of two differently weighted scores, the total score for overall life satisfaction (weighted 1.1),
and the mean of the eight semantic differentials (weighted to 1.0). Scores can range from 2.1 to 12.6.

Satisfactory reliability and validity are reported for the scale in research conducted on samples of 2160 (Campbell et al., 1976) and 114 (Reed, 1986). Alpha coefficients were reported consistently above .89, with item-to-total correlations ranging from .67 and above. In a study of 300 adults (three groups of 100), Reed (1987) estimated internal consistency using Cronbach's alpha at .90 or above for the three groups. Average inter-item correlations in the same study were reported and ranged from .51 to .61.

Data Collection Procedure. Clients who met the criteria for inclusion were initially contacted by colleagues in the clinical settings previously mentioned. The purpose of the study and time required for participation (approximately 1 to 1 1/2 hours) was explained. Potential subjects were asked if they could be contacted by the investigator for further information. Consenting subjects were either contacted by phone or in person (hospitalized subjects). A meeting time and location were mutually agreed upon. Detailed information about the study, the consent form, and an explanation of confidentiality and the right to
withdraw was provided at the initial meeting. Interviews were conducted following this introduction in the majority of the cases (n=20); four of the subjects were interviewed at a later date. Interviews were conducted in various locations of the subjects' choices including homes, offices, a park, clinic rooms, and hospital rooms. The data collection instruments were presented in systematic order for each interview: the Demographic Data Questionnaire, the Life-Change Scale, the Spiritual Perspective Scale, the Index of Well-Being, the Stoner Hope Scale, and finally the interview guide for the personal meaning of cancer recurrence. Interviews lasted from 40 minutes to 2 1/2 hours, with an average of one hour. Subjects were given a copy of the consent form which indicated how to contact the investigator or the Human Subjects Committee should they have questions concerning the study or their participation.

Data Analysis

Descriptive statistics were used to evaluate the data obtained from the instruments previously described. Pearson correlation coefficients were used to examine the relationships among the conceptual variables. Multiple
regression analysis were used to determine the amount of variance in life-change, spiritual perspective, and perceived well-being to explain hope. Content analysis of interviews on the LCS and open-ended questions designed to elicit the personal meaning of cancer recurrence assisted in analyzing the qualitative data. Demographic data were evaluated using frequency distributions, means, and standard deviations. Total scale and subscale reliability were estimated using Cronbach's alpha for each instrument.

Summary

A descriptive correlational design was used to describe the relationship of life-change, spiritual perspective and perceived well-being to the level of hope in adults with recurrent cancer. Consenting subjects were referred from outpatient and inpatient settings. Five instruments were selected for data collection based on proven psychometric properties in prior studies with cancer patients. Proposed data analysis included descriptive and correlational statistics, multiple regression analysis, and content analysis to describe the relationships between variables.
CHAPTER FOUR

RESULTS OF THE STUDY

The results of data analysis, including sample characteristics, the psychometric properties of the data collection instruments, analysis of data related to each of the major variables, and statistical analysis of the research questions are presented in this chapter. The major themes derived from content analysis of information obtained from the interview guides are also presented. The findings are discussed in Chapter Five.

Demographic Characteristics of the Sample

A convenience sample of 17 women (64%) and seven men (36%) whose ages ranged from 25 to 81 years ($\bar{x} = 53$, sd = 16.43) participated in this study. The majority of subjects were married (n=17, 70%) and had at least one child (n=23). Most subjects had completed high-school with an average of 12.5 years of education. Eleven of the subjects were unemployed (45.8%), seven were retired (29.2%), and six remained employed (25%). Religious affiliation was reported
by 20 subjects, and four subjects indicated no religious affiliation.

Frequencies for disease related information, including primary diagnosis and time since initial diagnosis are presented in Table 3. A total of 10 malignancies were represented. The most common diagnosis was breast cancer (n=10, 46%). The time since initial diagnosis ranged from two months to eight years (\( \bar{x} = 35 \) months).

Treatment information is provided in Table 4. All but four of the subjects were currently receiving some type of treatment for their disease. Those indicating no current therapy reported they had recently completed some form of treatment for their disease, and were waiting for "results" to determine what they would do next, or would soon be starting treatment. The treatment was identified as "something that must be tried" by many of the subjects, although they acknowledged many difficulties in receiving it due to both physical changes and the disruption of schedules needed to make appointments. No subjects were receiving treatment at home. Nineteen of the subjects indicated they were aware of a limited life-expectancy, although no definite time span was indicated. The length of time from
Table 3. Frequencies for Disease Related Information (n=24)

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>Number</th>
<th>Time Since Initial Diagnosis</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>10</td>
<td>1-6 months</td>
<td>1</td>
</tr>
<tr>
<td>Lung</td>
<td>4</td>
<td>6-12 months</td>
<td>8</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>1</td>
<td>1-2 years</td>
<td>2</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>2</td>
<td>2-5 years</td>
<td>7</td>
</tr>
<tr>
<td>Head/Neck</td>
<td>1</td>
<td>&gt; 5 years</td>
<td>6</td>
</tr>
<tr>
<td>Colo-rectal</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ovarian</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uterine</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4. Frequencies for Treatment Related Information (n=24)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Inpatient (n=8)</th>
<th>Outpatient (n=12)</th>
<th>No Current Treatment (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone Marrow Transplant</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental Chemotherapy</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy to begin soon</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Chemotherapy/Radiation</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation</td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Recently had Radiation</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Recently had Surgery</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Hormonal Therapy</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
the diagnosis of recurrence to the interview ranged from one to seven months (x = 3 months).

Reliability of the Instruments

Internal consistency reliability of the instruments used to measure the four conceptual variables was estimated using Cronbach's coefficient alpha. The criterion for adequate reliability was established at .80. All instruments obtained satisfactory coefficients with a range of .80 to .92 (Table 5); these findings are limited by the small sample size (n=24). However, use of each of the instruments in similar populations with proven psychometric properties provides support for the validity of the stated measures (Burns & Grove, 1987). Item-to-item and item-to-total correlations for each instrument are reported in relation to the conceptual variable being measured. The criterion for acceptable item-to-total correlation was set at ≥ .30, and .30 -.70 for item-to-item correlations (Zeller, 1980).
Table 5. Instrument Standardized Alpha.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Standardized alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stoner Hope Scale</td>
<td>.92</td>
</tr>
<tr>
<td>Life-Change Scale</td>
<td>.86</td>
</tr>
<tr>
<td>Spiritual Perspective Scale</td>
<td>.92</td>
</tr>
<tr>
<td>Index of Well-Being</td>
<td>.80</td>
</tr>
</tbody>
</table>
Findings Related to the Research Questions

Pearson correlation coefficients were calculated to determine the relationship between the major conceptual variables and selected demographic variables. The level of significance was set at $p \leq .05$. The strength and direction of the statistically significant relationships are identified. Table 6 provides the correlation matrix for the four conceptual variables of hope, life-change, spiritual perspective, and perceived well-being.

Research Question 1. What is the level of hope in a population of adults with recurrent cancer?

The Stoner Hope Scale was used to measure the conceptual variable of hope defined as the importance and probability of obtaining future oriented goals. The SHS measures hope with a 30 item 4-point likert format, with 1 indicating no importance and low probability, and 4 indicating extreme importance and high probability. Scores are calculated by multiplying the importance score by the probability score for each item, with the sum of all products representing the total hope score. Scores
Table 6. Correlation Matrix For Conceptual Variables (n=24)

<table>
<thead>
<tr>
<th></th>
<th>Hope</th>
<th>Life Change</th>
<th>Spiritual Perspective</th>
<th>Perceived Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope</td>
<td>----</td>
<td>----</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>Life Change</td>
<td>.03</td>
<td>----</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>(p=.42)</td>
<td></td>
<td>(p=.03)</td>
<td>(p=.24)</td>
<td></td>
</tr>
<tr>
<td>Spiritual Perspective</td>
<td>.36</td>
<td>.04</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>(p=.03)</td>
<td></td>
<td>(p=.24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Well-Being</td>
<td>.23</td>
<td>-.46</td>
<td>.39</td>
<td>----</td>
</tr>
<tr>
<td>(p=.13)</td>
<td></td>
<td>(p=.01)</td>
<td>(p=.02)</td>
<td></td>
</tr>
</tbody>
</table>
may range from 30 to 480. The mean item-to-item correlation for this study was -.29. Several items correlated very high (>.85), indicating redundancy among items, or very low (<.20), suggesting some disparity in conceptual measurement. Item to total correlations ranged from .17 to .81, with the majority above .40.

The total hope scores in the sample ranged from a low of 200 to a high of 410 ($\bar{x} = 330; sd = 59$), indicating a moderately high level of hope in this group. This is similar to the mean score for the SHS in a population of 55 cancer patients with varied diagnoses and phases of illness ($\bar{x} = 338, sd=52$) (Stoner & Keampfer, 1985). Individual scores by item may range from 1 to 16, with 16 indicating higher probability and importance of attaining each goal. The mean scores and standard deviation for each item are presented in Table 7.

The SHS contains three subscales measuring intrapersonal, interpersonal, and extrapersonal hope. Each subscale consists of 10 items with a possible range of total scores from 10 to 160. Items in each subscale with the mean and standard deviation for total scores are presented in Table 8. Subjects in this study indicated a higher level of
Table 7. Mean and Standard Deviation by Item for the SHS

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To see a decrease in unemployment in the U.S.</td>
<td>9.1</td>
<td>3.8</td>
</tr>
<tr>
<td>2. To have open communication with the people who are important to me.</td>
<td>13.4</td>
<td>4.0</td>
</tr>
<tr>
<td>3. To feel good about my life.</td>
<td>13.9</td>
<td>2.8</td>
</tr>
<tr>
<td>4. To have other people enjoy having me around.</td>
<td>11.0</td>
<td>4.5</td>
</tr>
<tr>
<td>5. To see a decrease in crime and violence.</td>
<td>9.5</td>
<td>3.4</td>
</tr>
<tr>
<td>6. To resolve conflicts with the people who are important to me.</td>
<td>13.5</td>
<td>3.1</td>
</tr>
<tr>
<td>7. To have people seek me out as a friend.</td>
<td>9.3</td>
<td>3.1</td>
</tr>
<tr>
<td>8. To see a decrease in the threat of nuclear war.</td>
<td>9.3</td>
<td>4.3</td>
</tr>
<tr>
<td>9. To overcome fears that I have.</td>
<td>11.1</td>
<td>4.5</td>
</tr>
<tr>
<td>10. To believe in myself as a person.</td>
<td>14.7</td>
<td>2.3</td>
</tr>
<tr>
<td>11. To see an improvement in efforts to resolve problems with pollution of the environment.</td>
<td>10.9</td>
<td>3.2</td>
</tr>
<tr>
<td>12. To have better education in our schools.</td>
<td>9.5</td>
<td>3.6</td>
</tr>
<tr>
<td>Item</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------</td>
<td>-----</td>
</tr>
<tr>
<td>13. To have the courage to deal with my life.</td>
<td>14.7</td>
<td>2.5</td>
</tr>
<tr>
<td>14. To resolve conflicts within myself.</td>
<td>14.2</td>
<td>3.1</td>
</tr>
<tr>
<td>15. To have better programming on television.</td>
<td>6.9</td>
<td>4.3</td>
</tr>
<tr>
<td>16. To have people come to me for help with problems.</td>
<td>8.3</td>
<td>4.0</td>
</tr>
<tr>
<td>17. To be free from pain.</td>
<td>12.6</td>
<td>2.7</td>
</tr>
<tr>
<td>18. To make lots of new friends.</td>
<td>7.6</td>
<td>4.4</td>
</tr>
<tr>
<td>19. To have access to cultural facilities like symphonies, theaters, and art museums.</td>
<td>6.7</td>
<td>4.3</td>
</tr>
<tr>
<td>20. To be mentally alert and always learning.</td>
<td>14.2</td>
<td>2.7</td>
</tr>
<tr>
<td>21. To have local government agencies be responsive to people in neighborhoods.</td>
<td>9.8</td>
<td>3.1</td>
</tr>
<tr>
<td>22. To be at peace with myself.</td>
<td>14.5</td>
<td>2.3</td>
</tr>
<tr>
<td>23. To have other people respect and admire me.</td>
<td>10.0</td>
<td>4.7</td>
</tr>
<tr>
<td>24. To spend more time with the people who are important to me.</td>
<td>14.1</td>
<td>2.7</td>
</tr>
<tr>
<td>25. To be persistent in solving my problems.</td>
<td>14.4</td>
<td>2.4</td>
</tr>
</tbody>
</table>
Table 7, continued

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. To be in control of what happens to me.</td>
<td>10.6</td>
<td>3.7</td>
</tr>
<tr>
<td>27. To participate in political activities.</td>
<td>3.7</td>
<td>2.2</td>
</tr>
<tr>
<td>28. To share joys and sorrows with the people who are important to me.</td>
<td>12.9</td>
<td>3.7</td>
</tr>
<tr>
<td>29. To have better mass transportation in our cities.</td>
<td>7.2</td>
<td>3.9</td>
</tr>
<tr>
<td>30. To have friends who will provide help when I need it.</td>
<td>11.6</td>
<td>4.0</td>
</tr>
</tbody>
</table>
Table 8. Items by Subscale with Mean and Standard Deviation for Total Score

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Items</th>
<th>Total Score</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrapersonal</td>
<td>3, 9, 10, 13, 14, 17, 20, 22, 25, 26.</td>
<td>135</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Hope</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal</td>
<td>2, 4, 6, 7, 16, 18, 23, 24, 28, 30.</td>
<td>112</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Hope</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extrapersonal</td>
<td>1, 5, 8, 11, 12, 15, 19, 21, 27, 29.</td>
<td>83</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Hope</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
intrapersonal hope ($x = 135, \ sd = 31$), with lower scores on the interpersonal hope ($x = 112, \ sd = 43$) and extrapersonal hope ($x = 83, \ sd = 35$) subscales.

**Additional analysis.** A strong positive correlation between level of hope and treatment status existed ($r = .45, \ p = .03$), with subjects receiving treatment as outpatients having the highest hope scores, indicating a higher level of hope than those who were not currently under treatment, and those who received treatment in the hospital. A significant positive relationship was also found between the level of hope and female gender ($r = .35, \ p = .04$), subjects who were married ($r = .32, \ p = .06$), and to identification of a religious affiliation ($r = .39, \ p = .02$). Employment was negatively related to the level of hope ($r = -.42, \ p = .01$), with unemployed subjects indicating a lower level of hope.

**Research Question 2.** What is the relationship between life-change and level of hope in a population of adults with recurrent cancer?

The degree of change in activities of daily living since the diagnosis of recurrent cancer was defined as life-change, and measured using the Life-Change Scale (Young & Longman, 1983). The scale consists of 18 items in a
7-point likert scale with 1 indicating very little change and 7 indicating a great deal of change. Subjects were asked to rate each item for the degree of change, indicate the direction of change (better or worse), and were then given the opportunity to explain their ratings. Total scale scores could range from 18 to 108, with higher scores indicating a greater degree of life change. Item-to-item correlations ranged from -.25 to .79, with a mean of .23. Item-to-total correlations ranged from .18 to .65. The items with the lowest correlation referred to job related activities which may be inappropriate in a sample with unemployed or retired subjects. In addition, the ratio of the small sample size and the number of items on this scale may have affected the correlation of items (Burns & Grove, 1987).

No significant relationship existed between the total degree of life change and the level of hope in these adults (r=.03, p=.42). However, three individual items on the LCS showed a significant relationship to the level of hope. These were: Sense of Independence (.32, p=.05), Financial Situation (.36, p=.04), and Relationship With Friends (.32, p=.06). The total degree of life change was negatively
correlated to perceived well-being (-.46, p=.01), implying the greater the degree of life-change the less satisfied individuals were with their current life experiences.

The mean total score for the degree of life change was 78 (sd = 25) indicating a moderate degree of change since the diagnosis of recurrence. Table 9 provides the mean and standard deviation by item for the degree of life change. Items with the highest mean degree of change included: Life Changed by Treatment (5.25), Physical Appearance (5.03), Physical Endurance (4.75), Financial Situation (4.25), Feelings about Self (4.20), Outlook Toward the Future (4.16), and Social Support (3.91). The direction of life change varied by item, with many subjects indicating the change as neither better nor worse for many of the items. Frequencies for the direction of change for each item are presented in Table 10. Table 11 provides a summary of the items which showed the greatest degree of change and the corresponding direction of that change. Discussion of the responses obtained from the open-ended question on each item is provided to add clarity to the responses of the subjects in this study. It is clear that the majority of change was
Table 9. Mean and Standard Deviation by Item for the Degree of Life Change for LCS (n=24).

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Appearance</td>
<td>5.03</td>
<td>2.02</td>
</tr>
<tr>
<td>Physical Endurance</td>
<td>4.74</td>
<td>2.09</td>
</tr>
<tr>
<td>Feelings About Self</td>
<td>4.20</td>
<td>2.00</td>
</tr>
<tr>
<td>Sense of Independence</td>
<td>4.20</td>
<td>2.00</td>
</tr>
<tr>
<td>Decision Making</td>
<td>3.41</td>
<td>2.37</td>
</tr>
<tr>
<td>Relationship with Spouse</td>
<td>3.16</td>
<td>2.50</td>
</tr>
<tr>
<td>Relationship with Children</td>
<td>3.16</td>
<td>2.47</td>
</tr>
<tr>
<td>Relationship with Inlaws/Relatives</td>
<td>3.50</td>
<td>2.46</td>
</tr>
<tr>
<td>Relationship with Doctors/Health Professionals</td>
<td>3.75</td>
<td>2.40</td>
</tr>
<tr>
<td>Relationship with Friends</td>
<td>2.87</td>
<td>2.09</td>
</tr>
<tr>
<td>Relationship with Associates at Work</td>
<td>1.62</td>
<td>2.39</td>
</tr>
<tr>
<td>Job Performance</td>
<td>2.25</td>
<td>2.87</td>
</tr>
<tr>
<td>Job Satisfaction</td>
<td>1.83</td>
<td>2.47</td>
</tr>
<tr>
<td>Financial Situation</td>
<td>4.25</td>
<td>2.17</td>
</tr>
<tr>
<td>Hobbies or Recreational Activities</td>
<td>3.70</td>
<td>2.27</td>
</tr>
<tr>
<td>Church or Religious Group involvement</td>
<td>2.45</td>
<td>2.43</td>
</tr>
<tr>
<td>Social Activities</td>
<td>3.70</td>
<td>2.27</td>
</tr>
<tr>
<td>Sense of Achievement</td>
<td>3.70</td>
<td>2.11</td>
</tr>
<tr>
<td>Social Support</td>
<td>3.91</td>
<td>2.20</td>
</tr>
<tr>
<td>Style of Dress</td>
<td>3.37</td>
<td>2.58</td>
</tr>
<tr>
<td>Life changed by Treatment</td>
<td>5.25</td>
<td>2.02</td>
</tr>
<tr>
<td>Outlook Toward</td>
<td>4.16</td>
<td>2.07</td>
</tr>
</tbody>
</table>
Table 10. Frequencies for Direction of Life Change by Item for LCS (n=24)

<table>
<thead>
<tr>
<th>Item</th>
<th>Better (n)</th>
<th>Worse (n)</th>
<th>Neither (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Appearance</td>
<td>2</td>
<td>17</td>
<td>5</td>
</tr>
<tr>
<td>Physical Endurance</td>
<td>2</td>
<td>17</td>
<td>5</td>
</tr>
<tr>
<td>Feelings About Self</td>
<td>5</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Sense of Independence</td>
<td>6</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Decision Making</td>
<td>5</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Relationship With Spouse</td>
<td>11</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Relationship With Children</td>
<td>10</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>Relationship With Inlaws/Relatives</td>
<td>8</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Relationship With Health Professionals</td>
<td>12</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Relationship With Friends</td>
<td>8</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Relationship With Associates at Work</td>
<td>7</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Job Performance</td>
<td>6</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Job Satisfaction</td>
<td>5</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Financial Situation</td>
<td>3</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Hobbies or Recreational Activities</td>
<td>3</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Church or Religious Group Involvement</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Social Activities</td>
<td>4</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Sense of Achievement</td>
<td>6</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Social Support</td>
<td>13</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Style of Dress</td>
<td>3</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Life changed By Treatment</td>
<td>3</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>Outlook Toward The Future</td>
<td>5</td>
<td>10</td>
<td>9</td>
</tr>
</tbody>
</table>
Table 11. Item Means With Greatest Degree of Life Change With Direction of Life Change (n=24)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean Degree Change</th>
<th>%Better</th>
<th>%Worse</th>
<th>%No Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Changed by Treatment</td>
<td>5.25</td>
<td>12.5</td>
<td>75.0</td>
<td>12.5</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>5.03</td>
<td>5.3</td>
<td>70.8</td>
<td>20.8</td>
</tr>
<tr>
<td>Physical Endurance</td>
<td>4.75</td>
<td>8.3</td>
<td>70.8</td>
<td>20.8</td>
</tr>
<tr>
<td>Financial Situation</td>
<td>4.25</td>
<td>12.5</td>
<td>58.3</td>
<td>29.2</td>
</tr>
<tr>
<td>Feelings About Self</td>
<td>4.20</td>
<td>20.8</td>
<td>54.2</td>
<td>25.0</td>
</tr>
<tr>
<td>Sense of Independence</td>
<td>4.20</td>
<td>25.0</td>
<td>45.8</td>
<td>29.2</td>
</tr>
<tr>
<td>Outlook Toward the Future</td>
<td>4.16</td>
<td>20.8</td>
<td>44.0</td>
<td>37.5</td>
</tr>
<tr>
<td>Social Support</td>
<td>3.91</td>
<td>54.2</td>
<td>8.3</td>
<td>37.5</td>
</tr>
</tbody>
</table>
related to physical, financial, intrapersonal, and interpersonal factors.

The item "Life changed by Treatment" showed the greatest degree of change ($\bar{x} = 5.25$) with 17 subjects (70.8%) indicating a change for the worse. Reasons for the degree and direction of change most often involved changing normal routines to accommodate treatment schedules and the limitations imposed as a result of the treatment. Subjects responses included: "Disruptions"; "Occupies your life"; "I spend a lot of hours here"; "Separation from family"; "Changed life to schedule treatment, then because of side-effects"; "Treatments wear me out"; "Endure a lot"; "Being sick all the time"; "Very difficult."

Changes in physical appearance ($\bar{x} = 5.03$) were most often due to weight loss, hair loss, and the visible effects of treatment such as scars from surgery, indwelling catheters, radiation burns, or skin discoloration. Changes in physical endurance ($\bar{x} = 4.75$) were most often for the worse (n=17, 70.8%). Subjects reported a lack of ability to do the things they used to do because of fatigue or an inability to concentrate for long periods of time. Decreased physical endurance was also cited as the cause of
changes in many other activities of daily life such as hobbies and recreational activities, social activities, church and religious group involvement, and sense of independence.

Fourteen subjects reported a change in their financial situation for the worse (\( \bar{X} = 4.25 \)). Many subjects reported the high cost of medical care with insurance paying only a percentage as the primary financial strain. Loss of job was also reported as a factor in declining financial status. Most subjects who reported difficulties with medical costs stated that the cost would not interfere with pursuing further treatment.

Comments related to a change in feelings about self indicated the change as a result of a reappraisal process. The mean degree of change for this item was 4.20 with 54% of the subjects indicating a change for the worse. Comments included: "It made me take a good look at myself"; "I don't dwell on silly things"; "Sometimes I wonder what I am living for"; "Makes you think about what is important, you analyze everything." Another common theme indicated a frustration with the failure of prior treatment or the limitation imposed by physical changes or current treatment. Comments
included: "Frustrated, I can't do what I used to"; "Very bad at first, I thought I had won, I felt guilty"; "I lost confidence in myself"; "No matter how hard I try I can't do much of anything"; "I was disappointed, after all the other treatments I didn't want to go through it all again just to have it reappear somewhere else."

Changes in the sense of independence ($\bar{x} = 4.20$) included changes for the worse ($n=11$), better ($n=6$), and no direction of change ($n=7$). Subjects indicating a change for the worse most commonly indicated a decreased ability to do things for themselves and the need to depend on others for help. Also reported were the limitations imposed by treatment schedules such as, "My independence is gone, everybody has something to say about what you do or don't do, your counts (blood) have control of you". Those reporting no change commonly indicated that they had "always been very independent". Of those indicating a change for the better, comments included: "I'm more independent now, lived my life for my children, not anymore, have to be brave, think of myself".

There was a moderate degree of change in subjects' outlook toward the future ($\bar{x} = 4.16$), with 10 subjects (44%)
indicating a change for the worse, nine subjects (33%) indicating no direction of change, and five subjects (20%) indicating a change for the better. Comments included: "Just trying to get by"; "Limited future"; "Taking life one day at a time"; "Wait and see"; "Focus on the here and now"; "Question my future"; "Determined"; and "Concentrate on getting well". The majority of subjects (n=19, 79%) indicated an awareness of a potentially limited length of survival.

Of interest are the items related to relationships with others and social support. The majority of subjects indicated either no change or a change for the better in relationships with family members, health professionals, friends and work associates. The mean degree of change in relationships with others ranged from 3.16 to 3.75. Several comments indicated relationships had become closer, that there was a greater appreciation, and sense of support, and that the effect of the disease and its treatment was extended to those around the subject. Many subjects indicated participation in groups in response to the item "social support".
Comments from each of the items were grouped by item to assist in identifying major themes. Content analysis was used to distill major themes represented in the subjects' comments. The major themes were then submitted to two reviewers with doctoral preparation and expertise in oncology nursing to verify the themes as representative of the information provided by the subjects. Ninety percent agreement was obtained indicating satisfactory content validity for the themes identified. A summary of the information provided by subjects for each of the items on the life change scale is provided in Appendix H.

Research Question 3. What is the relationship between spiritual perspective and level of hope in adults with recurrent cancer?

Spiritual beliefs and behaviors, and the extent to which they affect an individual's life was measured by the Spiritual Perspective Scale (Reed, 1987), a 10 item 6 point Likert scale. Items scores range from 1 (low spiritual perspective) to 6 (high spiritual perspective). Total scale scores are obtained by calculating the arithmetic mean across all items for a range in possible scores of 1.0 to 6.0. The range of scores in this study were a low of 1.0 to
a high of 6.0 with a mean of 4.5 (sd = 1.3) indicating a moderately high spiritual perspective. Reed (1986, 1987) reported mean scores of 4.5 (sd 1.3) and 4.1 (sd 1.2) in two studies with terminally ill cancer patients. The mean and standard deviation for each item on the SPS is provided in Table 12. Item-to-item correlations ranged from .21 to .95, with a mean of .55. Item-to-total correlations ranged from .43 to .88 indicating adequate psychometric properties of this scale.

The SPS includes an open-ended question to elicit information about the importance or meaning of spirituality which may not have been addressed in the structured questions. Ten subjects provided answers to the question. The major themes expressed by those responding were in three groups, those who did not indicate a religious affiliation (n=2), those who indicated a renewal of spiritual beliefs and/or increased participation (n=4), and those who expressed some dissatisfaction in their faith (n=2). Two subjects stated they still held strong beliefs but communicated a sense of conflict due to the inability to attend formal religious services. Comments included: "Gives me comfort and belief that there is 'more', brings me joy";
Table 12. Item Mean and Standard Deviation for Spiritual Perspective Scale. (n = 24)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>In talking with your family or friends, how often do you mention spiritual matters? *</td>
<td>4.3</td>
<td>1.6</td>
</tr>
<tr>
<td>How often do you share with others the problems and joys of living according to your spiritual beliefs? *</td>
<td>4.3</td>
<td>1.7</td>
</tr>
<tr>
<td>How often do you read spiritually-related material? *</td>
<td>4.2</td>
<td>1.8</td>
</tr>
<tr>
<td>How often do you engage in private prayer? *</td>
<td>4.9</td>
<td>1.8</td>
</tr>
<tr>
<td>Seeking forgiveness is an important part of my spirituality. **</td>
<td>4.1</td>
<td>1.8</td>
</tr>
<tr>
<td>I seek spiritual guidance in making decisions in my everyday life. **</td>
<td>4.5</td>
<td>1.7</td>
</tr>
<tr>
<td>My spirituality is a significant part of my life. **</td>
<td>4.7</td>
<td>1.5</td>
</tr>
<tr>
<td>I frequently feel very close to God or a &quot;higher power&quot; in prayer, during public worship, or at important moments in my daily life. **</td>
<td>4.8</td>
<td>1.5</td>
</tr>
<tr>
<td>My spiritual views have had an influence upon my life. **</td>
<td>4.6</td>
<td>1.7</td>
</tr>
<tr>
<td>My spirituality is especially important to me because it answers many questions about the meaning of life. **</td>
<td>4.4</td>
<td>1.6</td>
</tr>
</tbody>
</table>

* 1 = not at all, 6 = about once a day
** 1 = strongly disagree, 6 = strongly agree
"Don’t know what I would do without my faith"; "If I didn’t have a strong belief in God I would have lost it a long time ago. It’s given me inner peace - I don’t worry as much"; "It has not answered my questions on "why"; "The bible does not offer an explanation of experiences like this - of recurrence"; "Highly overrated, people have no idea what this is all about until they go through it themselves".

Spiritual perspective showed a statistically significant positive relationship (.36, p=.03) to the dependent variable, hope. Spiritual perspective also correlated positively with perceived well-being (.39, p = .03), female gender (.39, p=.02), and age (.36, p=.04). A statistically significant negative relationship existed between spiritual perspective and employment (-.44, p = .01), indicating a greater spiritual perspective in subjects who were unemployed.

Research Question 4. What is the relationship between perceived well-being and the level of hope in adults with recurrent cancer?

Satisfaction with life as it is currently experienced as measured by the Index of Well-being provides overall scores of 2.1 (low) to 12.6 (high). The scale consists of
nine items, eight semantic differentials and one item rating overall satisfaction or dissatisfaction.

The range of scores for the IWB in this study was 6.43 to 12.6, with a mean score of 9.46 (sd = 1.49) indicating a moderate to high perceived well-being in this sample. The mean and standard deviation for each item on the IWB is presented in Table 13. Item-to-item correlations ranged from .19 to .78 (\( \bar{r} = .31 \)). Item-to-total correlations ranged from .24 to .73. No significant relationship existed between the level of hope and perceived well-being in this study (.23, \( p = .13 \)).

Three items on the IWB are of particular interest to this study: Item 6: My present life is: Discouraging (1) .......(6) Hopeful, showed a mean score of 4.79 (SD = .93) indicating more hopefulness; Item 8: My present life: Doesn’t give me much chance .......Brings out the best in me, had a mean of 4.87 (sd = 1.15), and Item 9: In thinking about my life as a whole I am: Completely Dissatisfied....... Completely satisfied, was reverse coded prior to calculating the scale score. Item nine is weighted at 1.1, whereas all other items are weighted at 1.0;
Table 13. Item Mean and Standard Deviation for Index of Well Being. (n = 24)

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>My present life is:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boring ——— Interesting</td>
<td>4.9</td>
<td>1.0</td>
</tr>
<tr>
<td>Miserable ——— Enjoyable</td>
<td>4.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Useless ——— Worthwhile</td>
<td>5.2</td>
<td>.98</td>
</tr>
<tr>
<td>Lonely ——— Friendly</td>
<td>5.0</td>
<td>1.4</td>
</tr>
<tr>
<td>Empty ——— Full</td>
<td>4.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Discouraging ——— Hopeful</td>
<td>4.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Disappointing ——— Rewarding</td>
<td>4.3</td>
<td>1.3</td>
</tr>
<tr>
<td>My present life:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn’t give me ——— Brings out</td>
<td>4.7</td>
<td>.93</td>
</tr>
<tr>
<td>much chance the best in me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In thinking about my life as a whole, I am:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely ——— Completely satisfied</td>
<td>4.2</td>
<td>.94</td>
</tr>
<tr>
<td>dissatisfied</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
the mean score for item 9 was 4.25 (sd = .94) indicating a moderate level of satisfaction with life.

**Research Question 5.** How do the variables of life-change, spiritual perspective, and perceived well-being together correlate with the level of hope in the same population?

Multiple regression analysis was used to identify the relationship of the independent variables life-change, spiritual perspective, and perceived well-being together and the dependent variable of hope. Results are presented in Table 14. The three variables together showed no statistically significant relationship to the level of hope. Spiritual perspective alone explained 13 percent of the variance in the level of hope with a .07 level of significance.

**Additional analysis.** All demographic variables were entered with the independent variables in stepwise multiple regression analysis to determine the correlation to the level of hope. The criterion for tolerance was set at .05. Treatment and spiritual perspective together explained 35 percent of the variance in the level of hope (R² = .35, dF = 2, Sig F= .01).
Table 14. Hierarchical Regression for Conceptual Variables. Dependent Variable = Hope.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Multiple R</th>
<th>$R^2$</th>
<th>Change in R</th>
<th>Beta</th>
<th>dF</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spiritual Perspective</td>
<td>.36</td>
<td>.13</td>
<td>.09</td>
<td>.29</td>
<td>1</td>
<td>.07</td>
</tr>
<tr>
<td>Perceived Well-Being</td>
<td>.37</td>
<td>.14</td>
<td>.06</td>
<td>.16</td>
<td>2</td>
<td>.19</td>
</tr>
<tr>
<td>Life-Change</td>
<td>.38</td>
<td>.15</td>
<td>.02</td>
<td>.10</td>
<td>3</td>
<td>.33</td>
</tr>
</tbody>
</table>
Research question 6. What is the personal meaning of cancer recurrence to the individual experiencing it?

The personal meaning of cancer recurrence was measured using three open-ended questions. The responses to the questions were transcribed to facilitate content analysis. Major themes apparent in the data were identified by the investigator and then reviewed by two doctoral students with expertise in oncology nursing for validation. A 90 percent consensus was reached on the themes identified from the data. The questions and the corresponding themes are presented in Appendix I.

The major themes identified through content analysis described a wide array of emotions and responses. The response most commonly reported in relation to being told of the recurrence was one of disappointment and devastation. Subjects described many emotions occurring since learning about the recurrence, followed by renewed determination and increased involvement in decision making. "Taking one day at a time," "making every moment count," and "finding a purpose in life" were the major themes identified in relation to the meaning of the recurrence to the subject at the time of interview.
Summary

The results of the data analysis have been reported in this chapter. The demographic characteristics of the sample, psychometric properties of instruments used for data collection, measurement of the conceptual variables, and statistical analysis of the research questions were presented.

Subjects indicated a moderately high level of hope. Levels of intrapersonal hope were higher than interpersonal and extrapersonal hope. Spiritual perspective and treatment together explained 36 percent of the variance in the level of hope.
CHAPTER FIVE

Discussion, Conclusions, and Recommendations

The relationship between the conceptual framework and study findings and the conclusion based on these findings are presented in this chapter. Implications for nursing practice, recommendations for further research, and limitations of the study are included.

Findings Related to The Conceptual Framework

The purposes of this study were to describe the relationship between life-change, spiritual perspective, and perceived well-being to the level of hope in a population of adults with recurrent cancer, and to describe the personal meaning of cancer recurrence in the same population. The significant relationships between the conceptual variables and demographic variables in relation to the conceptual framework is depicted in Figure 2.

The level of hope in these adults with recurrent cancer was moderately high and a potentially limited future was acknowledged (n = 19). Stoner and Keampfer (1985) found a negative relationship between recalled life expectancy
Figure 2. Relationships among variables within the conceptual framework.
information and level of hope. The sample in the study cited included subjects in all phases of illness with no differences detected in the level of hope based on the phase of illness. Findings in the current study imply that subjects remained moderately hopeful despite their knowledge of a limited life span.

Subjects indicated a greater level of intrapersonal hope than either interpersonal or extrapersonal hope. Qualitative data related to life-change and cancer recurrence support the introspective search for meaning. Comments such as "It's made me take a good look at myself, family, friends"; "Look at myself, I knew I needed to address it, I can't deny it now - have to address it"; and "I give greater thought to the decisions I make, I think about how things will affect my future" depict the search for meaning and psychological well-being. Several authors support purpose and meaning in life and psychological well-being as integral components of hope (Dufault & Martocchio, Hickey, 1986; McGee, 1984; Miller & Powers, 1988; Nowotny, 1989).

Hope is described as an active, multidimensional, motivational phenomenon involving anticipation of attaining
future goals (Miller & Powers, 1988; Nowotony, 1989; Stotland, 1969). It is a unique experience based on the individual's appraisal of the current situation, the possibilities for the future, and the physical and social resources available (Nowotony, 1989; Scott et al., 1963; Taylor, 1983). The experience of cancer recurrence and the resulting life-change as defined by the subjects in this study although similar, may be interpreted differently by each individual. One subject commented, "This is different for everybody, everyone has to fight this disease their way". Another subject described her experience as similar to the Chinese students protesting for freedom in Tianmen Square in China. "Although the odds were against them, they continued to fight for what they believed in, fight for a future." The word "fight" was used by many subjects in their explanations indicating a strong desire to actively deal with the recurrence. Most subjects acknowledged the limited prognosis and indicated the "fight" as a way to have more time with those they loved and enjoy as many experiences as they could. This is consistent with the conceptual orientation of cancer recurrence in relation to stress and adaptation.
Spiritual perspective is consistently identified as a component of hopefulness (Miller & Powers, 1988; Nowotny, 1989; Reed, 1987; Taylor, 1983). Spiritual perspective and level of hope showed a positive correlation in these subjects (.36, p = .03). Reed (1987) suggests spirituality is greater in populations with an increased awareness of mortality. Spirituality is also viewed as a significant source of support (Dufault & Martocchio, 1985; Hickey, 1986; Reed, 1987). Psychological well-being and perceptions of support systems are correlated in the literature (Reed, 1987; Taylor, 1983). Perceived Well-being and Spiritual perspective were positively correlated at (.39, p = .02).

Although the total degree of life-change was not significantly related to the level of hope in this study (.03, p=.44), analysis of individual items on the life-change scale provided useful information for understanding the changes created by cancer recurrence, its treatment, and how those changes affect the ability to maintain hope. The total degree of life-change showed a strong negative relationship to perceived well-being (-.46, p=.01) indicating a decreased satisfaction with life as it is currently experienced as greater changes in activities of
daily living occur. A greater sense of well-being was correlated to a greater spiritual perspective (.39, p=.02), although perceived well-being and hope were not significantly correlated (.23, p=.13).

The underlying theme of the data analyzed in this study is that of the need to maintain a perception of active participation in the treatment for recurrent cancer as a means of maintaining hope. The qualitative data support the life-change induced by treatment schedules, side-effects, and cost. The relationship between the level of hope and treatment (.45, p = .04) further supports this as a central theme. The decrease in stamina, financial resources, and social activities because of treatment may create further vulnerability in this population. Thus, although the treatment creates changes which are perceived as worse, it provides a focus for actively dealing with the situation, an object for hope which allows the patient to assimilate the variability and persevere.

Experience of Cancer Recurrence

The personal meaning of cancer recurrence was not clearly defined by the responses of subjects to the
questions in the interview guide. The majority of subjects described reactions to the diagnosis in response to question 1 which asked for meaning. Question 2 asked what feelings subjects had experienced since the diagnosis. Many subjects identified feelings and then described their adaptation to manage their feelings. Responses to question 3, asking what the recurrence meant to the subject now, elicited responses which again described the experience of cancer recurrence and their strategies for living with the experience. Many subjects reflected on their plans for the future. Thus, information was elicited which appears to describe the experience of cancer recurrence more than the personal meaning of cancer recurrence. This may be due in part to the length of time since diagnosis ($\bar{x} = 3$ months). It is possible they were still reacting to the diagnosis and did not have time to assimilate the significance of the recurrence and thus describe the meaning. Additional research is needed to describe both the experience of cancer recurrence and the meaning of that experience to the patient.

Taylor (1983) developed a theory of cognitive adaptation to threatening life events based on extensive
interviews with 78 women with breast cancer. Three distinct themes were identified: a search for meaning in the experience, an attempt to regain mastery over the event and over one’s life, and an attempt to feel good about oneself again (Taylor, 1983).

Many of the themes identified in the responses to the interview questions about the meaning of cancer recurrence depict these same states. For example, for these subjects the initial responses to the diagnosis of recurrence were feelings of disappointment, devastation, fear, and surprise. Many subjects questioned the significance of the diagnosis, attempting to assimilate its implications. Taylor (1983) suggests this as a search for meaning in the event.

Following the initial response to the diagnosis of the recurrence, many subjects described a renewed sense of determination, persistence, and hope. Comments such as, "I need to get strength back to fight again, fight harder"; "Keeping positive feelings - trying to remain hopeful"; "Making decisions for myself now"; and "Concentrating on treatment" depict what Taylor (1983) suggests is a refocusing of one’s personal control. An individual faced with a stressful life event, such as a recurrence of cancer,
feels a loss of personal control over the disease progression. There is a refocusing to something that can be controlled. Active participation in the treatment for recurrence may promote a sense of gaining mastery.

The third state described by Taylor is that of enhancing one's self-esteem or feeling good about oneself again. A process of social comparison is suggested as a common method to enhance self-esteem. Comparisons are usually made with someone perceived as less fortunate. Comments by subjects which depict this state include: "I want to help, I want to make a difference, have people around"; "I'm 81, I've had a full life, I really have no complaints"; "Think about the donor - what kind of person would let you do a bone marrow biopsy for a stranger?"; "Resolved to pay attention to myself, put myself first without interfering with others' lives." A renewal of self-esteem through comparisons, suggests Taylor (1983), allows the individual to refocus his/her own situation to make it appear more favorable.
Implications for Nursing Practice

Cancer recurrence imposes considerable physical and emotional demands. Hope may provide the patient with the fortitude to assimilate the experience of recurring cancer and optimize the use of available resources. Findings from this study support the dimensions described by Taylor (1983) as present in the experience of recurrence, namely searching for meaning, gaining mastery, and enhancing one's self-esteem. The search for meaning is intrapersonal and unique to each individual. Allowing the person time to assimilate the experience, providing information to promote understanding, and being available to listen can assist the individual in finding purpose and meaning while conserving energy.

The inclusion of the family and significant others in the treatment plan is essential (Cherkyn, 1984; Scott et al., 1983). Findings from this study support the significance of relationships with others to the cancer patient's perception of their own situation.

Treatment became a central focus in these subjects. The treatment may be the object of hope, allowing the subject to take an active part in determining their future
and thus gain mastery. The variability in responses to treatment require continued support from nursing professionals. Promoting understanding and allowing the patient to take an active part in their treatment may assist them to perceive increased control and maintain hope. Symptom management and interventions which reduce fatigue and promote adequate nutritional status may assist in maintaining the energy needed to continue the "fight". Efforts to decrease the disruptions imposed by treatment schedules, although difficult, should be a priority.

Limitations of The Study

The major limitation to this study was the small sample size (n=24) which limits the generalizability of the findings. The heterogeneity of the sample may limit the findings related to the conceptual variables and their relationships as well. The referral process by colleagues may have imposed some selection bias in the sample. Subjects were initially screened prior to being referred, thus explanations of the study purpose and requirements may have varied and effected the decisions of subjects. In addition, the difficulty in contacting people through
telephone contact may have altered participation and thus representation in the sample.

Although standardized alpha coefficients for the instruments were adequate, several item-to-item and item-to-total correlations were low which may limit the measurement of the conceptual variables as they were defined.

Recommendations for Further Research

1. Replication of the study with a larger sample size all of whom have one cancer diagnosis.

2. Secondary analysis of the data following adjustment of the items on the instruments.

3. Conduct a qualitative study focusing on the experiences of cancer recurrence in selected cancer patients.

4. Assessment of nursing interventions which promote hope in patients with recurrent cancer who are receiving treatment.
Summary

The experience of cancer recurrence was described as an unique entity requiring cognitive adaptation to assimilate the changes imposed by the diagnosis and treatment. Hope can provide the energy and motivation to maintain an active role in the situation allowing the patient to persevere. Spiritual perspective may promote hopefulness. Perceived well-being is negatively affected by a greater degree of change in the activities of daily living. A positive perception of life as it is currently experienced (well-being) is associated with greater spiritual perspective. Thus, findings in this study support the concept of hope as an active, multidimensional, motivational phenomenon, involving anticipation of a future which is unique to the individual, his/her situation, and the adaptive resources available. Nurses are in a unique situation to assist the patient to maintain hope, provide support to the patient and the family, reduce the changes and disruptions imposed by treatment, and promote active participation of the patient and family in living with recurrent cancer and its treatment.
APPENDIX A

HUMAN SUBJECTS APPROVAL
The University of Arizona
Human Subjects Committee
1690 N. Wain (Bldg. 326B)
Tucson, Arizona 85724
(602) 626-6721 or 626-7575

28 July 1989

Sandra E. Kurtin, R.N., B.S.N.
c/o Alice Longman, Ph.D.
College of Nursing
Arizona Health Sciences Center

RE: THE RELATIONSHIP OF LIFE-CHANGE, SPIRITUAL PERSPECTIVE, AND PERCEIVED WELL-BEING TO HOPE IN ADULTS WITH RECURRENT CANCER

Dear Ms. Kurtin:

We received documents concerning your above cited project. Regulations published by the U.S. Department of Health and Human Services (45 CFR Part 46.101[b][3]) exempt this type of research from review by our Committee.

Consult your department chairman for approval, the requirement of a subjects' consent form and any other departmental guidelines.

Thank you for informing us of your work. If you have any questions concerning the above, please contact this office.

Sincerely yours,

Milan Novak, M.D., Ph.D.
Chairman
Human Subjects Committee

cc: Departmental/College Review Committee
APPENDIX B

SUBJECTS' CONSENT FORM
SUBJECTS' CONSENT FORM

The Relationship of Life-Change, Spiritual Perspective, and Perceived Well-Being to Hope in Adults with Recurrent Cancer.

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE MY CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I CAN KNOW THE NATURE AND THE RISKS OF MY PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT TO PARTICIPATE IN A FREE AND INFORMED MANNER.

"I am being invited to voluntarily participate in the above-titled research project. The purpose of this study is to describe the personal meaning of cancer recurrence and the relationship of life-change, spiritual perspective, and perceived well-being to hope in adults who have experienced a recurrence of cancer. I am being invited to participate because I have experienced a recurrence of cancer. Approximately 40 subjects will be enrolled in this study."

"If I agree to participate, I will be asked to complete four questionnaires and three interview questions. Completion of the questionnaires and interview questions will take approximately 1 to 1 1/2 hours which may be divided into two sessions. All questionnaires will be explained verbally and will be administered in an interview format. The interview(s) will be conducted in a location which ensures maximal privacy and is mutually agreed upon. I may choose not to answer some or all of the items on the questionnaires or the interview questions."

"I understand that there may be some discussion of topics which are sensitive in nature and I may choose to withdraw at any time. Every effort will be made to minimize any potential risk. I may be referred to supportive services if potential risks are identified. I may also benefit from discussion of these topics. There are no monetary rewards or costs."

"I understand that by consenting to participate, selected information will be taken from my medical records, and that the information to be collected will be explained to me. I understand that my identity and any information I provide will remain confidential. I will be assigned a number and my name will not be identified. Sandy Kurtin RN, BSN the principal investigator for this study, will collect the information. The information will be shared in coded form with the Departmental Review Committee. No other persons will have access to this information. Upon completion of this study the information I have provided may be used in group form for publication."
"If at anytime I have questions concerning this study I may contact Sandy Kurtin RN, BSN, at 694-2148, or 293-0905. If I have questions concerning my rights as a research subject, I may call the Human Subjects Committee office at 626-6721."

"BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS, AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS OR AFFECTING MY MEDICAL CARE. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR OR BY THE SPONSOR FOR REASONS THAT WOULD BE EXPLAINED. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN TO ME AS IT BECOMES AVAILABLE. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNATED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, SANDY KURTIN, RN, BSN, OR AUTHORIZED REPRESENTATIVE OF THE NURSING DEPARTMENT. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS CONSENT FORM WILL BE GIVEN TO ME."

Subject's Signature ______________________ Date ____________

Witness Signature ______________________ Date ____________

Investigator's Affidavit

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Signature of Investigator ______________________ Date ____________
APPENDIX C

DEMOGRAPHIC DATA QUESTIONNAIRE
DEMOGRAPHIC DATA QUESTIONNAIRE

Subject number: __________

Age: __________ Gender: __________

Marital Status: __________

Children: ____________________________

Employment: ____________________________

Years of Education: ______________________

Religious Affiliation: ____________________________

Primary Diagnosis: ____________________________

Date of Initial Diagnosis: ____________________________

Date of Diagnosis of Recurrence: ____________________________

Past Therapies and Response: ____________________________

Current Therapy: ____________________________

Current Prognosis: ____________________________
APPENDIX D

STONE HOPE SCALE
DIRECTIONS:
Listed below are 30 sentences which contain goals which any person might want to achieve in their lifetime. As you read each sentence, please think about your own future and about what is important to you. Circle the number of the opinion which best describes how you feel.

1 = NOT IMPORTANT. I do not care if this happens or not.
2 = SOMEWHAT IMPORTANT. I would like this to happen, but I could adjust if it did not occur.
3 = QUITE IMPORTANT. I would like this to happen, and I will work toward it.
4 = EXTREMELY IMPORTANT. My life would not be the same without it.

1. To see a decrease in unemployment in the U.S.  1 2 3 4
2. To have open communication with the people who are important to me.  1 2 3 4
3. To feel good about my life.  1 2 3 4
4. To have other people enjoy having me around.  1 2 3 4
5. To see a decrease in crime and violence.  1 2 3 4
6. To resolve conflicts with the people who are important to me.  1 2 3 4
7. To have people seek me out as a friend.  1 2 3 4
8. To see a decrease in the threat of nuclear war.  1 2 3 4

Note: Adapted from Erickson, R.C., Post, R.D. and Paige, A.B. (1975)
<table>
<thead>
<tr>
<th>Subject No.</th>
<th>Question</th>
<th>Rating</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9. To overcome fears that I have.</td>
<td>1 2 3 4</td>
<td>(57)</td>
</tr>
<tr>
<td></td>
<td>10. To believe in myself as a person.</td>
<td>1 2 3 4</td>
<td>(58)</td>
</tr>
<tr>
<td></td>
<td>11. To see an improvement in efforts to resolve problems with pollution of the environment.</td>
<td>1 2 3 4</td>
<td>(59)</td>
</tr>
<tr>
<td></td>
<td>12. To have better education in our schools.</td>
<td>1 2 3 4</td>
<td>(60)</td>
</tr>
<tr>
<td></td>
<td>13. To have the courage to deal with my life.</td>
<td>1 2 3 4</td>
<td>(61)</td>
</tr>
<tr>
<td></td>
<td>14. To resolve conflicts within myself.</td>
<td>1 2 3 4</td>
<td>(62)</td>
</tr>
<tr>
<td></td>
<td>15. To have better programming on television.</td>
<td>1 2 3 4</td>
<td>(63)</td>
</tr>
<tr>
<td></td>
<td>16. To have people come to me for help with problems.</td>
<td>1 2 3 4</td>
<td>(64)</td>
</tr>
<tr>
<td></td>
<td>17. To be free from pain.</td>
<td>1 2 3 4</td>
<td>(65)</td>
</tr>
<tr>
<td></td>
<td>18. To make lots of new friends.</td>
<td>1 2 3 4</td>
<td>(66)</td>
</tr>
<tr>
<td></td>
<td>19. To have access to cultural facilities like symphonies, theaters, and art museums.</td>
<td>1 2 3 4</td>
<td>(67)</td>
</tr>
</tbody>
</table>
20. To be mentally alert and always learning. 1 2 3 4
21. To have local government agencies be responsive to people in neighborhoods. 1 2 3 4
22. To be at peace with myself. 1 2 3 4
23. To have other people respect and admire me. 1 2 3 4
24. To spend more time with the people who are important to me. 1 2 3 4
25. To be persistent in solving my problems. 1 2 3 4
26. To be in control of what happens in my life. 1 2 3 4
27. To participate in political activities. 1 2 3 4
28. To share joys and sorrows with the people who are important to me. 1 2 3 4
29. To have better mass transportation in our cities. 1 2 3 4
30. To have friends who will provide help when I need it. 1 2 3 4
DIRECTIONS:

Listed below are 30 sentences which contain goals which any person might want to achieve in their lifetime. As you read each sentence, please think about your own future and about what is likely for you. Circle the number of the opinion which best describes how you feel.

1 = CANNOT POSSIBLY BE REALIZED
2 = PROBABLY WILL NOT BE REALIZED
3 = MAY BE REALIZED
4 = DEFINITELY WILL BE REALIZED

1. To see a decrease in unemployment in the U.S.
   1 2 3 4

2. To have open communication with the people who are important to me.
   1 2 3 4

3. To feel good about my life.
   1 2 3 4

4. To have other people enjoy having me around.
   1 2 3 4

5. To see a decrease in crime and violence.
   1 2 3 4

6. To resolve conflicts with the people who are important to me.
   1 2 3 4

7. To have people seek me out as a friend.
   1 2 3 4

8. To see a decrease in the threat of nuclear war.
   1 2 3 4
1 = CANNOT POSSIBLY BE REALIZED
2 = PROBABLY WILL NOT BE REALIZED
3 = MAY BE REALIZED
4 = DEFINITELY WILL BE REALIZED

9. To overcome fears that I have. 1 2 3 4
10. To believe in myself as a person. 1 2 3 4
11. To see an improvement in efforts to resolve problems with pollution of the environment. 1 2 3 4
12. To have better education in our schools. 1 2 3 4
13. To have the courage to deal with my life. 1 2 3 4
14. To resolve conflicts within myself. 1 2 3 4
15. To have better programing on television. 1 2 3 4
16. To have people come to me for help with problems. 1 2 3 4
17. To be free from pain. 1 2 3 4
18. To make lots of new friends. 1 2 3 4
19. To have access to cultural facilities like symphonies, theaters, and art museums. 1 2 3 4
Subject no.______
Section 2, Page 3

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2 = PROBABLY WILL NOT BE REALIZED
3 = MAY BE REALIZED
4 = DEFINITELY WILL BE REALIZED

20. To be mentally alert and always learning.  1 2 3 4
21. To have local government agencies be responsive to people in neighborhoods.  1 2 3 4
22. To be at peace with myself.  1 2 3 4
23. To have other people respect and admire me.  1 2 3 4
24. To spend more time with the people who are important to me.  1 2 3 4
25. To be persistent in solving my problems.  1 2 3 4
26. To be in control of what happens in my life.  1 2 3 4
27. To participate in political activities.  1 2 3 4
28. To share joys and sorrows with the people who are important to me.  1 2 3 4
29. To have better mass transportation in our cities.  1 2 3 4
30. To have friends who will provide help when I need it.  1 2 3 4
APPENDIX E

LIFE CHANGE SCALE
Personal Interview Guide
Life-Change Scale

Date: ______________________

Subject I.D.: ______________________

For this study I am interested in finding out how your life has been affected by the recurrence of your cancer. There are several areas that I would like to discuss with you and give you an opportunity to tell all that comes to mind. For a few minutes, then, tell me HOW YOUR LIFE IS DIFFERENT NOW FROM WHAT IT WAS BEFORE THE RECURRENCE OF YOUR CANCER. (This is to be open-ended discussion with the interviewer beginning with focus on a subject and then allowing the interviewee to generate own views, interject only for clarification or elaboration of points. Before each subject has been discussed, offer card and have client rank the amount of change in the area being discussed).

PHYSICAL APPEARANCE

PHYSICAL ENDURANCE

FEELINGS ABOUT SELF

SENSE OF INDEPENDENCE

DECISION MAKING

RELATIONSHIP WITH SPOUSE

RELATIONSHIPS WITH CHILDREN
RELATIONSHIPS WITH INLAWS, RELATIVES

RELATIONSHIPS WITH DOCTOR OR OTHER HEALTH PROFESSIONALS

RELATIONSHIPS WITH FRIENDS

RELATIONSHIPS WITH ASSOCIATES AT WORK

JOB PERFORMANCE (If housewife or retired, what would be normal for them)

JOB SATISFACTION

FINANCIAL SITUATION

HOBBIES OR RECREATIONAL ACTIVITIES

CHURCH OR RELIGIOUS GROUP INVOLVEMENT

SOCIAL ACTIVITIES

SENSE OF ACHIEVEMENT
SOCIAL SUPPORT

STYLE OF DRESS

CHANGED BY TREATMENT

THOUGHT OF STOPPING TREATMENTS?  (No card)

SAME CHOICE OF TREATMENT?  (No card)

OUTLOOK TOWARD THE FUTURE (Include future plans in areas of work, family, travel, education, home purchase or building, location in neighborhood or other geographic area, other ambitions or goals)

What are some of the things that make life meaningful to you?  (Have subject prioritize and rank the top three.)
APPENDIX F

SPIRITUAL PERSPECTIVE SCALE
**SPRITUAL PERSPECTIVE SCALE**

**Introduction:** Spirituality has different meanings for people. In general, it is defined as that which relates people to a transcendent or non-physical realm, or which relates people to something greater than themselves without disregarding the value of the individual. I am interested in your views on the questions below. There are no right or wrong answers, of course.

**Directions:** In answering the following questions about your spiritual views, think about what spirituality means to you personally. Answer each question by marking an 'X' in the space above that group of words which best describes you.

1. In talking with your family or friends, how often do you mention spiritual matters?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Less than once a year</th>
<th>About once a month</th>
<th>About once a week</th>
<th>About once a day</th>
</tr>
</thead>
</table>

2. How often do you share with others the problems and joys of living according to your spiritual beliefs?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Less than once a year</th>
<th>About once a month</th>
<th>About once a week</th>
<th>About once a day</th>
</tr>
</thead>
</table>

3. How often do you read spiritually-related material?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Less than once a year</th>
<th>About once a month</th>
<th>About once a week</th>
<th>About once a day</th>
</tr>
</thead>
</table>

4. How often do you engage in private prayer?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Less than once a year</th>
<th>About once a month</th>
<th>About once a week</th>
<th>About once a day</th>
</tr>
</thead>
</table>

(Please continue on next page)
Directions: Please indicate the degree to which you agree or disagree with the following statements by marking an 'X' in the space above the words which best describe you.

5. Seeking forgiveness is an important part of my spirituality.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree more than agree</th>
<th>Agree more than disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

6. I seek spiritual guidance in making decisions in my everyday life.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree more than agree</th>
<th>Agree more than disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

7. My spirituality is a significant part of my life.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree more than agree</th>
<th>Agree more than disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

8. I frequently feel very close to God or a "higher power" in prayer, during public worship, or at important moments in my daily life.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree more than agree</th>
<th>Agree more than disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

(Please continue on next page)
9. My spiritual views have had an influence upon my life.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree more than</td>
<td>agree</td>
<td>more than</td>
<td>disagree</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. My spirituality is especially important to me because it answers many questions about the meaning of life.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree more than</td>
<td>agree</td>
<td>more than</td>
<td>disagree</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you have any views about the importance or meaning of spirituality in your life that have not been addressed by the previous questions?

________________________________________

____________________________

Thank you very much for answering the questions.

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APPENDIX G

INDEX OF WELL-BEING
IWB

Here are some words and phrases which I would like you to use to describe how you feel about your present life. Put an "X" over the number that you think best describes how you feel about your present life.

1. My present life is:
   - BORING
   - ENJOYABLE
   - USELESS
   - LONELY
   - FULL
   - ENCOURAGING
   - REWARDING
   - DOESN'T GIVE ME MUCH CHANCE

2. My present life is:
   - INTERESTING
   - Miserable
   - USELESS
   - LONELY
   - EMPTY
   - DISCOURAGING
   - DISAPPOINTING
   - BRINGS OUT THE BEST IN ME

3. My present life is:
   - WORTHWHILE
   - FRIENDLY
   - USELESS
   - LONELY
   - EMPTY
   - HOPEFUL
   - SATISFIED
   - COMPLETELY DISAPPOINTED

4. My present life is:
   - BRINGS OUT THE BEST IN ME
   - SATISFIED
   - COMPLETELY SATISFIED
   - THANK YOU!
APPENDIX H

PERSONAL MEANING OF CANCER RECURRENCE

INTERVIEW GUIDE
Personal Meaning of Cancer Recurrence
Interview Guide

Date

Subject I.D.

For this study I am particularly interested in finding out what the recurrence of cancer means to you. I would like to ask you three questions and have you tell me anything that comes to mind.

1. What did it mean to you when you were told your cancer reappeared?

2. What feelings have you experienced since learning about the recurrence?

3. What does the recurrence of your cancer mean to you now?
APPENDIX I

RESULTS OF CONTENT ANALYSIS

FOR LIFE CHANGE SCALE
### APPENDIX I

MAJOR THEMES FROM CONTENT ANALYSIS OF LCS INTERVIEW GUIDE BY ITEM

<table>
<thead>
<tr>
<th>Theme</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Appearance</strong></td>
<td>Losing hair.</td>
</tr>
<tr>
<td></td>
<td>Losing weight.</td>
</tr>
<tr>
<td></td>
<td>Scars and holes from radiation and surgery.</td>
</tr>
<tr>
<td></td>
<td>Having to work at it.</td>
</tr>
<tr>
<td></td>
<td>Look like a ghost.</td>
</tr>
<tr>
<td><strong>Physical Endurance</strong></td>
<td>Can't do now what I used to.</td>
</tr>
<tr>
<td></td>
<td>Decreased endurance and increased fatigue.</td>
</tr>
<tr>
<td><strong>Feelings about self</strong></td>
<td>Reappraisal of priorities and beliefs.</td>
</tr>
<tr>
<td></td>
<td>Strength and confidence in faith.</td>
</tr>
<tr>
<td></td>
<td>Frustration with self because not able to do what I used to.</td>
</tr>
<tr>
<td><strong>Sense of Independence</strong></td>
<td>Disease and treatment have control.</td>
</tr>
<tr>
<td></td>
<td>Acknowledging dependence is bothersome.</td>
</tr>
<tr>
<td><strong>Decision Making</strong></td>
<td>Making decision all the time.</td>
</tr>
<tr>
<td></td>
<td>Decisions are my own now.</td>
</tr>
<tr>
<td></td>
<td>Decisions more important now that future is limited.</td>
</tr>
<tr>
<td></td>
<td>Inability to concentrate to make decisions.</td>
</tr>
</tbody>
</table>
| Relationship With Spouse | Increased appreciation of time together.  
|                         | Don't take things for granted.  
|                         | Realizing how much you love those around you.  
|                         | Underlying tension. |
| Relationship With Children | Change in subject:  
|                         | Don't see them.  
|                         | Answering more questions.  
|                         | Appreciating time with them.  
|                         | Planning for their future.  
|                         | Concern for care of young children—feeling guilty.  
| Relationship With Inlaws/Relatives | More frequent contact.  
|                         | Increased support.  
|                         | Getting along better.  
|                         | Resolving ill feelings.  
|                         | No one in town.  
| Relationship With Doctors and Other Health Professionals | Change in subject:  
|                         | Taking an active role in treatment.  
|                         | Trusting the doctors' judgement.  
|                         | Scrutinizing their decisions.  
|                         | Change in Professionals:  
|                         | More concerned and attentive.  
|                         | Supportive. |
Relationship With Friends

Change in subject:
- Appreciating them more.
- Difficulty maintaining friendships due to limitations.
- Pulling away to protect them.

Change in friends:
- Very supportive, helping out.
- Pulling away.

Relationship With Associates at Work

Considerate
Understanding
Supportive
Thoughtful

*Many subjects not working

Job Performance

Concentrating on work.
Working harder.
Adjusting the workload.

Job Satisfaction

Appreciate the ability to work.
Dissatisfied because not able to do what is required.

Financial Situation

Difficulties related to medical costs, even with good insurance.
Hard to keep track of forms payments.
Cost can’t control decisions for treatment.
Changing living arrangements.
Inability to work due to treatment or disease.
Hobbies or Recreational Activities
Limited by fatigue, disabilities, and/or treatment.
Limited contact with others.
Enjoying what you can do.

Church or Religious Group Involvement
Little change for many.
No involvement due to inability to get to church or lack of interest.
Always active in church - helpful now.
Finding support elsewhere.

Social Activities
Limited by fatigue.
Treatment takes up leisure time.
Don’t get out much.
Don’t have any.

Sense of Achievement
Proud of past accomplishments.
Analyzing achievements - afraid there aren’t enough.
Glad just to make it through the day.
Unfinished business.

Social Support
Appreciating support.
Necessity of support now.
Asking for support.
Good friends, church, and family.

Style of Dress
Clothes not fitting because of weight loss.
Adapting style for comfort.
Limited wardrobe.
Trying to look good.
| Changed By Treatment | Creates vulnerability.  
Life disrupted by treatment.  
Enduring a lot.  
Life planned around treatment.  
Treatments wear me out.  
Fighting to get better.  
Separation from family. |
|----------------------|--------------------------------------------------|
| *Thoughts of Stopping Treatment | Yes, but needed to do this.  
No, but there may come a time.  
Assimilating options. |
| *Same Choice of Treatment | Will do what is necessary to  
feel better.  
Very little choice.  
Hoping I won't have to.  
Treatment was difficult - got very sick. |
| Outlook Toward The Future | Focus on the here and now.  
Outlook varies from day to day.  
Making a difference.  
Concentrating on getting well.  
Concern for family members.  
Waiting to see, anticipating, preparing. |
| *Things That Make Life Meaningful - Top Three | Family  
Church, Faith, Relationship with God.  
Ability to do things, being independent. |

* Items were not measured in Likert scale format.
APPENDIX J

CONTENT ANALYSIS OF RESPONSES TO
CANCER RECURRENCE INTERVIEW GUIDE
APPENDIX J

CONTENT ANALYSIS OF RESPONSES TO
CANCER RECURRENCE INTERVIEW GUIDE (n-24)

Question 1. What did it mean to you when you were told your cancer reappeared?

Major Themes:

Disappointed - thought it was gone.
Unexpected even though suspected.
Thought I had more time.
Scared and fearful - not a good sign.
Devastated - hurt.
Need to get strength back to fight again, fight harder.

Question 2. What feelings have you experienced since learning about the recurrence?

Major Themes:

Every emotional response possible - Depressed,
Determined, Positive, Angry, Fearful,
Hopeful, Thankful, Don't worry, Tearful,
Ashamed, Disappointed, Let Down.
Determined to fight harder - persistent courage for the future.
Keeping positive feelings - trying to remain hopeful.
Making decision for myself.
Disappointed in treatment failure.
Thankful for treatment available.
Concentrating on treatment.
Relying on faith in God.
Question 3. What does the recurrence of your cancer mean to you now?

Major Themes:

Taking one day at a time - wait and see.
Not giving up - staying hopeful.
Every moment counts.
Reminiscing - finding a purpose in life.
Out of my hands - depends on treatment.
Setting priorities.
Concern for others who will be left behind.
"In the end I will find peace and comfort.
I wouldn't mind dying while I feel good."
REFERENCES
References


